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Individuals with disabilities as parents and their earliest connections to systems of support

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INDIVIDUALS WITH DISABILITIES AS PARENTS AND THEIR EARLIEST CONNECTIONS TO SYSTEMS OF SUPPORT

BY

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DISSERTATION

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Ph.D. DISSERTATION

This dissertation has been examined and approved.

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DEDICATION

The Becker and the Schultz families, as well as other parents with disabilities who try to live their lives as ordinary families under extraordinary circumstance, have been the driving and guiding influences behind this study. I can only hope that this effort will be a positive force in changing the attitudes and beliefs surrounding, and improving services and supports for, parents with disabilities. Thank you Catherine, Rick, Sheila, Amy, and Matt for sharing your stories and giving life to this study.

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ABSTRACT

INDIVIDUALS WITH DISABILITIES AS PARENTS AND THEIR EARLIEST CONNECTIONS TO SYSTEMS OF SUPPORT

BY

MARY C. SCHUH

UNIVERSITY OF NEW HAMPSHIRE, MAY 2002

The purpose of this study is to better understand the experiences of individuals with disabilities as parents, and the variables influencing the referral processes used by pre and postnatal care professionals to connect parents with disabilities to systems of family support. This process was examined through the experiences, beliefs, and attitudes of pre and postnatal care professionals as well as through the experiences and perspectives of parents with disabilities. Research objectives included both an increased understanding of the relationship between parents with disabilities and their earliest connections to systems of support and policy and practice recommendations for pre and postnatal care professionals, child protective services, and other agencies involved in supporting parents with disabilities. Primary research findings include the lack of training and understanding for pre and postnatal care providers about parents with disabilities; a higher level of parental referral to child protective services for professionals who have received training; the perception of discrimination by parents with disabilities; and recommendations for changes in the field of supporting parents with disabilities. Finally, the proposed research further defines best practices in the delivery of formal and informal supports to parents with disabilities. Outcomes of this research will ultimately influence policy development and direct practice in the areas of child wellness and family support when parenting with a disability is a presiding factor.

CHAPTER 1

INTRODUCTION

PARENTS WITH DISABILITIES AND COMMUNITY MEMBERSHIP

> *People never thought it was possible. I don't know why but they assumed we just wouldn't have children. I have my own home. I'm married. I have a full-time job and I have a kid. I'm living the American dream. Some people would say in spite of the fact that I am disabled. That's bunk, being disabled is just part of who I am.* (Auliff, 2001)

Including individuals with disabilities in each strand of the fabric of community presents long-term challenges as well as a thoughtful, forward thinking, decision making process. Supporting children with disabilities and their families is now an undeniable right. Education for ALL - including students with the most severe disabilities – has been upheld in multiple courts of law in the United States. Institutions, or large congregate living spaces, are considered inhumane places for individuals with disabilities to live, and efforts to close their doors have been under way since the early 1970s. Individuals with disabilities are supported to grow up with their families, go to school, work, own their own homes, and are protected by anti-discrimination laws in all aspects of public life. Despite these efforts to recognize individuals with disabilities as people entitled to live ordinary lives with ordinary dreams, parenting with a disability remains poorly understood, unplanned for, and sorely neglected in our society.

The purpose of this study is to better understand the experiences of individuals with disabilities as parents and the variables influencing the referral processes used by pre and postnatal care professionals to connect parents with disabilities to systems of family support. This process was examined through the experiences, beliefs, and attitudes of those professionals as well as through the experiences and perspectives of parents with disabilities. Research objectives included not only an increased understanding of the relationship between parents with disabilities and their earliest (or lack thereof) connections to systems of support, the research will also further define best practices in the delivery of formal and informal supports to parents with disabilities. Outcomes of this research will be translated into policy and practice recommendations that will ultimately influence policy development and direct practice in the areas of child protection, child wellness, and family support when parenting with a disability is a presiding factor. Let's begin with a story to illustrate some of the experiences of parents with disabilities and the involvement (or lack thereof) of service systems to support the family.

In Northern New England, in a cozy neighborhood of mobile homes decorated with Christmas lights and American flags, Catherine Schultz[1] *lives with her husband Rick, daughter Sheila, and two grandchildren Ava and Noelle. Catherine, a painter and avid gardener, has custody of her granddaughter Ava - a smiley, blond, curly haired, four-year-old with multiple disabilities. Catherine's story of gaining legal control to fight for her granddaughter's life illustrates the complexities of a service delivery system not fully equipped to support families in which one or both parents experience a disability.*

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[1] Pseudonyms have been used for all case study examples in this dissertation.

Sheila, Catherine's middle child, was diagnosed with a developmental disability[2] *in the third grade. Following an education spliced with the best and worst of both regular and special education, including a three-year period living in an institution in her early teens, Sheila entered the world as an adult wanting to live an ordinary life. At age 21 she was employed in the kitchen of a residential facility when she fell in love with David, who later became the father of her two children. David also has labels of developmental disabilities and mental illness and is the father of three children from a previous relationship.*

Catherine and Sheila describe Sheila's prenatal care as good during her first pregnancy. Ava was born following a cesarean section delivery with the usual three-day postpartum hospital stay. Sheila went home to David, with her new baby and feeling excited and nervous about her new role as a mother. In Sheila's words, "My whole life, I have wanted nothing more than to be a mother."

Let us jump ahead six months to capture Catherine's version of her daughter's role as a mother. Catherine observed that the typical anxieties and feelings of inadequacy described by any new mother were of epic proportions for Sheila. As Catherine visited her infant granddaughter, Ava, and attempted to provide support she observed activities

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[2] A developmental disability as defined in NHRSA 171-A2, V is a disability which is attributable to mental retardation, cerebral palsy, epilepsy, autism or a specific learning disability or any other condition of an individual found to be closely related to mental retardation as it refers to general intellectual functioning or impairment in adaptive behavior or requires treatment similar to that required for individuals with mental retardation; and originates before such individual attains age 22, has continued or can be expected to continue indefinitely, and constitutes a severe handicap to such individual's ability to function normally in society. This study has adopted an operational definition of disability similar to that used by the U.S. Bureau of the Census (McNeil, 1997). Indicators of disability include: longtime user of mobility devices such as a wheelchair or cane; difficulties performing functional tasks such as seeing, hearing, speaking, walking, using stairs, lifting; difficulty performing activities of daily living such as: getting out of bed, dressing, bathing, eating, toileting, difficulty performing instrumental activities of daily living such as personal finances, preparing meals, doing light housework, taking medication as prescribed; the presence of specified conditions such as a learning disability, developmental disability, dementia, mental or emotional disability; limits in the ability to work; and receiving federal benefits based on the ability to work.

(or a lack thereof) that seriously concerned her. Ava spent hours listlessly swinging in front of a television set that was always on. She rarely drank from her bottle and was not gaining weight. Her daughter seemed unaware of her own child, and the father's interactions with Ava bordered on abuse, both sexual and physical. During this period, there was no post partum care other than an obligatory visit from a visiting nurse in the days following Sheila and Ava's return home.

Fast forward six more months as Catherine finds herself at the hospital bedside of her twelve-month-old granddaughter who has been diagnosed with a serious seizure disorder and severe disabilities. Following Catherine's numerous attempts to access support for the family, Ava's physician called child protective services. Catherine needed to make a choice: to allow her granddaughter to enter into the foster care system, or become her granddaughter's legal guardian. She chose the latter and desperately works to get both her daughter and two granddaughters the support necessary to live their lives as an intact family.

As this story illustrates, at any given time, the supports and services available to families with or without the presence of disability have been sparse and unevenly available. While some might question the "wisdom" of "allowing" Sheila to become a mother, I chose to examine questions related to the role of the medical community and human service system in supporting families who fit beyond the natural comfort zone and traditions these professionals have been trained to address. Although individuals with disabilities are encouraged to live ordinary lives in their communities, the prospect of individuals with significant disabilities as parents was rarely anticipated as a possibility among service providers, care givers, and the system of pre and postnatal care providers.

For individuals with disabilities, the ability to be loving and nurturing parents has not been questioned by the field of human services. Rather, concerns about the risk of abuse and neglect of their children are associated with the other demands and expectations of parenting such as safety issues, appropriate nutrition, and support for their own and their children's educational and career achievement. There are broad assumptions that if an individual has a low IQ, physical disabilities, or a label of mental illness, she/he will endanger the life of a child and therefore should not be a parent. These assumptions have been observed time and time again through my own experiences with individuals with disabilities. The vast majority of the 400 individuals with disabilities and their family members with whom I have had contact during the past twelve years have not articulated parenting as a realistic goal for themselves or their family member with a disability. Individuals with disabilities who are parents typically do not have contact with their children and heart wrenchingly describe their participation in an uncoordinated system of uninformed and unavailable family support. Some parents will work diligently to avoid any contact with the system, fearing the removal of their children. Too often their children are removed from their homes as the final result of these "services."

As we continue to dismantle barriers that prevent individuals with disabilities from fully participating in their communities, attention needs to be focused on systems that provide parents with support to reduce or eliminate child abuse and neglect. For parents with disabilities, this support may be difficult to attain. Although there is a plethora of national well-funded and well-developed resources that serve parents, most of these programs have failed to recognize that the families they serve may include parents with disabilities. This lack of recognition exists from the earliest stage of family care – pre and postnatal care providers. Concomitantly, there is a growing network of consumer-driven disability services and supports, but many of these providers have failed to recognize the needs of parents with disabilities. Formal systems targeted for individuals with disabilities are not well prepared to support individuals as parents, and family support agencies are likewise not prepared to address unique issues of disability within the parenting process. A recent national study discovered only 40 programs designed to serve the needs of families where at least one of the parents experiences a disability (Kennedy & Garbus, 1999). This lack of awareness and lack of informed programs effectively excludes parents with disabilities (Barker & Maraloni, 1997). Presumed abuse and neglect, assumptions about the incapability of parents with disabilities, and uninformed judgments by professionals can permanently sever parents with disabilities from their children. Knowledgeable assessments (beginning as early as the prenatal care stage) and appropriate interventions and referrals are critical to sustain and support families where a parent experiences a disability.

Background to this Research Topic

In the early stages of development of this dissertation topic, I anticipated an effort directed toward the examination of children with disabilities involved in the system of child protective services. At that point, I met with representatives from the child protective system (policymakers and direct care workers) and posed the following question: "If I could fill, through conducting research, an unmet need in the area of disability and child protective services, what would it be?" Expecting the response to be in the area of information and support for children with disabilities involved in the system of child protective services, I was surprised to hear that parents with disabilities pose the most significant challenge to the overall system of child protective services in New Hampshire. Case workers and policymakers described as deplorable the lack of information related to supporting families where at least one parent experiences a disability. At this point in time, as the next chapter elucidates, there are no orientation or inservice training opportunities about parents with disabilities, yet parents with disabilities represent a disproportionately high number of referrals into the system of child protective services. Thus, this dissertation took shape – following a different path than was originally intended.

Biases and Assumptions

I would be remiss not to disclose my own biases and assumptions toward this research. In my 20 years of experience in the field of disability studies, my perception of the nature and quality of real systems change is this: changes in an individual's life can happen overnight, while changes in overall beliefs and attitudes in the culture surrounding individuals' lives take decades to occur. With this said, the ability for individuals with disabilities to become parents is being rightly realized in ever-increasing numbers, but cultural changes in the surrounding systems have yet to be realized. An individual with a disability is able to create new life, yet she/he is not allowed to be a parent. The following assumptions will be tested based on measurement results, inferences, and interpretations of my research:

1) The factors that influence out-of-home placement recommendations for children of parents with disabilities are based on societal biases and a "medical model" approach in existence prior to the birth of a child.

2) Pre and postnatal care professionals are unfamiliar with the myriad of supports that may be available for parents with disabilities.

3) Formal systems of support for parents with disabilities do not coincide with the best interests of children and families.

4) New systems merging parenting and disability supports need to be developed to respond to the new family structures in today's society.

Just as these biases and assumptions have informed this study, these biases and assumptions will influence the formulation of grounded theory (Glaser & Strauss, 1967) in the field of disability and family studies, professional decision making, and descriptive research. It may be that accepting and supporting people with disabilities as parents is the final frontier in the disability rights movement.

CHAPTER 2

REVIEW OF THE LITERATURE

WHAT THE RESEARCH TELLS US ABOUT PARENTS WITH DISABILITIES

Why this Research is Significant

Although some literature exists regarding parenting with a disability, it has only been since the early 1980s that a research base has developed. Thus, much care must be taken when researchers examine and report findings. The majority of the available research presents the topic of parenting with a disability from a negative perspective. According to Kirshbaum (2000), the research that does exist has led to pathologizing parents with disabilities. This pathology involves an overgeneralization based on societal stigma and assumptions about disability, which preclude parenting. Human service systems, even in the disability community, do not tend to gather or identify information about parents with disabilities. Such parents are not included in traditional human service needs assessments, and funds are not allocated to supporting these families. In the absence of a large and consistent body of quantitative and qualitative research and knowledge related to the experience of parents with disabilities, the development of adequate ways to respond to the challenges is lacking. Therefore, this research is significant because the results will ultimately lead toward an increased recognition of the experience of parents with disabilities and the development of adequate supports for the growing number of families sharing the experience of parenting with a disability.

Who are Parents with Disabilities? When parents experience disabilities, families are often comprised of a woman and her child (or children) as is in Sheila's situation, one of the parents interviewed for this study. Although there may be male partners, the woman often bears the responsibility for the family as well as the brunt of questions regarding her competence (Tymchuk, 2001). According to Barker and Maraloni (1997), census data reveals that about 8 million parents (age 18 to 64, with children under the age of 18) have disabilities. Close to one third of women with disabilities and a quarter of men with disabilities are parents. On average, about 30 percent of adults with disabilities are parents compared to 40 percent of adults without disabilities.

However, these proportions differ significantly across disability groups, with individuals with sensory disabilities more likely to be parents than those with cognitive disabilities. Students with disabilities are more likely to drop out of school early or exit the school system without a high school diploma. Once they have left the school system, young women with disabilities are five times more likely to become a parent within five years than are their peers without disabilities (Barker & Maraloni, 1997). With the frequencies of these experiences, one wonders why systems of care are not better equipped to support parents with disabilities and why educational systems do not provide preconceptual planning and parenting classes. For the purposes of this study, individuals with disabilities are defined as those experiencing more significant challenges. For example, the interest behind this study focuses primarily on people with labels of cognitive and sensory disabilities and those with mental illness, not chronic health conditions, amputations, or substance abuse.

Parent Perspectives There are approximately 120,000 babies born to parents with disabilities in the United States each year. A recent documentary on the topic of parenting with mental illness suggests that only approximately 50 percent of these babies are allowed to remain with their birth parents with disabilities (Kennedy & Garbus, 1999). The first-ever national survey of parents with disabilities (Barker & Maraloni, 1997) provides insight to this startling statistic. The responses regarding possible discrimination and attitudinal biases by pre and postnatal care professionals were a predominant theme. It should be noted however, that the survey sample differs from the national population of the 8.1 million parents with disabilities because it includes fewer minorities, more women, and fewer individuals of low economic and educational status. Forty-four percent of the 1,200 parents with disabilities who completed the survey reported that pregnancy and birthing for themselves or their partner was an issue affected by their disability; 36 percent reported that the lack of disability expertise among pre and postnatal care professionals caused problems; and 42 percent reported that these providers' attitudinal problems created barriers to receiving quality care. According to Preston and Jakobsen (1997), survey analysts anticipate that even higher numbers of parents with disabilities would have reported problems if more parents with lower incomes, lower education levels, and more members of minority groups had participated.

The 42 percent of parents with disabilities who reported they faced attitudinal barriers described their perception of discrimination as the pressure to have a tubal ligation or pressure to have an abortion. Responses included referrals to child protective services by pre and postnatal care providers intended to remove children from their families. These responses were noted despite the sample population's high economic and educational status and limited participation of parents with cognitive, developmental, or psychiatric disabilities.

Parents with labels of mental illness candidly described their fear of losing their children in the videotape "I Love You Like Crazy" (Mental Illness Education Project, 1999). Treatment was avoided in order to prevent losing their children. Parents described how difficult it is to be involved in a system more focused on removing children from families than on providing families with the necessary supports to raise children. Also described was the complete lack of adequate representation from the legal system. One father discussed losing his job, returning home to find his house on fire, and having his child taken away following a clinical diagnosis of manic depression. "What I really needed from the system was support to rebuild my home and career," he said.

The majority of individuals with disabilities live in poverty because they are unemployed, underemployed, and severely lacking in educational opportunities[3]. In fact, the average monthly household income for parents with disabilities is $1,000 less than that of parents without disabilities. Families in which one or both parents experience a disability are faced with even greater challenges than poverty (Kirshbaum, 2000; Tymchuk, 2001). As individuals with disabilities participate in the community and navigate the available resources to care for themselves, caring for their children is an additional and often times overwhelming responsibility. More specifically, according to Tymchuk (2001), for these individuals, community participation means finding friends, building relationships, establishing networks of support, and ensuring their own livelihood during all stages of their lives.

To achieve these objectives, parents with disabilities have to communicate with physicians, teachers, human service workers, other parents, and perhaps child protective services, courts, and police officers. Parents with disabilities are challenged in many ways beyond their immediate disability. Challenges include not knowing what society expects regarding their roles as parents, the lack of preparation and practice to meet those expectations, and unavailable services and supports to meet these challenges. Maintaining a marital or other relationship, maintaining a household, caring for oneself while caring for a child, working, and all the other things a family does, while perhaps being the target of scrutiny, is overwhelming (Tymchuk & Andron, 1990; Tymchuk, 1990, 1992). Some families manage; but most, like Sheila and Ava, do not.

> Acquaintances and total strangers showed a fair amount of prejudice and ignorance. I received numerous comments during my first pregnancy and the baby's infancy that showed erroneous assumptions -- that my disability would be genetically transmitted to the children or that I couldn't parent responsibly (Auliff, 2001).

Medical Profession Perspective While parents with disabilities describe their experiences through a societal lens of discrimination, attitudinal barriers, and lack of expertise among medical professionals, Toub (2000) and Stein (1999) reinforce this perspective by stating that gynecologists frequently have little or no specific training to address the needs of women with developmental disabilities or other special needs. According to Toub, women with disabilities

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[3] Due to a history of regulatory statutes in the Social Security and Medicaid systems, people with disabilities are unable to earn enough income to support their cost of living without losing necessary benefits such as health care.

represent an underserved population who in their pursuit of medical care face a number of barriers. These barriers include physical inaccessibility to healthcare services, lack of psychological support for women with psychiatric disabilities, frequent use of sedation for routine exams, and lack of complete medical history information. In addition, common assumptions and misconceptions on the part of healthcare practitioners may act as a barrier to quality care. For example, Stein (1999) concludes that screening for sexually transmitted diseases may not be offered to patients because of the mistaken belief that women with disabilities are not sexually active. Additionally, men with disabilities are not immune to research that suggests discrimination by the medical profession. A (1999) study by Banks concluded that the presence of physical disability influenced doctors' perception of their suitability for risk assessments for coronary heart disease. Culley and Genders (1999) found that nurses did not feel that they are adequately prepared to address the needs of adults with disabilities, particularly parents with disabilities. They concluded that adults with disabilities are at a serious medical disadvantage compared with adults without disabilities. Some of this may explain the World Health Organizations findings (2002) that the majority of people with disabilities do not participate in health maintenance care and are at high risk for the acquisition of secondary disabilities due to their lack of care.

According to Tymchuk (2001), within the healthcare field and the advent of managed care, the move of public expenditures from services controlled by the needs of the patient to services controlled by a system has had a dramatic deleterious impact upon the heath status of individuals with disabilities i.e. managed care. While consideration was made for individuals with disabilities within the changing field of healthcare, no consideration has been given to the potential impact of those changes on families headed by a parent with a disability (Tymchuk, 2001). The health status and availability of services for families continues to decline as a result of lack of knowledge about initiatives or services and their usage rules.

Societal Impact As individuals with disabilities assume their rightful place in society, there is a critical need to examine the impact of societal roles and responsibilities. Individuals with disabilities are attending regular schools and classes, employed as tax paying citizens, purchasing homes, marrying, and raising children in increasing numbers (Braddock et al, 1998; Pomerantz & Pomerantz, 1990; Ray & Rubenstein, 1994; Taylor, 1995, 2000). Since the end of forced sterilization of people with disabilities in the 1960s, new families are emerging. While individuals with disabilities are assuming their legal rights to be recognized as fully contributing citizens, these same rights are not being translated to parenthood. Mothers and fathers with disabilities and their families remain invisible to the vast majority of service providers.

> It seems some people are surprised that women with disabilities can birth and raise children. Do some see people with disabilities as asexual and childlike, unable to reproduce? Or perhaps they think we are not able to care for our children. Maybe they fear we will produce disabled offspring, adding to society's burden (Auliff, 2001).

Llewellyn (1995,1998) found in her studies on family support and parenting with a disability that people with intellectual disabilities are unduly subjected to negative opinions about becoming a parent. Immediate family members as well as acquaintances may react to impending parenthood with disbelief and dismay and think competent parenting is unlikely. Parents perceive their disability as a major factor influencing these judgments.

Statistics of Abuse and Neglect In the United States the number of children reported to be abused and neglected rose from 1.4 million in 1986 to 3 million in 1997 (Califano, 1999). The estimated substantiated cases of child maltreatment in 1998 were 1,009,000. For every substantiated allegation of abuse or neglect, there were another two families reported for suspicion. A total of 3,154,000 children were reported for abuse and neglect in 1998. In 1999, an estimated 3,244,000 children were reported to Child Protective Services. Child abuse reports have maintained steady growth for the past ten years, with the total number increasing 45 percent since 1987. This is a rate of 45 per 1,000 children (National Committee to Prevent Child Abuse, 2000). Studies reported by the New York State Task Force in 1991 and 1992 indicated 16 percent of children in foster care had a parent with a severe mental illness (Blanch & Nicholson, 1994); and at least 2,000 children in out-of-home care and another 800 children enrolled in the state's child protective and prevention services programs had at least one parent with mental retardation (Ray & Rubenstein, 1994).

Parents with Disabilities and Abuse and Neglect Formal interviews conducted recently with pre and postnatal care professionals and child protective services workers in New Hampshire suggest that not only is the involvement of parents with disabilities in the system of child protective services high (Reischel, 1999), butthe system itself is not equipped to support these families to maintain their children adequately at home. It was determined that among more than 60 percent of families involved in child protective services in New Hampshire, one or both parents experienced some type of disability based on the U.S. Census definition of disability (see footnote 2). Despite the high number of families needing services in the system, there are no formal services in place for parents with disabilities.

Additionally, research findings indicate that individuals with disabilities are more likely themselves to be victims of abuse and neglect (Sobsey, 1999). In light of the patterns associated with abuse and neglect and people with disabilities, this evidence may suggest that parents with disabilities are more likely to engage in behavior that can be characterized as neglectful or abusive. Although a number of studies suggest that parents with labels of cognitive disabilities are more likely to be inadequate parents who abuse or neglect their children, intelligence cannot be separated from other confounding factors and may not be the primary contributing factor to abuse and neglect. Sobsey (1994) describes these contributing factors as an increased likelihood of parents experiencing abuse in their own history, an increased risk of family isolation, an increased likelihood of out-of-family care during the parents' own childhood, and differences in detection and reporting.

In case studies conducted by Taylor (1995) and Pomerantz and Pomerantz (1990), parents with mental retardation have historically been sources of concern to professionals in the field of human service with respect to their ability to raise children in a complex society. Taylor's 1995 study illustrates the negative perspective and broad assumptions about the ability of individuals with disabilities to parent and their propensity toward child abuse and neglect when the words "parent and mentally retarded are paired" (p. 24). Child protective workers, developmental disabilities personnel, and law officers hold these views. McConnel and Llewellyn (1997, 1998, 2000) found parents with disabilities in contact with child protective services in disproportionate numbers. Whitman and Accardo (1987) write that adults with disabilities live in the community, have children and experience significant parenting problems. Ronai (1997) in an ethnographic account of growing up with a mother with mental retardation, describes a life filled with sexual, physical, and emotional abuse. Parents with disabilities "contribute more than a simple headcount to the statistics for illiteracy, homelessness, child abuse, child neglect, failure to thrive, child sexual abuse, medical neglect, malnutrition, unemployment, and poverty (Whitman & Accardo p. 203). "

Anecdotal evidence and quantitative and qualitative research studies (Espe-Sherwindt, 1991; Pomerantz & Pomerantz, 1990; Taylor, 1995; Tymchuk, 1999) suggest that for parents with disabilities recommendations for out-of-home placement of children are significantly higher than for parents without disabilities. McConnell and Llewellyn (2000), offer alternative explanations for the high rates of child removal. These explanations are derived from reviews of child protection legislation, court protocols, and records of court cases. According to McConnell and Llewellyn (1998, 2000), children are removed from their families even when the evidence of neglect is refuted and despite evidence that the parents with disabilities were making progress toward overcoming the difficulties that led to the removal. These cases support the notion that parents with disabilities are held to a higher or different standard of parenting performance. The evidence presented by state court cases, which, if used against parents without disabilities, would not be enough to sever the family relationship. McConnell and Llewellyn conclude that without exception, parents with intellectual disabilities are seriously disadvantaged and subject to discrimination in child protection proceedings (1998, 2000).

Additional evidence of discriminatory practice is found when neglect has been substantiated yet children are removed before support services are provided. This contradicts the requirement in many states (including New Hampshire) in which the provision of services prior to child removal is a statutory prerequisite. While serious cases of child neglect may result in removal of the child from the home, the majority of interventions are designed to keep families together. This is not necessarily the case for parents with disabilities. Factors leading to these circumstances may include the lack of appropriate support services as well as the lack of understanding by the court systems about the needs of parents with disabilities. Child protective services and court systems play a significant role in the removal of children from their homes when a parent experiences a disability. However, anecdotal evidence strongly suggests that recommendations for out-of-home placements of children often occur during the earliest stages of pre and postnatal medical care prior to any demonstrated abuse or neglect when one or both the parents experiences a disability. This was the case for Ava.

Although individuals with disabilities partially achieved the legal right to become parents with the end of forced sterilization, this right is not routinely and legally protected. For example, a recent study of California adoption agencies (Estrada, 1996) concluded that the agencies were less likely to consider parents if one of the parents experienced a disability. Anecdotal evidence and quantitative and qualitative research studies (Taylor, 1995; Pomerantz & Pomerantz, 1990;

Espe-Sherwindt, 1991; Tymchuk, 1999) suggest that recommendations for out-of-home placement are higher for parents with a label of developmental disability connected to the child protective systems than for he population of parents without a disability. In Spokane, Washington, for example William Miller reported in the Spokesman Review (April 10, 11, 12, 1994, Spokane, Washington) on the tendency of child protective services to target young pregnant women with an IQ of 70 and below in order to remove their children at birth. Knowledge about protective service practices was so well known that in self-defense, some women left the state rather than subject themselves to this possibility of losing their children. Berry's (1992) research on the effectiveness of family preservation programs concluded that when parents experience developmental disabilities, child neglect and out-of-home placement is more likely to occur. Ray and Rubentein's (1994) research reports unmet service needs for parents with developmental disabilities in their communities despite Berry's claims of "equivalence" of service delivery in her 1992 study. These findings suggest that attitude and discrimination may play a significant role in the availability of appropriate support services for parents with disabilities.

Parents with Disabilities are Involved with Many Service Delivery Systems

Evidence shows that families in which parenting with a disability is present are involved with many service systems (Llewellyn,1995; Tymchuk, 2001). Involvement can be either voluntary or involuntary. These components include public and private healthcare, education, housing, welfare, vocational, mental heath, developmental disability, and other social services as well as child and adult protective services. Because each of these factors focuses on different aspects of the life of the person with the disability, each with differing requirements for participation, they seldom act in a manner that is integrated or holistic in their approach to meet the family's needs. In fact, there is strong evidence to suggest that agencies and organizations within the relationship of the family often work at cross-purposes. For instance, many children's protective services departments send parents with cognitive disabilities to generic parenting classes which are more likely to undermine self-esteem than be helpful. If parents do not benefit from these classes, they are typically portrayed as incapable – rather than questioning the appropriateness of the intervention (Kirshbaum, 2000).

Epse-Sherwindt (1991) found in her study of six parents with developmental disabilities participating in the Individualized Family Support Plan (IFSP) process that the parents were all connected to child protective services and an average of 4.7 agencies were involved. The chance for families to "succeed" was diminished considerably by the variety of professional expectations conflicting with the families' attention and resources. She described one mother with a label of mental retardation who had three children with disabilities. Each child received services from a different service provider, and all had unique and differing expectations for the mother.

> One professional wanted the mother to focus on feeding techniques for her oldest child with cerebral palsy; another wanted her to toilet train her middle child in preparation for preschool; another service provider was teaching her exercises to improve the baby's hypotonia, while the mother's own case manager wanted her to focus on her personal appearance and vocational opportunities (Epse-Sherwindt, 1991, p. 111).

It is no surprise that the professionals all felt frustrated by the lack of progress within the family. While this mother received a great deal of service support, the lack of interagency coordination resulted in confusion and failure on the part of everyone involved.

In Llewellyn's study (1995) of parent perspectives on supports and services, parents perceived assistance as highly valued resources when people offered help that was a "good fit" with their own perceptions of their needs, but they were less willing to comply if advice conflicted with their own views. Parents with disabilities described people as intrusive or unhelpful when assistance was based on judgments by outsiders or agencies about parental needs and ignored parental wishes. Many parents described the fear that their child would be taken away if they didn't comply with the plans of professionals. The number of people paid to provide support and the complexity of the various systems may be overwhelming. However, what many families need are not recognized as "services," including in-home support, housing services, and financial support.

Family Preservation Programs Family preservation programs are a form of family services that are receiving attention in both the popular and scientific press. These programs consist of three types of prevention: primary, secondary, and tertiary (Reppuci, et al., 1997). Primary consists of interventions to prevent a specified problem, such as child neglect and abuse, from ever happening; secondary prevention suggests early identification and early intervention; and tertiary prevention aims to reduce the severity and effects of the problem after it has occurred through some measure of rehabilitative treatment. Family support and parent education programs are unique in that they can be used for all three types of preventative interventions. Family preservation programs, according to

Bell (1995) are based in part on crisis intervention theory. This theory holds that families experiencing a crisis (such as removal of a child from their home) would be more amenable to receive services and learn new approaches to parenting and family living. Early supporters of this theory also believed that crises are experienced for a short time (e.g., six weeks) before they disappear or are resolved. Proponents of this theory developed programs to prevent out-of-home placements as well as created strategies for family reunification after children were placed in foster care.

Family preservation services vary within states and across the nation. Services for children and families designed to help families (including adoptive and extended families) at risk and in crisis include: parent training designed to improve parenting skills, respite care to provide temporary relief for parents and other care givers, and follow-up support to a family following the return of a child from foster care. Increasing the focus on family preservation programs is the result of legislative pressures to keep children out of costly out-of-home placements and preserve the integrity of the family unit. Studies conducted in 1992 (Berry); 1995 (Bell); and 1997 (Reppuci, et al.) concluded that the results of family preservation programs are promising. However, there is a need for additional longitudinal research to verify the effectiveness of strategies and long-term outcomes. These programs must now face the difficult task of justifying their funding and need sound evidence of their efficacy in preventing abuse and neglect.

While national research on family preservation programs holds promising results, these programs are not as effective for parents with disabilities. Parents with disabilities connected to child protective services, unfortunately, do not reflect the same outcomes as parents without disabilities. Berry (1992) evaluated the progress and outcome of 367 cases served during three years, noting that 30 percent had one or more parents who experienced a disability or serious illness and 10 percent experienced a developmental disability. Results of this research indicated that "mentally incapacitated families have a much higher out-of-home placement rate and workers judged these families to be significantly less cooperative and less physically and mentally capable" (Berry, 1992, pg.49).

Many parents with developmental disabilities have been unable to make their children's needs a priority without first addressing their own needs (Epse-Sherwindt, 1991). Limited research has demonstrated that when services take into account the parental living situation and learning needs, health-risks can be reduced and well being promoted for both parents and children (Feldman, 1994; Llewellyn, 1996; Tymchuk, 1999, 2001). Another outcome of more individualized services is that parents also may feel more comfortable in their parenting roles.

By their definition and design, family preservation programs are short-term in nature, intended to resolve a crisis in order to preserve the family. For many individuals with disabilities the need for intensive long-term supports in their life is a critical factor in the lack of success of family preservation programs. According to research conducted by McConnel and Llewellyn (1997) and Greene, et al. (1995), more time was considered necessary with parents with disabilities than with other parents to establish good relationships and determine preferences and needs. Additionally, child protective workers described a lack of training and experience in adapting traditional parent training programs to the needs of parents with developmental disabilities.

Promising practices have been identified which could effectively support parents with disabilities (Epse-Sherwindt, 1991; McConnel & LLewellyn, 1997; Pomerantz & Pomerantz, 1990; Taylor, 1995; Tymchuk, 1999). These practices include intensive home-based intervention, collaboration among service delivery agencies, systematic instruction as a parent education strategy, community support measures to actively assist parents to become part of their local community, and additional training for child protective agency workers. Preston and Jackobsen (1997) of the National Task Force on Parents with Disabilities and their Families recommend the following priorities and strategies:

1) Promote recognition and inclusion of parents with disabilities and their families by developing linkages to mainstream and disability organizations directed at families and adults with disabilities.

2) Promote informed regional and national policies which address the needs of families in which one or both parents experience a disability through changes in child protective service regulations, greater flexibility of personal assistance routines, Fair Housing Laws, changes in transportation policies, equal access to adoption services, and financial mechanisms to enable parents to purchase services and equipment to raise their children.

3) Increase access to services appropriate for parents with disabilities through parent and professional training, resource libraries, and accessible childcare sites.

4) Broaden the availability and development of adaptive parenting equipment.

5) Promote and support parents with disabilities and their families to speak for themselves.

6) Advocate for parents with disabilities across all disability categories, across all ethnic groups, and across all family constellations.

While these strategies suggest positive outcomes for parents with disabilities and their children, they are not widely recognized or implemented within the fields of child protection services and disabilities. There is also evidence from anecdotal sources that professionals in the field of pre and postnatal care are not aware of and do not recommend these programs and innovative strategies.

How children and their families grow depends on a variety of interconnected variables. The strength of a family does not rely solely on the competence of the parents (Booth & Booth, 2000). Numerous other relationships play an important part – from brothers and sisters, grandparents, aunts and uncles, and other relatives to childcare providers, neighbors, friends, peers, educators, and other more distant influences. Parenting is a shared activity that reflects and depends on the interdependencies and a network of social relationships that are important resources to the family.

Innovative Research

As the number of parents with disabilities raising children grows, so grow the concerns of pre and postnatal care professionals, child protective agency workers, disability professionals, and society. Parents with disabilities are an under-served and under-represented group in the research on child abuse and neglect. As a result, additional research is needed to understand the issues of parenting with a disability as well as promising practices in this area. This research will support the need to examine policies and practices related to parents with disabilities, particularly with respect to the actions, beliefs, and attitudes of pre and postnatal care professionals.

CHAPTER 3

LEARNING MORE ABOUT PARENTS WITH DISABILITIES: QUANTITATIVE AND QUALITATIVE APPROACHES

This study attempted to utilize multiple data sources for the telling of "disciplined stories" (Pugach, 2001) about the attitudes, beliefs, and experiences of pre and postnatal care professionals caring for parents with disabilities and highlight the perceptions and experiences of families receiving care. Concepts discovered regarding the attitudes, beliefs, and experiences of pre and postnatal care providers and experiences and perceptions of parents with disabilities may be investigated through the use of multiple measures applied to this topic. Both quantitative and qualitative methods such as survey methodology, in-depth interviews, and case study observation strengthen the validity of findings.

Researcher Assumptions and Research Questions

Researcher Assumptions As stated in the introduction, personal biases and experience as well as anecdotal evidence, suggest that the following assumptions should be explored through formal research. While it would be presumptuous to assume that a single study could confirm or refute the assumptions that guide the research questions of this study, it is likely that the topic of parenting with a disability will be better understood through the efforts of this work. Researcher assumptions that lead to the development of research questions are as follows:

1) The factors that influence out-of-home placement recommendations

for children of parents with disabilities are based on societal biases and a medical model approach in existence prior to the birth of a child.

2) Pre and postnatal care professionals are unfamiliar with the myriad of supports that may be available for parents with disabilities.

3) Formal systems of support for parents with disabilities do not coincide with the best interest of children and families.

4) New systems of support merging parenting and disability supports will need to be developed to respond to the new family structures in today's society.

Central Research Questions The questions central to this study are: What are the experiences, beliefs, and attitudes of pre and postnatal professionals in New Hampshire connected to parents with disabilities; and what is the experience of parents with disabilities with respect to their early connections to formal systems of family support such as child protective services and family support agencies?

In order to confirm or refute my assumptions related to the central inquiry, the following specific questions were addressed:

1) Are pre and postnatal care professionals more likely to refer parents with disabilities than parents without disabilities to child protective services?

2) Is there a relationship among pre and postnatal care professionals' career experiences, personal experiences with disability, and the likelihood of referral of parents with disabilities to child protective services?

3) How aware are pre and postnatal care professionals of supports and

services available for parents with disabilities?

4) What are the experiences of parents with disabilities receiving child protective services?

5) What ways do parents with disabilities perceive they have encountered discrimination as parents because of their disability?

6) How can services and supports be more appropriate for parents who have disabilities?

The goal of this research is to explore these questions and generate hypotheses through the comparison of similarities and differences among the groups studied. Suggested hypotheses will emerge which will lead to: potential solutions to the problems identified through this research; new areas of research; policy recommendations; and the integration of this information into substantive and formal levels of theory regarding parenting, disability, and professional decision-making.

Research Methodology

This study utilized descriptive survey research, in-depth interviewing and case study design to address the research questions. Descriptive survey research was selected in order to provide anonymity as well as elicit responses from a broad population of pre and postnatal care professionals. In-depth interviewing and case study designs were chosen in order to bring to life problems and successes shared by parents with disabilities and their families and pre and postnatal care providers.

Descriptive Survey Research Survey research was utilized to collect descriptive data through a written questionnaire based on self-reporting by respondents. Survey research is the most effective way, according to Portney and Watkins (1993), to obtain information relative to the psychological variables of fears, perceptions, motivations, and attitudes. By employing Dillman's (2000) Mail and Internet Surveys: The Tailored Design Method of surveying, respondents were able to view their participation in this research as a valuable social exchange to help solve important societal problems. In this instance, the important societal problem of parenting with a disability was described within the pre-survey notice and the letter accompanying the survey. Dillman's method (1999) of mail, Internet, and telephone surveys has achieved an average response rate of 74 percent with no effort achieving less than 50 percent. The high return rate was the impetus for utilizing Dillman's Tailored Design Method.

This survey research involved six steps; 1) the organization of a focus group to refine and field test the survey, 2) mailing a pre-notice letter to the survey census sample, 3) mailing the cover letter and survey, 4) mailing a follow up postcard thank you/reminder, and finally, in order to achieve a response rate close to 70 percent, 5) the mailing of a second survey and 6) when necessary conducting telephone interviews.

Focus group. A national Internet focus group was recruited and assembled prior to the development of the survey instrument. Participants were recruited through a national closed listserve for pre and postnatal care professionals where a description of the study and request for focus group members was placed. Interested members were asked to e-mail me and were then sent research questions and the survey drafts in all stages of development. The focus group included eight professionals in the field of pre and postnatal care interested in the topic of parenting with a disability. The focus group responded to early drafts of the survey and provided input in the development of the pre-notice letter, survey cover letter, and survey. This input was highly valuable in developing an instrument that would lead to a high response rate among the professionals involved in pre and postnatal care.

Survey design. The survey instrument is a questionnaire designed specifically for this research to produce descriptive information, which was analyzed following the tabulation and synthesis of data. There is no existing published survey that addresses these issues.

Ability to gain access to research participants. Medical professional organization staff agreed via telephone to share their mailing lists for the purpose of the survey. All organizations provided up-to-date mailing lists for the purpose of this research. A small fee was charged by two of the participating organizations.

Item construction and format. Prior to dissemination, field testing was conducted among the internet focus group (n = 8) to check for ambiguity, poorly prepared items, and confusion. Additionally, in-depth interviews based on survey questions occurred with approximately one percent of survey recipients (n = 9). Items constructed for the questionnaire involved demographic information about the respondent and content information related to the respondents' attitudes, behaviors, knowledge, and experience working with parents with disabilities. The questionnaire consists primarily of forced-choice, multiple response options, and selected-response to keep the process as simple as possible to obtain the necessary data, prevent measurement error, and maximize the amount of information from respondents. Open-ended questions were included as a strategy to elicit additional information.

Measures. The survey contains a multitude of variables including nominal, ordinal, and measurement (interval and ratio). For example, professional experience with disability is captured by nominal measures. An ordinal 5 point scale with "always" to "never" as anchor points is used to characterize and code survey responses related to real and scenario-based referral practices of pre and post natal care providers, and measurement variables include questions related to frequency of contact and referrals for parents with disabilities.

Survey participants. A census questionnaire was developed and disseminated to all NH certified direct entry and nurse midwives, NH certified ObGyn doctors, NH pre and postnatal nurse practitioners, and NH certified pediatricians included in professional organization mailing lists. Professional medical organizations associated with these groups provided access to current mailing lists totaling approximately 719 pre and post natal care providers. See Appendix A for the pre-notice, cover letter, and survey. The responses of this group of medical pre and postnatal care professionals provided a picture of professional attitudes and practices as they relate to parents with disabilities and recommendations for connections to formal and informal support services. The survey assisted in determining the knowledge, experience, and attitudes of pre and postnatal care professionals as they relate to the process of family referral to resources following a child's birth.

Survey mode. An introductory letter explaining the research was mailed prior to the cover letter and survey. Follow-up postcards were sent to 715 professionals and telephones calls were made to ensure a response rate close to 70 percent. In-depth interviews, using the survey questions, occurred with nine self-selected participants representing all categories of pre and postnatal care professionals.

Data analysis. Quantitative data analysis will be presented in a descriptive manner provided with percentages and proportion of respondents as backup to address the following research questions:

1) Are pre and postnatal care professionals more likely to refer parents with disabilities than parents without disabilities to child protective services?
2) Is there a relationship between pre and postnatal care professional's career experiences, personal experiences with disability, and the likelihood of referral of parents with disabilities to child protective services?
3) How aware are pre and postnatal care professionals of supports and services available for parents with disabilities?
6) How can services and supports be more appropriate for parents who have disabilities?

In order to answer question 1, a descriptive frequency analysis approach was used. Survey questions 21 through 24 contained scenarios of families with a variety of parenting issues. Respondents were requested to refer parents to select services based on the presenting issues. An analysis of frequency of referrals to child protective services compared to other services answered question 1.

Question 2, requires the most intensive quantitative analysis approach. Frequency analysis, chi-square, are the central statistical techniques. The results of these data are presented in summary tables in Chapter Four. All of the independent variables related to the outcome of referral to child protective services have been measured. Additionally, a second dependent variable, intended result of referral, was examined. Chi-square analysis is the most appropriate approach because these variables are both categorical and measurement. Dependent variables include professional experience, personal experience with disability, age, location of professional practice, number of children, and knowledge of services. A frequency analysis reported in a pie chart sheds light on pre and postnatal care professionals' opinion of the supports and services available to parents with disabilities.

Open-ended qualitative responses have been examined and organized according to themes to answer question 3. Survey questions 4a, 11, and 19 solicit answers to questions about professional training experience regarding parents with disabilities, guidelines in providing services to parents with disabilities, and knowledge of programs noted for their services and supports for parents with disabilities.

Timeline. This research component was completed within nine months beginning April 2001 and ending December 2001.

In-depth Interviews with Pre and Postnatal Care Providers

Participants. In-depth interviews were conducted with nine self-selected pre and postnatal care professionals as a method to elicit additional information beyond the survey instruments and corroborate the information gained through the survey.

Interviewees self-nominated by completing the portion of the mail survey that asked: "Would you be interested in participating in an in-depth interview on the topic of parenting with a disability?" Interview participants were selected based on their willingness to participate in the interview process, availability to participate within the timeframes of this research study, geographic location of their professional practice, and professional affiliation represented. Interview participants represent small towns, small cities, and the rural North Country of New Hampshire. Professional pre and postnatal care affiliations represent visiting nurses, pediatricians, obgyns, healthcare coordinators, and a midwife. Interviews were conveniently arranged at the interviewee's location of employment.

Semi-structured interview questions. Interviews were approached with a broadly structured script that guided the discussion and provided a basis to compare responses. The script was flexible enough, however, to allow for probing and the ability to ask follow-up questions specific to the individual's circumstances. The semi-structured script included the following questions:

1) Tell me how you come into contact with parents with disabilities?

2) What prompted you to participate in an in-depth interview?

3) Describe some of your most challenging professional situations dealing with parents with disabilities.

4) What resources do you typically access for parents with disabilities?

5) If a woman with Down syndrome were pregnant and in your care, what would be your response?

6) Do you have any recommendations for addressing the challenges of supporting parents with disabilities?

Order and structure were imposed on the interview transcription through a coding process and content analysis that was reviewed by a research assistant to achieve inter-rater reliability. Interviews typically lasted an hour and all interview notes were audiotaped, recorded verbatim, reviewed, organized according to presiding themes, and then coded according to the potential for the particular theme to have a positive or negative influence on the topic of parenting with a disability. This process was developed following all data collection. The next phase was open coding, which involved applying a code to each designated unit of meaning in the interview transcripts and field notes to generate a coding list. At this stage the codes represented concepts in the data that were organized into clusters of categories. For example, an interviewee may describe her sister with a disability and the likelihood that the sister could ever marry and have children because of her disability. This response would fall into the category of "personal experience with disability" and receive a coding of "-" to indicate the potential negative influence toward attitudes about parenting with a disability because the respondent discussed the unlikelihood that the sister could ever be a parent and raise children.

These interviews provided data related to the research questions:

1) Are pre and postnatal care professionals more likely to refer parents with disabilities than parents without disabilities to child protective services?

2) Is there a relationship between pre and postnatal care professional's professional experiences, personal experiences with disability, and the likelihood of referral of parents with disabilities to child protective services?

3) How aware are pre and postnatal care professionals of supports and services available for parents with disabilities?

6) How can services and supports be more appropriate for parents who have disabilities?

Case Studies Case study methods were a third component of this research. The purpose of the case studies was to provide detailed descriptions of a range of experiences shared by parents with disabilities through in-depth interviews, participant observation with families, and review of archives. By utilizing these techniques, the sequence of life events, coping responses, and the responses of the formal and informal systems of support for parents with disabilities were studied. Corroboration or dissonance of data was assessed through the examination of the multiple data sources from survey research, in-depth interviews, and case studies.

<u>Sample.</u> Two families representative of parents with disabilities with young children were selected from a pool of five for intensive case studies to understand their experiences with formal and informal connections to services and supports. The two participating families have at least one parent with a developmental or mental health disability and are connected to at least one formal system of support such as child protective services or/and family support agencies. Family selection took place following the advice and guidance of child protection workers within the New Hampshire Division for Children Youth and Families and family support coordinators within the Area Agency system. Families selected were determined representative of typical families when parenting with a disability is an issue by the family support coordinators and staff from the parent support programs interviewed for this study. Additionally, both families were selected because they have young children and the focus of this study being on current and early practices and systems of support for parents with disabilities. Although access was granted, the Division for Children Youth and Families was non-responsive in the efforts to select families. A potential explanation to this challenge was the competing stresses of an overworked, understaffed agency needing to respond to numerous requests for information – most pressing being that of the New Hampshire Legislature (Rollins, personal communication, 2002). Numerous meetings, follow-up letters, and follow-up telephone calls occurred to select families identified through the Division for Children Youth and Families, but ultimately these attempts did not result in the identification of families. Families selected for participation were

chosen via family support coordinators and informal connections within the system of disability service delivery in New Hampshire.

Review of archives. A review of archives, such as caseworker reports and medical records, was not as available to the case study approach as originally believed because of the constraints from the Division of Children Youth and families.. Families did provide informed consent to this process but, because of the lack of cooperation from the Division of Children, Youth, and Families, archives of case study family's records were not available for review for each of the families participating in the study. In place of archival review, for the purpose of corroborating information, interviews were conducted with parent support programs and parent educators involved in the lives of the two families.

Data coding and analysis. Data analysis encompassed Taylor and Bogdan's (1984) three phases: 1) ongoing discovery of identifying themes and developing concepts; 2) coding the data and refining how to interpret the data; and 3) discounting the data findings by understanding the data in the context they were collected. Prior to sorting data into categories, data were coded, refined, added to, collapsed, and expanded. All field notes, transcripts, and documents were coded by assigning data to categories placed in the margins and highlighted with colored pencils. Data that were left out were accounted for and all data were discounted according to the influence of the context such as solicited and unsolicited data, observer's influence, data sources, and personal assumptions and biases.

Outcomes. The final product or outcome of the case study approach is a narrative description constructed as a process of putting a story together in such a way that it captures the research participant's own feelings, views, and perspectives. This process has been incorporated into the whole study in the effort to answer the research questions.

4) What are the experiences of parents with disabilities receiving child protective services?

5) What ways do parents with disabilities perceive they have encountered discrimination as parents because of their disability?

6) How can services and supports be more appropriate for parents who have disabilities?

Timeline. This research effort was completed in nine months beginning in May 2001 and ending January 2002.

Protection of Human Subjects assurance. All participants in the proposed study were assured that their participation was completely confidential and voluntary. Survey responses were aggregated to avoid identification by their individual answers. Names and identifiable demographics were changed for case study participants. Approval was obtained from the University of New Hampshire's Institutional Review Board. See Appendix A for IRB Approval.

CHAPTER 4

AN EMERGING UNDERSTANDING OF THE EXPERIENCE, ATTITUDES, PERCEPTIONS, AND PRACTICES OF PRE AND POSTNATAL CARE PROVIDERS AND PARENTS WITH DISABILITIES

Insights, issues, and new concepts discovered through examining the experiences of pre and postnatal care providers and parents with disabilities are reinforced and confirmed through the multiple methodologies applied to the interpretation of this topic. Both qualitative and quantitative methods - such as survey methodology, in-depth interviews, and case study observation - strengthen the validity of the research results. As detailed in the previous chapter, the study's findings are drawn from data collected through a mail survey of all New Hampshire pre and postnatal care providers, in-depth interviews with nine pre and postnatal care providers, and case studies with two families in which one or both of the parents experience a disability. First, broad findings that relate to all research questions will be presented. Specific findings related to each research question will follow.

Survey Response

The survey, conducted in the spring and summer of 2001, was mailed to all registered pre and postnatal care professionals (n = 719) in the state of New Hampshire. These professionals included registered visiting nurses, obstetrician-gynecologists, midwives, pediatricians, and birth coordinators. The survey resulted in an overall response rate of 64 percent of all pre and postnatal care providers in New Hampshire. This high rate of response can be attributed to the use of Dillman (2000) method of mail and Internet surveys. The respondents were asked to return a postcard on which they were requested to check off either "I have completed the survey," or, "My field of work does not apply to pre and postnatal care." The return of a postcard was counted as a response. The number of returned postcards totaled 457. A more accurate response rate based on completed surveys and the subtraction of response cards stating "My field of work does not apply to pre or postnatal care" is 46 percent. Each survey in the data set represents a case and there are 234 completed surveys of the 244 returned.

The highest rate of return from respondents whose field of work does not apply was registered visiting nurses. Not all of these professionals work in the field of pre and postnatal care and it was not possible to delineate categories within the mailing list provided by the professional association. Additionally, mailing lists contained a multitude of duplicates in various categories. For example, approximately 80 pediatricians and obgyns were cross-listed on both mailing lists. Birth coordinators represent the highest rate of return at 69 percent and midwives the lowest at 26 percent. The geographic location professionals identified with in the survey represented 52.6 percent rural, 36.3 percent suburban, and 9 percent urban. Women comprised 69.7 percent and men 29.5 percent of the respondents; 87.6 percent were parents and 11.5 percent are not. Age ranges from 27 years (n=1) to 70 (n=1) The median age was 45. Table 1 depicts survey returns by professional categories.

Table 1: Survey Returns by Professional Group

Professional Title	**Frequency**	**Percent**	**Valid Percent**	**Cumulative Percent**
RN/ARNP	91	38.9	38.9	38.9
OBGYN	43	18.4	18.4	57.3
Midwife	8	3.4	3.4	60.7
Pediatrician	76	32.5	32.5	93.2
Birth Coordinator	16	6.8	6.8	100.0
Total	N=234	100	100	

Data analysis was conducted utilizing SPSS. Data were defined and coded numerically for every survey question. Frequency analysis, cross tabulation, chi-square, and Pearson correlation were the statistical tests used to analyze survey data. An alpha level of .05 was used for all statistical tests. The data set contains both measurement and categorical variables. Measurement variables include years of professional experience, number of parents cared for, age of respondent, and number of children of respondent. Categorical variables include professional affiliation, referral rates to support services, relationship to disability, training received about parents with disabilities, and personal information. Additionally, opened- ended questions were asked requiring the respondent to describe their professional training experience (question 4a), guidelines followed in caring for families when a parent experiences a disability (question 11), and programs of which professionals are aware that are noted for their involvement with parents with disabilities (question 19).

Interviews with Pre and Postnatal Care Providers

Nine face-to-face interviews were conducted with professionals in the field of pre and postnatal care. Interviewees self-selected by completing the portion of the mail survey that asked, "Would you be interested in participating in an in-depth interview on the topic of parenting with a disability?" Of the 244 returned surveys, thirty-eight individuals volunteered to participate. All these individuals were contacted via telephone and/or e-mail, and arrangements were made to conduct the interviews with respondents who were still interested in participating. Interview participants were ultimately selected based on their willingness to participate in the interview process, availability to participate within the timeframes of this research study, geographic location of their professional practice, and professional affiliation represented. Interview participants represented small towns, small cities, and the rural North Country of New Hampshire. Professional pre and postnatal care affiliations represented visiting nurses (n3), pediatricians (n2), obgyns (n2), a birth coordinator (n1), and a midwife (n1). The number of participants in the selected categories was in direct correlation with the percentage of respondents comprising the breakout of professional titles in the returned surveys. Interviews were conveniently arranged where the interviewee worked. Interviews took place in environments ranging from large medical centers, small doctor's offices, and a community health center office, to a human service agency office, and in the midwife's home. Six women and three men were interviewed.

The clusters of categories that emerged through the coding and analysis of the transcripts were 'personal experience with disability,' 'professional experience and training in disability,' 'types of disabilities and ability to parent,' 'knowledge of disability resources,' and 'recommendations for change.' Each theme within all categories except 'recommendations for change' received a positive or negative valence based on my subjective interpretation of the respondents' perspectives and attitudes about the topic at hand. For example, the following quote would fall in the category of 'type of disability and ability to parent' (Down syndrome) and receive a '-' regarding the professional's attitude toward a person with Down syndrome in the role of parent.

> Downs children, I believe, are less fertile, so you aren't going to see that many Downs parents. I think they would need help raising a child. They would not be able to do it on their own, they would need their parent's support, they would need someone, I don't think they could be left alone with the baby. (obgyn)

The category " Professional Training in Disability and Ability to Parent" followed the same coding process. For example, the following quote is categorized as "no training in care when parents experience a disability" and be coded "-."

> I think it it is a lack of training on our part to really ask any family illness questions. I think we have to ask questions better. But I had no training in taking care of parents and helping the families where parents have disabilities. (pediatrician)

Positive and negative coding represents only one response within each category per interviewee. In a few instances professionals seemed ambivalent. This is important to acknowledge and were sometimes coded as both "+' and "-." Selected quotes are included in sections below to add richness and reliability to the presentation of findings. The research assistant was utilized to achieve interrater reliability in the coding of all transcripts. For all data coding in which consistency was not achieved, discussion took place to agree on a code or discard the data. Approximately 85 percent of all relevant transcript data achieved 100 percent interrater reliability and are contained in this study. Many of the data that were not included related to discussions regarding people with chronic health conditions such as asthma, cancer, and HIV therefore were not appropriate to include in this study. I began each of the interviews with an explanation of my interest in the topic of parenting with a disability. The following statement is an example of how I began each interview:

> This topic is not an area I started out saying I am really interested in the topic of parents with disabilities. I became fascinated by it because of the absence of information. As I listen to the stories of parents with

disabilities, I often hear that parents are concerned about the availability (or lack thereof) of parenting support. I began to wonder...where does this support come from and how do parents access it?

Family Case Studies

Selected Families The Schultz and the Becker families participated in the case study process. Families were interviewed in their homes, in their neighbor's home, in their parent support programs, and over the telephone. A total of eight hours of interviews and observations took place. The Schultz family consisted of a single parent with developmental disabilities of two children living with her parents in semi-rural New Hampshire. The Beckers included two parents with mental illness and their three children, living in urban New Hampshire. Both families were willing and interested participants in the case study aspect of this research project.

In-depth interviewing with families. In-depth interviewing occurred with both families. Interviews involved face-to-face encounters between myself and the participants in order to understand the participants' perspectives on their own lives, experiences, and situations as described in their own words (Taylor & Bogden, 1984). This interview process was modeled after respectful conversations among equals rather than a formal predetermined question and answer method. Through the process, I gathered information by learning what questions to ask along the journey of data gathering. By asking non-directive questions initially, I learned what is important to the participants. This process guided the data collection. Interviews were conducted over a two-month period and across a variety of settings such as home, a neighbor's home, family support program, and a parent training event.

Parents were given every opportunity to ask questions about the study and seek reassurance about anonymity and confidentiality. When they were satisfied about what their involvement entailed, I asked them to sign an informed consent form. Another family member assisted when necessary to help the interviewee understand the informed consent form.

Interviews were tape recorded with parental permission. In a few instances however, tape recording was not appropriate due to concern for privacy or background noise in a public place. In these circumstances, I made extensive field notes during and immediately following the interview period. One family was interviewed two times in two different settings. One family was interviewed three times in three different settings for a total of approximately four plus hours per family.

Participant observation. Participant observation goes hand-in-hand with in-depth interviewing. Observations that were not part of the interviews occurred at the parents' invitation. This method of observation took place within the natural contexts of the subjects. For example, I was invited to observe family interactions in the home of one of the families and attend a parent-baby support program that was determined helpful to one of the families. For information that may not be gathered through the interview process, a keen eye and ability to acquire and interpret meaning from ordinary surroundings are critical to the data collection process. Observation took place in the individuals' homes, social, and community surroundings, and other places determined by the participant. A minimum of two visits each lasting two hours occurred. Telephone calls to verify additional questions and information were made following each visit.

Presentation of Specific Research Results

Results of this research study are presented in direct correspondence with the appropriate research question. This approach allows for data to be organized into meaningful themes and responses to questions.

Are pre and postnatal care professionals more likely to refer parents with disabilities than parents without disabilities to child protective services?

While this question was not specifically asked in the survey of pre and postnatal care professionals, descriptive survey data regarding information about referral practices and results from in-depth interviews with professionals in pre and postnatal care are utilized to address this question.

Survey data. These data reflect an analyzed frequency count of 81.8 percent of respondents who have actually cared for parents who have disabilities. Only 18.2 percent of survey respondents have never cared for a parent with a disability. There was no data for three respondents. See Table 2.

Table 2: Number of Respondents Caring for Parents with a Disability

Professional Title		**Treated parent w/disability**		**Total**
		Yes	**No**	
ARNP/RN	Count	78	13	91
	% within professional title	85.7%	14.3%	100%
OB-GYN	Count	42	1	43
	% within professional title	97.7%	2.3%	100%
Midwife	Count	5	3	8
	% within professional title	62.5%	37.5%	100%
Pediatrician	Count	50	23	73
	% within professional title	68.5%	31.5%	100%
Birth Coordinator	Count	14	2	16
	% within professional title	87.5%	12.5%	100%
Total	**Count**	**189**	**42**	**231**
	% within professional title	**81.8%**	**18.2%**	**100%**

Descriptive survey data include the results to question 14, "Have you ever made a referral to child protective services for a family in your care when one or both parents experience a disability?" 36.8 percent responded "yes" and 63.2 percent responded "no." See Figure 1 for professional responses.

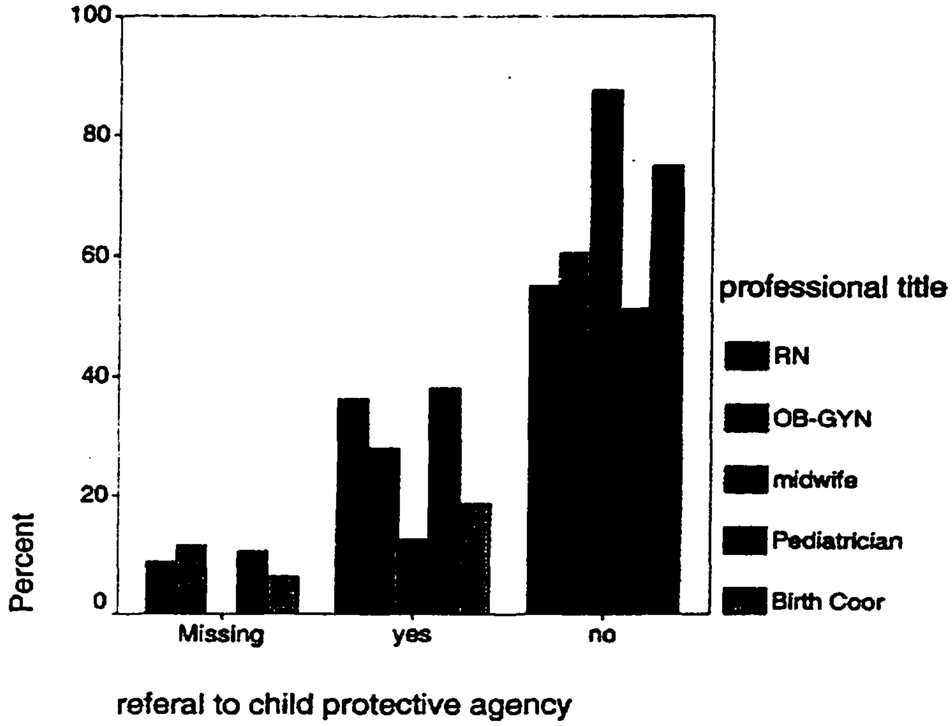


Figure 1: Percent of Referrals to Child Protective Services by Professional Categories

The most frequent reason for referral was the perceived risk of child abuse - 55.7 percent as opposed to actual evidence of child abuse - 38.9 percent. To question 18, "In your opinion are parents with certain types of disabilities more likely to be referred to child protective services?" 57 percent responded "yes" and 43 percent responded "no." The type of parental disability most likely to lead to referral was mental illness (n=58), followed by cognitive disabilities (n=40). Physical and sensory disabilities were not cited by any respondents (n= 0).

The questions most specifically designed to answer research question "Are pre and postnatal care professionals more likely to refer parents with disabilities than parents without disabilities to child protective services?" were survey questions 20 through 24. These questions presented four scenarios of different types of families with a variety of disability and nondisability experiences. Respondents were asked to make referrals based on the issues presented by the family described in the scenarios. Referral sources included home visiting services, adoption, foster care, parent training program, child protective services, early intervention, a local area agency, mental health centers, Granite State Independent Living, Disability Rights Center, welfare agencies, housing agencies, and others. Circumstances the families presented changed in each scenario. Challenges included poverty in rural New Hampshire, unemployment, an employed mother with cerebral palsy, a single mother who is blind, and a mother with a low IQ whose husband has schizophrenia. See Appendix A for a copy of the survey.

Only two scenarios resulted in referrals to child protective services. One scenario concerned a mother with an IQ of 70 married to a man with schizophrenia. Fifty professionals (21%) of all respondents recommended referral to child protective services. The other scenario represented the single mother who was blind. Eleven professionals (4.7%) of all respondents recommended referral to child protective services. In both scenarios, the frequency of these referrals was too low to analyze beyond a simple count.

The data represents a 95.3 percent response rate to these questions (n=223) from a total number of 234 surveys.

In-depth interview data. Data derived from the in-depth interviews with pre and postnatal care professionals were categorized according to "type of disability and ability to parent" and coded according to whether the disability type led to a positive or negative attitude toward one's ability to parent. The synthesized data are presented in the table below followed by specific quotes from pre and postnatal care providers regarding disability and parenting.

Table 3: Type of Disability and Ability to Parent

Type of Disability	Ability to Parent
Deafness	+, +,+,+, +,+
Physical Disabilities	+,+,+,+,+,+, +,+, -
Loss of Hand	+
Mental Retardation/Cognitive Disabilities	-,-,-,-,-,-+,-
Down Syndrome	-,-,+,-,-,-
Mental Illness	-, -,-,-,-,-,-
Arthritis	+
Spinal Cord Injuries	+
Chronic Illness	+
Blindness	-
Addiction	+
Communication Disability	-

> I would have to really step back and ponder the big ethical issue of whether people with significant limitations in life should be encouraged to be all they can be and go out and reproduce or when they should be discouraged. From which side of Darwin's theory - I don't know the answer to that one. (obgyn) (-)
>
> There are lots of people on these injectable, long-acting contraceptives because they are vulnerable to pregnancies and that is what their care taker says is appropriate. And

whether you can get informed consent from somebody who cannot carry on a conversation. It is hard. You won't solve that one. (obgyn) (-)

I think, particularly with parents with cognitive disabilities there are issues of neglect, and I say, benign neglect in that I don't think that anyone maliciously or intentionally is neglecting their child, but certainly couldn't attend to the needs of their child, and therefore the child should be removed from the home. This is a gray zone we end up doing with parents with cognitive disabilities. (pediatrician) (-)

In the cases of mental impairment, the parent of a child with normal intelligence can sometimes present additional difficulties, particularly at adolescence, in that the child may be embarrassed when they become aware that they are smarter than their parents. (pediatrician) (-)

If you take a population of parents with an IQ of 80 and compare it to a population of parents with an IQ of 100, there would be a higher percentage of failure to parent well among the population of parent's with lower IQs. SO I am sure you could find information that there is discrimination toward parents with intellectual disabilities. You start out with the bias that a parent with an IQ of 80 is a risk factor. Some of these parents will do a perfectly good job on their own. Some of them will do an adequate job with some help and some aren't going to do a good job, even with help. You don't know which category a particular parent is going to fall until you see how they are doing. (pediatrician) (-)

I was a little surprised that these kids were still with their mothers (mothers w/ addiction problems) where it looked to me like they shouldn't be. So I had to change and broaden my whole perspective to recognize that we should try to keep these kids with their parents - knowing that the kids probably do better.(midwife) (+)

It is possible to visualize people becoming parents and falling in love when they are in a wheelchair but harder when I look at my own prejudices. (midwife) (+)

Deaf parents and those with physical disabilities are both challenges that are fairly obvious and people are willing to jump in and help people manage.(pediatrician) (+)

A mother I know who is severely cognitively impaired and she couldn't set an alarm clock and yet she parented this child with

> huge amounts of support. But that is mostly because we looked at the surrounding issues and said 'in this situation, given everyone's time and effort, we feel strongly enough that we are willing to put in the time and effort for this mother and child. I can envision the same mother and child in different circumstances where it wouldn't happen. (pediatrician) (+) (-)

In-depth interviews resulted in a clear preference that people with certain types of disabilities are more likely to be referred to child protective services than others. Attitudes toward the parenting ability of people with physical disabilities or who are Deaf were positive and mental retardation, cognitive disabilities, and Down syndrome all were perceived to negatively influence parenting.

Question one summary. The culmination of data from the survey and in-depth interviews resulted in findings that suggest that the majority of pre and postnatal care providers have cared for parents with disabilities yet only 36.8 percent have made referrals to child protective services for parents with disabilities. Mental illness and cognitive disabilities were the disabilities most likely to be referred. Further analysis will be provided in Chapter Five.

Is there a relationship between pre and postnatal care professional's career experiences, personal experiences with disability, and the likelihood of referral of parents with disabilities to child protective services?

The response to this question requires the most intensive quantitative analysis approach utilized in this study. Chi square, Pearson Correlation, and cross tabulation analysis were the statistical techniques that compared the variables of professional experience and personal experience with likelihood of referral. All of the independent variables related to the outcome of referral to child protective services were measured. These variables include professional experience, personal experience with disability, age, location of professional practice, number of children, and knowledge of services. Additionally, specific results from in-depth interviews add context and life to the analyzed data.

Survey data. A simple frequency analysis to survey question 4 "Did you receive training and information about parents with disabilities in your professional training program?" resulted in a 100 percent response rate to the question with 21.4 percent having received training and information on the topic of parenting with a disability and 78.6 percent responding that they have not received training and information on the topic. See Figure 2.

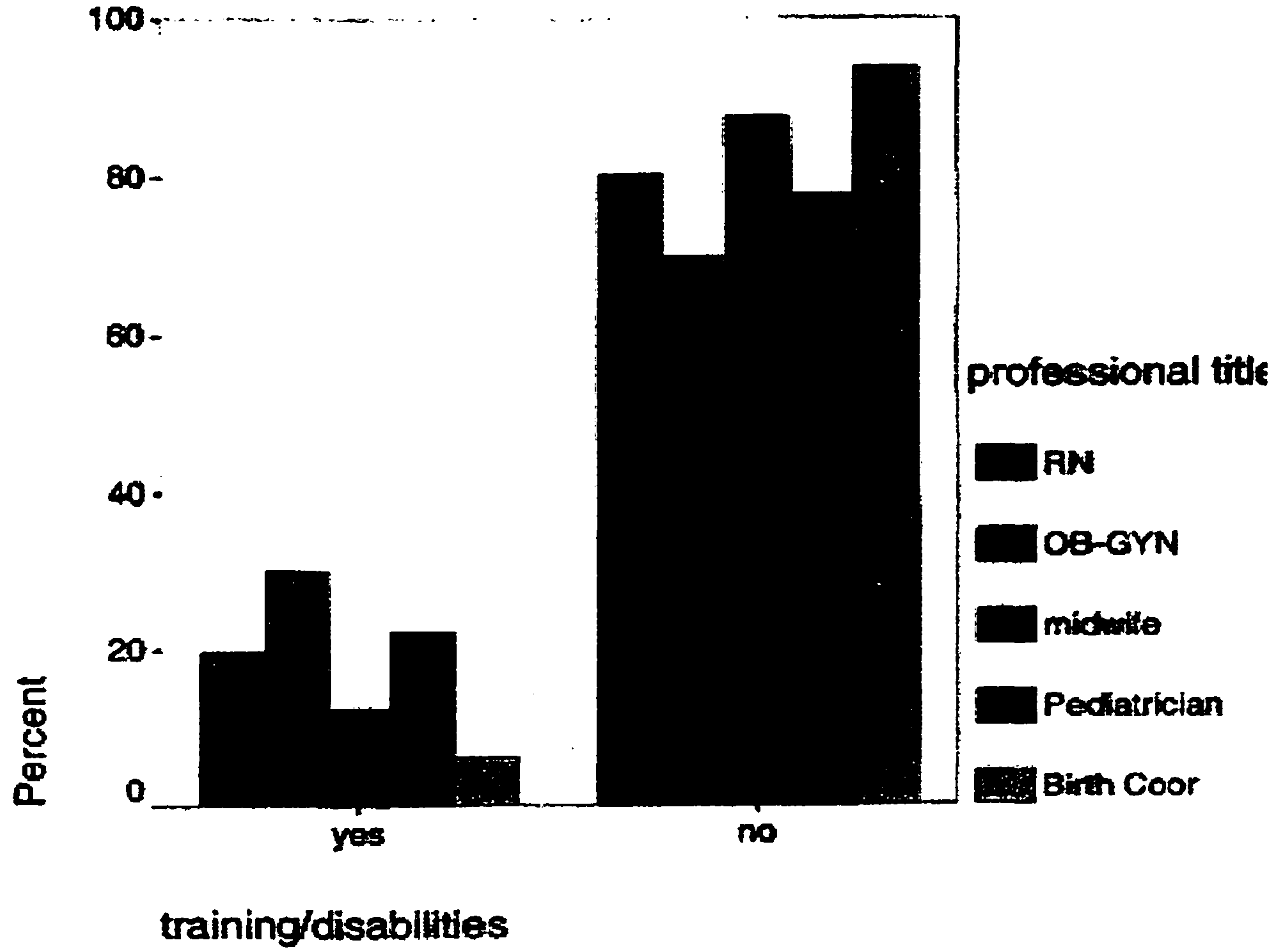


Figure 2: Professional Training and Experiences in Parenting with a Disability

Chi-square analysis revealed variables impacting referral to child protective services as well as the intended outcomes of those referrals. With an alpha level of .05 the effect of training was statistically significant. In addition, geographic location shows the promise of significance.

Table 4: Variables Impacting Referral to Child Protective Services

Variables	Chi-square	df	P
Training	6.28	1	.013*
Gender	.353	1	.553
Professional Title	5.609	4	.230
Geographic location	5.923	2	.052
Personal experience	2.520	1	.112
Marital status	2.77	3	.563
Parental status	.979	1	.323

*p < .05

Pearson correlation revealed the potential significance of age and years of experience in relation to referrals to child protective services as shown in Tables Five and Six. Years of experience were significant at .05.

Table 5: Correlation of Referral Practices and Age

Pearson Correlation		Referral	Age
Referral	Correlation	1	-.056
	Sig (2-tailed)	.	.423
	N	212	204
Age	Correlation	-.056	1
	Sig (2-tailed)	.423	.
	N	204	225

Table 6 Pearson correlation referral/year of experience

Pearson Correlation		Referral	Experience
Referral	Correlation	1	-.148*
	Sig (2-tailed)	.	.423
	N	212	209
Experience	Correlation	-.148*	1
	Sig (2-tailed)	.033	.
	N	209	229

*p < .05

The following table indicates the intended result of referring to child protective services when one or both parents experience a disability.

Table 7: Intended Result of Referral

Variables	Chi-square	df	P
Referral to remove child	.272	1	.602
Referral for family support	4.207	1	.040*
Referral for family training	4.543	1	.033*

*p < .05

Professionals who received training in disability issues were more likely to refer parents with disabilities to child protective services than professionals who did not receive training. Cross tabulation and a chi-square hypothesis test confirmed this result. Training was the predominant variable showing statistical significance. Geographic location (rural) and years of experience also showed significance. Age of respondent, personal experience with disabilities, marital status, gender, and status of parenting were all insignificant variables. Additionally, the intended outcome of referral was parent training and support (not child removal) at statistically significant levels (.05) confirmed by cross tabulation and chi-square hypotheses tests.

In-depth interview data. Data derived from in-depth interviews with pre and postnatal care professionals were categorized according to "personal experience with disability and ability to parent" and coded according to whether the disability type led to a positive or negative attitude toward one's ability to parent. Professional training was also discussed. The synthesized data are presented in the table below, followed by specific quotes from pre and postnatal care providers regarding disability and parenting.

Table 8: Personal Experience with Disability and Ability to Parent

Personal Experience with Disability	Ability to Parent
Sister with developmental disabilities	-
Aunt with developmental disabilities	+
Family friend with down syndrome	+
Parent of child with emotional disability (didn't want to imply it was major)	neutral
Knew someone with spina bifida	+
Mother was a teacher of students with visual disabilities	+
Son in school with girl w/cognitive disabilities in wheelchair	_

> I knew someone who was in a wheelchair and had a baby. I was like, really impressed watching how she managed to carry the baby and nurse at the same time as managing her disability. (pediatrician) (+)

For the most part, data derived from in-depth interviews corroborated the data gathered from the survey regarding professionals' personal experience with disability and their attitude 's about parenting with a disability. Physical disabilities and sensory disabilities were viewed more favorably with respect to one's ability to parent and cognitive disabilities were viewed both favorably and negatively. In the two instance (aunt w/ developmental disabilities and family friend with Down syndrome) that were reviewed favorably represent counter examples of the data because these were the only two instances in which the individuals with disabilities held productive and valued roles in the lives of the respondents. In both instances, the individuals mentioned were caregivers of the children within the family.

Table 9: Professional Training in Disability and Ability to Parent

Professional Training in Disability	Ability to Parent
Never a focus on parenting and disability in preparation programs	-
No training in care when parents experience disabilities	-
No special training in disability issues	-
Disability training occurred from a biomedical model	+
Informal training through connection with a colleague's child with Down syndrome	+
Neonatal care training had broad focus on disability	+
Read a book about parenting with a disability	+

> The only time in my medical career I went against the protective services order and guaranteed this child safety because I felt he would manage better at home with the Mom. The mother has cognitive disabilities and the baby had obvious mental retardation and some significant medical issues - g-tube, tracheoscopy. The child was admitted multiple times over the course of a couple of months and we got the opportunity to see the Mom in action. She adores him - I mean she spent every waking hour in the hospital with him. She was really concerned that if he found his way into a foster home he wouldn't live. He ended up back at home and I actually got a picture of him. It stood out in my mind because we really had to assess how devoted the parent was and the best interest of the child. Some of the original neglect issues were because she couldn't read the clock, really couldn't plan her day, couldn't organize herself and so we had to do some significant interventions that she was willing to do. Each of their roles revolved around each other and we realized that they were each better off because of each other. (pediatrician) (+)

> I once read a very concrete book and it really helped me to think, O.K., what is the issue here and what are some practical ways to address it? If the parent can't see and the baby is turning blue, she or he can't notice. So, what are the other things the parent knows when she or he is holding the baby, they make noise. If the baby isn't making noise and is limp, what do you do? Call 911, turn the baby over, etc. These are practical solutions for parents. (visiting nurse) (+)

> When we do a home birth, we go into the home and spend time there. We can see if the child had a bed, a room, clothes, and it isn't total filth, but clean. This says a lot. (midwife) (+)

> I think decisions made about children staying with parents are things that the social service, judiciary system, protective services weigh very carefully. That is not a casually made decision. I don't think that kids are taken away without a whole lot of careful thought in most instances. (obgyn) (+)
>
> I think it is lack of training on our part to really ask any family illness questions. I think we have to ask questions better. But I had no training in taking care of parents and helping the families where the parents have disabilities.(pediatrician) (-)
> I know that most obstetrical care providers are happy NOT to care for someone with an extensive list of problems so they very commonly refer to someone else. (obgyn) (-)
>
> Can I ask a parent 'tell me about your disability? Tell me what you are able and unable to do? Because if they tell me what they are unable to do I have the power to take their child away. (pediatrician) (-)
>
> I think it is pretty clear that there is a range of opinions, but by and large, nurses and physicians who provide neonatal intensive care really have to deal with possible issue of future disabilities. And I am seeing a lot of children with poor outcomes. We tend to be more concerned about those outcomes and what they mean and the impact on families. I think that is the dilemma, part of the uncertainty of our work. (pediatrician) (-)
>
> I haven't gotten any information from anybody on what is available for people with disabilities, cognitively impaired people. (birth coordinator) (-)
>
> Occasionally we will see somebody who doesn't seem to be bonding very well or doesn't want to hold the baby or see the baby. Not very often, actually very rarely. That usually passes - a transitory thing. I remember one family in particular where there was a concern about the mother not being able to really care for the children very well. She was sort of neglecting them. Not really holding them very well, not supporting their heads, that sort of thing. (midwife) (-) (+)

In-depth interview data suggest that individuals who received some level of training had a more positive attitude toward the idea that individual's with disabilities could in fact be effective parents.

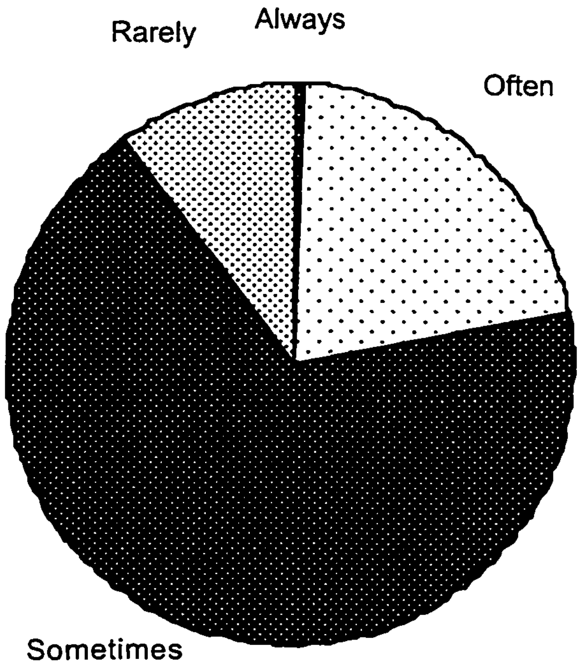
Open-ended survey responses. Survey question 4a asked respondents to describe their professional training experiences related to parents with disabilities. A synthesis of these responses revealed limited training on the topic of disability in general and of that training, information was primarily related to children with disabilities, not adults or parents. Training that was mentioned was typically associated with on-the-job experiences, mental, and emotional disabilities as they relate to post-partum depression, selected coursework after graduation, and cursory reviews of the potential needs of parents with disabilities.

Question two summary. As evidenced from both the survey and in-depth interview data, the majority of pre and postnatal care professionals did not receive training on the topic of parenting with a disability. Those that did were more likely to refer parents to child protective services than those who did not. Additional variables such as age, personal experience with disability, marital status, parenting status, and geographical location were not statistically significant factors in the referral practices of professionals who completed the survey although probing through the in-depth interviews revealed that personal experience might in fact influence one's attitude toward parenting with a disability. The relationships between geographic location (rural) and referral practices and years of experience and referral practices merit deeper exploration. Additionally, the summary of these data reinforces the results of question one. Survey data and in-depth interviews suggest that parents with certain types of disabilities (mental illness, cognitive disabilities are more likely to be referred to child protective services) than parents with sensory or physical disabilities, or parents without disabilities as evidenced in scenario questions 20 – 24.

How aware are pre and postnatal care professionals of supports and services available for parents with disabilities? The research methods of descriptive data analysis and in-depth interviews were utilized to gain information to address this question.

Survey data. While not specifically designed to address the awareness level of supports and services for parents with disabilities, question 25 on the survey asks "In your opinion, how well do you think the system of service delivery responds to parents with disabilities" Respondents were requested to select among a five point rating scale of ranging from "always" to "never."

Figure 3: Delivery System and Supports



The responses were as follows: always .8 percent, often 18.3 percent, sometimes 56.4 percent, and rarely 6.6 percent. See Figure 3.

Additionally, survey questions 20-24 examined referral practices as they relate to scenarios in which disability is present. While all scenarios resulted in referrals to home visiting services at rates of 72 percent to 94 percent, referrals to disability service delivery organizations were as follows: area agency system (10%-54%), independent living center (1.3%-27.4%), mental health center (.9%-54%). This would indicate a lower level of knowledge about disability specific supports and services. See Appendix C for significance testing results for survey questions 20 – 24.

In-depth interview data. Data derived from the in-depth interviews with pre and postnatal care professionals were categorized according to "knowledge of referral sources and attitudes about ability to parent." Data were coded according to whether the knowledge and availability of referral sources led to a positive or negative attitude about an individual with a disability's ability to parent. The synthesized data are presented in the table below followed by specific quotes from pre and postnatal care providers regarding disability and parenting.

Table 10: Knowledge & Availability of Referral Sources and Ability to Parent

Knowledge and Availability of Referral Sources	Ability to Parent
County social workers	-
Visiting nurses	+,+,+
Division of Children Youth and Families	-, -
Parenting support group	-, +

List of referral sources for parents	-
Translators	+
Care manager	+
Parent Support Program for Young Children	+,+
Developmental Services (Area Agency)	+,-,-,-,-
Out of print book on "Parenting the Handicapped-practical solutions	+
Mental health center	?
Internet	?
Early intervention	+,+
Early head start	+

I can't imagine someone who is in a wheelchair and pregnant has not thought about 'how am I going to bathe the baby, get it in and out of bed' all those kinds of things - this would certainly vary with the disability and be different for everybody. So, some clear planning in the course of the pregnancy with what you are going to do after this, and I think the point person is an obstetrical care provider. They should be very much aware of what the community has. (obgyn) (+)

There may be a list of resources for families, but it is so broad and complicated, you don't want to send a family to six different agencies before you find the one that you need. Because their time is valuable, too. (pediatrician) (-)

The developmental disabilities system is extremely lacking their supports for parents with disabilities. (visiting nurse) (-)

Family Strengths is not allowed in unless it is a child protective services case. The system is flawed by the need to identify parents as neglectful or abusive before necessary services can be made available. (visiting nurse) (-)

Social work kind of takes over and does their thing to make sure that everything is all set to take care of the child. I don't know if they automatically refer to child protective services. (pediatrician) (-)

I know I have never personally given a referral to child protective services because my feeling was if this family was doing the best they could through the help of social workers and programs, I never thought bringing in DCYF would do any good. (pediatrician) (-)

> Frankly, I don't know what services the women receive. (pediatrician) (-)
>
> It was interesting because there was no stability in class participation. You know, just because a mom and her baby came one week doesn't mean that she would come the next week and it was built as a five-week course. One of the things I really noticed about is that sometimes people with disabilities really need to focus on what's important to them and what's going on with their child at that point in time. (visiting nurse) (-)
>
> What's the sense of making referrals if nothing is ever gonna happen? (birth coordinator) (-)
>
> I guess I could call mental health agencies for mental illness, as far as a physical disability goes. I don't know where I would look - the Internet? (midwife) (-)

Data from the in-depth interviews corroborated data gathered from the survey regarding pre and postnatal care professionals' knowledge about supports and services for parents with disabilities. Interview responses indicated a low level of knowledge, and the level of knowledge that was reported did not lead to significant positive attitudes toward the idea of parenting with a disability. Identified resources that were particularly perceived as negative were child protective services and the area agency system for people with developmental disabilities.

Question three summary. Overall, data did not indicate a high level of training for pre and postnatal care providers on topics related to parenting with a disability, or disability issues in general. Training experiences that were identified may fall into a category defined as "on the job" experiences. Additionally, professional's knowledge level about potential resources and supports for parents with disabilities was very low as evidenced from the survey and in-depth interviews. Despite the lack of training and knowledge about resources, these professionals had opinions about the capacity of the service delivery system to offer appropriate supports and services to parents with disabilities.

4) What are the experiences of parents with disabilities receiving child protective services? 5) In what ways have parents with disabilities encountered discrimination as parents as a result of their disability? As mentioned earlier, case studies were conducted with two New Hampshire families selected because of the experience of parenting with a disability and their connection to the system of child protective services.
These case studies were done to address questions four and five.

The Beckers live in an urban area and have three children. The makeup of the Becker family involves a mother and father connected to the mental health system and three children (two of whom experience disabilities). The Schultz family, described in the introduction, is an extended family comprised of grandparents who have gained custody of one of their two grandchildren born to their daughter with disabilities. Additionally, a parent education program, Family Circle, was included in the observation and interviews because of the significant role in supporting families where parenting with a disability is a factor.

The Becker family. Arriving at the Becker's home was a bit like being a player walking into a sports event without knowing what team they were on. Observing the scene, interacting with the main players, and trying to remain focused on the goals of my visit was a challenge to say the least. I was involved in a game without clearly understanding the rules. To the Becker's, I was another professional "from the state" whose presence added one more intrusion to their already complex family life. While my purpose was to gain information about the topic of "parenting with a disability," the family's underlying intention to participate in the interview appeared to be to gain my assistance in navigating the complex system of benefits and services to which they are entitled. I made a point to continuously inform them of the purpose of my visit throughout the time I spent with them. I let them know that I was not an expert on the benefits system but that I would do my best to find a qualified and knowledgeable person to assist with their concerns.

Amy and Matt, together for nine years, have three children. Neither one is legally employed and both receive benefits and services from the developmental disabilities and mental health systems. They met following Amy's high school graduation in a day program connected to the local mental health center. Both were connected to the program because of their histories with mental health issues. According to Matt and Amy, rather than finding employment, they found each other and fell in love. Amy became pregnant and they married two months before the birth of their first son, Max. They both quit the day program after receiving the advice from a mental health center worker that Amy should have an abortion. According to Amy, the case worker told them, "No two people with serious mental illness would ever last in a relationship and you will be a single mother." Simon, their second child was born 16 months later with disabilities of his own. A serious bout of post-partum depression following Simon's birth brought additional challenges to the family, and Amy and Matt divorced. Amy stated that she was unable to cope as a single parent, although she said that she resented the assistance from the local agency to manage her finances. The length of the separation between Matt and Amy is unclear, but Matt eventually moved back in with the family. They have decided against remarriage due to the negative financial impact it would have on their benefits.

The involvement of child protective services seemed like a minor annoyance to this lively family. While child protective services has been contacted many times, each report has come back unfounded. The first and most serious report followed a medical crisis when an accident occurred as the result of a malfunctioning stove in an unheated apartment. Amy Becker told of numerous other encounters with child protective services because of allegations of child abuse or neglect – all of which came back unfounded.

According to Amy, the malfunctioning stove incident was the most troubling and painful interaction with child protective services. This crisis followed the birth of her second son while the family lived in subsidized housing without heat. She was told her children would be placed in foster care if she did not find an adequate way to heat the apartment and repair the stove. Amy stated that she was already aware of the safety issues of the malfunctioning stove, and if it was possible for her to heat the apartment and repair the stove while taking care of three children she would have done so. Child protective services were quick to recommend placing the children in a foster placement, yet was not helpful in resolving the immediate problem. The landlord was unwilling to make the repairs, and the Beckers did not have the financial, emotional, or intellectual resources to force the landlord to make the repairs necessary to keep their children from the foster care system. Eventually, the Beckers moved in with relatives until family members assisted them to find another home of their own. The Beckers described this as a particularly volatile and challenging period of their lives. According to Amy:

> Me and Matt were fighting a lot. We didn't know what was going to happen to our kids and we didn't know how to get the landlord to fix the stove. Thank God for our family – but that was no piece of cake either.

The Beckers described other encounters with child protective services. Instances of arriving home to notes of allegations tacked to their door from child protective service workers were described as common experiences in the life of this family. The parents believe a neighbor with whom they were feuding made the reports, and they eventually secured a lawyer to assist them in refuting the allegations. The allegations have all come back unfounded. The Beckers said that because of their disabilities and the poverty they experience they feel as though they are on a watch list for child protective services.

The children appeared healthy, happy, and obviously well loved. Both parents discussed their strong relationship with their children's teachers and principals and proudly discussed monthly breakfasts at their children's school. Children's bikes were parked in the entryway of their rented, inner-city duplex, and bike helmets hung in the hallway. Walls were adorned with smiling family portraits and school photos taken throughout the years. Amy is content to stay home while her children are young while Matt works a little "on the side" for cash and groceries at the corner store. In the winter, he keeps the neighbor's driveways and sidewalks shoveled in exchange for childcare assistance and meals. Both parents expressed their primary concern of feeding their children with such anxiety that Matt actually showed me the $60 worth of meat he "earned" while working part-time at the corner store.

Amy discussed the ways she believes the system has helped and also hurt her family. She described a parenting class she has been attending since the birth of her second child as a lifesaver. "They provide rides when I can't get there and meals for my family at the end of the month. They never forget my kid's birthdays and give us help during the holidays."

The system has not been helpful, however, when it comes to controlling the family's finances or providing counseling. "They are quick to call child protective services without checking out the situation." Amy repeatedly reminded me of the episode with the gas stove. Amy believes that this scenario, which could have happened to any family in any home, became a "case" of severe neglect and trauma because of the stigma of disability and poverty. It was this instance that connected the family to the parenting support program they now attend.

The Becker children are no strangers to their local pediatrician. They are all members of the children's health insurance program and utilize the benefits to the fullest. Amy does not hesitate to call the clinic whenever she has a health question about one of her children. The parenting program Amy attends and the family support coordinator who is familiar with the Beckers corroborated this information.

Amy made the decision, on her own, to have a tubal ligation following the birth of her third child, Andrew. Andrew is now one and she has no regrets about the ligation. While Amy has always wanted a daughter, she told me, "Three kids is enough for anybody."

The parenting program the Becker's currently attend is available as a result of their connections to the system of child protective services. Both Amy and Matt describe this program as extremely supportive and claim it helps them feel successful as parents. Neither the Beckers nor the administrators at the parenting program describe their participation in the program as an ultimatum provided by child protective services. They were not told to either participate in the program or have their children placed in foster care.

Family Circle. The Family Circle program is an innovative prevention program run by the Visiting Nurse Association for parents who need extra support and education to be good parents. Through the support of this program, parents learn the importance of forming a strong bond with their baby and developing effective parenting skills. A current marketing brochure states that the goal is "successful parents and healthy babies." The program provides group-based parenting education and individualized home visiting support to parents with newborns, infants, and older children and utilizes modeling, education, and support to teach parents how to care for their children. The program is offered in an old New England home that has been converted to meet the needs of families. The upstairs contains a room arranged classroom style, a lending library for families, and an office for staff. The downstairs houses a comfortable child-friendly living area, a large dining room, and a kitchen. A front porch and soon-to-be landscaped backyard complete the scene. The seasoned staff includes a director, an assistant to the director, a part-time parent educator, and a social worker. Student interns from the local educational institutions are always present. The program brochure boasts:

- Parent Education: infant/childfeeding, diapering and bathing, basic child development, safety, infant stimulation and play;
- Human Service Networking: WIC (supplementary food program), childcare, family planning, counseling, employment training, GED preparation, immunizations, medical services, financial resources;
- Personal Growth and Development: building self-esteem, peer support, successful bonding, enhance parenting skills; Additional Services

include: transportation to and from the program and other appointments, lunch and snacks, infant development assessment, guest speakers, home visits, and day and evening programs.

These claims and more were evident in the observation of this program and interviews with staff and participants in their homes and in the program. Parents interviewed (not selected by the program) claim the Family Circle program saved the integrity of their family and supports them to be good parents. The program, by addressing the basic living needs of the families interviewed for this study (housing, nutrition, and healthcare) allowed parents the ability to focus on the skills of parenting. Parents described the difficulty of paying attention to their children's daily needs while worrying about feeding their family and providing a roof over their head. According to the interviewees, Family Circle supported parents to connect with necessary services such as health insurance and healthcare, housing support, WIC, daily meals, and employment services. This networking enabled parents to focus their attention on understanding and encouraging their children to love, learn, express themselves, and grow.

Parents become connected to the program through a variety of referral sources. Hospital social workers, child protective service workers, and court-ordered participation are the most popular sources of connection to the Family Circle program. More than 50 percent of the 125 families participating are parents who experience some type of disability. For many of these parents, lack of participation in the program results in a removal of children from their families. As mentioned, the program offers supports that are program-based such as nutrition, health, and safety classes and evening classes on topics such as discipline and anger management as well as home visiting services that are defined by the needs of the families. The director of the program, herself a mother of three and grandmother, described the challenges of running this program on a shoestring budget. The treadmill of grant writing has garnered funds from a variety of state and local agencies. The home where the program is located is owned by and rented through the nearby hospital. Despite the program's success rate maintaining children with their families, only six percent of child protective services funds are allocated statewide to prevention initiatives such as Family Circle .

The poverty experienced by the families participating in the program was evident and the program's lack of funding was alarming. Children's books were tattered and old. A selection of old and broken toys was scattered throughout the clean and comfortable living room. Emergency supplies such as diapers, bottles, and sippy cups were nonexistent due to lack of flexible funding, and efforts were underway through a local church to donate these goods.

The Schultz family. Catherine is 55 years old and lives with her husband Rick, her daughter Sheila, and Sheila's two children, Ava and Noelle. They live in a two-room mobile home in semi-rural New Hampshire. They are familiar to the human service system and the various agencies providing support to people with disabilities. Sheila and Ava have developmental disabilities and Noelle is undergoing testing for a possible label of Pervasive Developmental Disorder. Catherine has legal custody of Sheila's oldest daughter, Ava.

Catherine described her daughter Sheila in her childhood days as a beautiful little blond girl, but very different. From the beginning Sheila behaved as every mother's dream child. She slept all night and most of the day. The only time she cried was when she was hungry. She walked and talked quite late, was later described as "slow" until she was eventually tested and received the label of developmental disability. Following an educational career of segregated special education services, Sheila fell in love with her coworker in her job employed as a kitchen worker in a hospital, and together they had two children. Sheila stated: "It is really all I ever wanted -- kids of my own."

Ava was born in 1997 following an uncomplicated cesarean delivery. Her mother and father cared her for until she was 12 months old. Ava clearly was not reaching typical developmental milestones according to Sheila and Catherine. Sheila described routine visits to a pediatrician who was "horrible and unhelpful." At 12 months Ava ended up in a large medical center with grand mal seizures. She remained in the hospital for 50 days while doctors attempted to get her seizures under control. The complexity of Ava's condition prevented Sheila from taking her home and caring for her without support. In addition, she was prevented from doing so by the doctor who called child protective services and recommended removing Ava from her parents. Catherine stepped in and gained legal custody of Ava in order to keep the family together and prevent Ava's placement in an unknown foster care arrangement.

According to Sheila and corroborated by her mother, the system provided no support or access to services other than routine intervention following Ava's birth. Sheila describes those days as the most painful time in her life - when the state came in and took her daughter away. While Sheila understood why her mother gained custody of Ava, she described the guilt she feels not being able to care for her child and the responsibility she feels living such a crowded lifestyle in her mother's mobile home. She dreams of the day when an addition can be added to the mobile home and the family can have more room.

Sheila currently attends a weekly parenting class, which she describes as a chance to meet people. She drives. She goes to group counseling sessions with other people with disabilities one night a week. She does not work, but she is interested in returning to school someday to learn a new skill. She is unsure of what skill she would like to learn. For the time being, Sheila stated that she is content being at home and trying to be the best Mom she can be.

Since Catherine took over legal custody of Ava, the family's life is full of services and supports from a myriad of agencies. A sampling of the services received by the family includes visiting nurse services three-four times a week, in-home parent training once a week, assistive technology services, student interns from the local university, clinic services from the local university, early intervention services, and connections to additional supports as defined by the family. Catherine describes her own tenacity as responsible for connecting the family to necessary supports and services. She describes herself as an activist who will never sit back and do nothing. She is extremely interested in children with disabilities and how to "make a better future for them." Professionally, Catherine describes herself as a businesswoman in the area of home decorating. She teaches painting and also paints antique furniture. She paints commercially and in people's homes. She likes to think she makes a positive difference in whatever she becomes involved with.

For Sheila Schultz, her first involvement with the system of child protective services was when Ava was in the hospital experiencing grand mal seizures. Sheila was not allowed to bring her daughter home following the doctor's referral to have Ava removed from her family and placed in foster care. Sheila felt fortunate that her mother, Catherine, stepped in and obtained legal custody of Ava. Both Sheila and Catherine described the trauma of navigating the court system in order to transfer legal custody from Sheila to Catherine. Catherine also discussed the roller coaster ride of emotions in facing the realization that she needed to reorganize her entire life in order to take on the responsibility of raising her granddaughter. First and foremost Catherine needed to discuss was discuss Ava's move to her home with Rick, her husband. Second, adaptations needed to be made to their modest two-room mobile home to accommodate a wheelchair; and finally, Catherine needed to adjust to life with a granddaughter with significant disabilities.

Catherine turned to the area agency system of community developmental services for support. She enrolled Ava in an early intervention program, and accessed respite care and family support services. Additionally, she unsuccessfully tried to secure parenting support services for Sheila and David because she was concerned about their ability to raise their second daughter. Sheila returned home to David and their child Noelle with little hope of reinstating her role as Ava's mother. It wasn't until Sheila ended her relationship with David and returned to live with her mother that child protective services re-entered their lives. In this instance it was at Catherine's request as she pursued every available service and support within the uncoordinated systems of parenting and disability. Currently, Sheila receives the support of an in-home parent educator who assists her to learn about the responsibilities of parenthood and attends a weekly parent support group that she described as meeting her need to get out of the house. This support was made available because of Sheila's past experiences with the system of child protective services.

Question four and five summaries. The experiences of parents interviewed suggest discrimination and high level of contact with child protective services because of parental disability. Chapter Five will offer further discussion of these findings.

How can services and supports be more appropriate for parents who have disabilities? This question is addressed through 1) open-ended survey question 19, "Please describe programs you are aware of noted for their involvement with parents with disabilities," 2) targeted questions requesting recommendations asked during the in-depth interviews with pre and postnatal care providers, and 3) experiences and desires discussed by the case study participants.

In-depth interview data. Data derived from the in-depth interviews with pre and postnatal care professionals were categorized according to "recommendations for changes." Again, these data were reviewed by a secondary source for the purpose of achieving interrater reliability of organization and coding of the responses. The synthesized data are presented in the table below followed by specific quotes from pre and postnatal care providers regarding recommended changes to better support disability and parenting.

Table 11: Recommendations for Change

Recommendations for Change
• One-on-one support for parents • Better communication between obgyn and primary care physicians • Preconceptual pregnancy planning, family planning • Stronger bridge between medical and supports • Creation of family mentors, "foster family for families" • Home visits prior to the birth of the baby • Services should be more centralized - one stop shopping - people shouldn't have to have different intake methods for so many different services • Expand reproductive awareness - preparation and consequences of parenting

> It would be great if there were an agency or statewide program to help parents that didn't give off negative feelings of punishment for parents rather than help. And if there is an agency outside of VNA, then I wouldn't know what it is. (pediatrician)

> Perhaps if there were a system, where if people had the option to say (if they could recognize it) that their mental health is falling apart, I need help, and if the help was available for the parents, I don't think they would necessarily remove the kids. (obgyn)

> I think there needs to be more services in rural areas for parents who don't have anything - like a one stop shopping place, so when they go to the doctors to get their babies their shots, they can attend a parenting class, or have someone signing them up for available programs. I have to hunt for everything and it is difficult for me to decide what is available and who can use the service. (birth coordinator)

Open-ended survey questions. The survey offered opportunities for respondents to highlight notable programs and guidelines for supporting parents with disabilities. A synthesis of this information revealed a preponderance of suggestions. These suggestions and comments have been examined and coded for categories. Themes within categories are highlighted below:

- Base care on individuals' needs; create individualized care plans which highlight clear and concise communication; and include availability of home supports in care plans
- Provide more time for parents with disabilities
- Refer to appropriate community programs including child protective services, social work, social services
- Increase screening availability such as hearing or genetic screening for parents with disabilities and their children
- Make frequent home visits and telephone calls to parents with disabilities and their family members (pending insurance authorization)
- Promote parent aid programs

A summary of survey data and in-depth interviews of the identified needs for pre and postnatal care professionals includes the ability to offer more one-on-one support to parents, better communication between the obgyn and the primary care practitioner, more training in the area of preconceptual planning, a more secure bridge between the medical system and the support system for families, family mentors or foster families for whole families not only the children, home visiting prior to the birth of a baby to begin to identify parenting needs, and more centralized locations and intake processes for services and resources.

Case study findings. The case studies offered a wealth of information that could be utilized to develop recommendations for an improved system of supports for parents with disabilities. Families described helpful interventions as well as interventions that they more aptly described as interference.

Parents described the difficulty of paying attention to the daily needs of their children at the same time as worrying about feeding their family and providing a roof over their heads. The Beckers described a parenting class Amy has been attending since the birth of her first child as a lifesaver. The system has not been helpful in controlling the family's finances or in providing counseling.

While the Schultz family was not as clear in their descriptions of interventions they deemed to be helpful or able to articulate their vision of ways the system might change to be more supportive of families, they were clear in identifying their own needs and hoped to find ways to meet those needs. Building an addition on their home, appropriate diagnostic and medical care for Ava and Noelle, technical support to access information on the internet, and career services for Sheila were top priorities on the Schultz family's list of needs. Family Circle supported parents to connect with necessary services such as health insurance and healthcare, housing support, WIC, daily meals, and employment services. This networking enabled parents to focus their attention on understanding and encouraging their children to love, learn, express themselves, and grow strong.

Question six summary. All of the research methodologies produced concrete suggestions for developing improvements in the systems of care for parents with disabilities. These suggestions will be further summarized and analyzed in Chapters Five and Six to result in policy and practice recommendations.

Chapter Summary

The process of gathering information and coding information into meaningful categories and themes, as well as using quantifiable inquiry methods which rely on complex data analysis, has resulted in the emergence of a portrait that presents the experiences, perceptions, and attitudes of pre and postnatal care providers and perceptions and experiences of parents with disabilities. The next chapter will provide additional insight and clarity to these experiences as they relate to an improved system of understanding and support for parents with disabilities.

CHAPTER 5

PARENTS WITH DISABILITIES AND THEIR EARLIEST CONNECTIONS TO SUPPORTS

ANALYSIS OF THE FINDINGS

As a researcher, one needs to use extreme caution when analyzing data and interpreting findings. The analysis and interpretation needs to be conducted not only on the data collected but also with thoughtful regard for researcher assumptions and biases. In Chapter One, I presented my assumptions and biases; and while they will be revisited through the analysis of the data, it is important to state that they have also influenced the journey of collecting data, reporting findings, and developing new understandings about parenting with a disability and earliest connections to supports and services. Research questions tend to lead to more questions rather than definitive answers. Results from this study of the complex issue of parenting with a disability provide no simple answers to the research questions posed in this dissertation. Analysis of data and interpretation of findings are presented in this chapter in direct response to the questions posed.

Are Pre and Postnatal Care Professionals More Likely to Refer Parents with Disabilities than Parents without Disabilities to Child Protective Services?

While a summary of the literature on parenting with a disability and interviews with parents with disabilities confirm the high referral rate to child protective services for parents with disabilities and the ultimate removal of children from these families, this study does not support my assumption that pre and postnatal care providers are the earliest and primary source of referral to child protective services for parents with disabilities. Nor does it definitively indicate that pre and postnatal care professionals are more likely to refer parents who have disabilities to child protective services more frequently than they refer parents without disabilities.

Unfortunately the survey did not have the capacity to specifically compare referral practices for parents with and without disabilities, and so only hypotheses can be drawn from the analysis of the survey data presented in response to this research question. Survey question #14 asked, "Have you ever made a referral to child protective services for a family in your care when one or both parents experience a disability?" Of the 81.8 percent of survey respondents, who have actually cared for families when parenting with a disability is a factor, 36.8 percent answered "yes" to this question. In order to make a clear comparison of parents with and without disabilities, follow-up questions should have been asked. These questions would have included "If yes, approximately how many referrals have you made?" and, "Have you ever made a referral to child protective services for parents without a known disability? If yes, approximately how many referrals have you made?" Additionally, questions related to overall numbers of parents with and without disabilities would have been necessary.

With this said, analysis of types of disabilities most likely to be referred <u>may</u> provide insight to the referral practices of pre and postnatal care providers and parents with disabilities. Data findings strongly suggest that the type of disability may be a factor in pre and postnatal care professionals' referral practices to child protective services. Survey questions 20-24 described scenarios of a variety of parenting situations and requested respondents to select services considered most appropriate for the families. Cognitive disabilities and mental health issues resulted in the largest number of referrals to child protective services – more so than families experiencing poverty, unemployment, lack of education, and substance abuse. Interviews with pre and postnatal care providers support the finding those parents with cognitive disabilities and mental health issues are more likely to be referred to child protective services.

Research findings indicate that parents with cognitive disabilities and parents with mental illness are more likely to be referred to child protective services than parents with physical disabilities, sensory disabilities, or chronic health conditions are. Interview participants were not overwhelmingly positive or supportive of the notion that individuals with cognitive disabilities or mental health issues should have the opportunity to be supported as parents.

> I think particularly with parents with cognitive disabilities there are issues of neglect, and I say benign neglect, in that I don't think that anyone maliciously or intentionally is neglecting his or her child, they certainly can't attend to the needs of their child, and therefore the child should be removed from the home. (pediatrician)

Getting at the core of the attitudes and opinions of pre and postnatal care professionals toward parents with disabilities will take more than a well thought out survey and series of in-depth interviews. These attitudes and opinions are deeply rooted in the belief systems of these professionals and have been cultivated through their own life experiences and professional development.

While survey and interview data resulted in a somewhat neutral – to – positive attitude toward parenting with a disability (except in the case of cognitive disability and mental illness), and a moderately low level of direct referral to child protective services, one can continue to assume that their influence in the process of parent referral is high.

The Relationship between Pre and Postnatal Care Professional's Career Experiences, Personal Experiences with Disability, and the Likelihood of Referral of Parents with Disabilities to Child Protective Services

The only statistically significant relationship discovered in this study is the relationship between training experiences of pre and postnatal care professionals and their referral practices to child protective services. Pre and postnatal care professionals who have received training on the topic of parenting with a disability (as scant as the training might be) are more likely to refer parents with disabilities to child protective services than professionals who have not received training. Survey results found no statistically significant relationships among referral to child protective services and personal experiences with disabilities, age, geographic location of professional practice, marital status, or whether they themselves are a parent. In-depth interviews provided a glimpse of evidence that professionals are influenced by their personal experiences with disabilities. The personal experiences identified involved two individuals with disabilities in roles of child care providers or babysitters.

Analysis of These Relationships My initial assumption was that pre and postnatal care professionals were more likely to refer parents with disabilities to child protective services if they did NOT have training and did not have personal or professional experiences with disabilities. I assumed that training in parenting with a disability, personal experiences with disability, and their own parenting experiences would lead to a greater understanding, sensitivity, and acceptance of individuals with disabilities as parents; therefore, resulting in fewer referrals to child protective services. An examination of the findings did not support this assumption. Further analysis of the survey data indicates that when referrals were made to child protective services, the anticipated outcome of the referral was parent support and training – not the removal of children from their families. This was corroborated through the in-depth interview findings. Further analysis may conclude that pre and postnatal care professionals made referrals to child protective services because they were anticipating that supports and services would be made available to enable families to remain intact and healthy. While the survey did not produce significant evidence that personal experience with disability influences one's attitude toward parenting with a disability, the interviews offered a potentially different conclusion. When one does interact with people with disabilities in socially valued productive roles such as childcare providers, a positive attitude toward parenting may result.

The Awareness Level of Pre and Postnatal Care Professionals Regarding Supports and Services Available for Parents with Disabilities

Survey data and in-depth interviews found a very low level of awareness of the services and supports available for parents with disabilities. The following quotes reflect findings learned through the survey and in-depth interviews.

> Frankly, I don't know what services the women receive. (pediatrician)

> What's the sense of making referrals if nothing is ever going to happen? (birth coordinator)

> The developmental disabilities system is extremely lacking in their supports for parents with disabilities. (visiting nurse)

> I guess I could call mental health agencies for schizophrenia; but as far as a physical disability goes, I don't know where I would look - the Internet? (midwife)

The services most frequently mentioned during in-depth interviews and open-ended questions on the survey included child protective services, visiting nurses, and early intervention services through the area agency for developmental services. It is important to note that the services most frequently mentioned are services designed to support child development– not the development and well-being of individual's with disabilities as parents. As a follow-up to the question about knowledge of supports and services available to parents with disabilities, the question "In your opinion, how well do you think the system of service delivery responds to parents with disabilities?" provides insight to the views of pre and postnatal care professionals. Only 19.1 percent feel that the system "often – always" responds to the needs of parents with disabilities while 63 percent believe that the system "sometimes – rarely" is responsive to parents with disabilities. Additionally, survey respondents demonstrated a very low level of knowledge in their referral practices for the scenarios (questions 20-24). While home visiting resulted in an overwhelmingly high response rate for every question, referrals to disability specific service delivery was low on all accounts – even in the clearest of situations of the need for such services.

Summary Analysis Results from the survey and interviews suggest that pre and postnatal care providers are unaware of the services and supports available to parents with disabilities; yet, they somehow recognize that the system does not adequately address the needs of parents with disabilities. These seemingly contradictory outcomes may be attributed to professionals being informed about services enough to recognize shortfalls and gaps in the system of supports for parents with disabilities, but not involved enough to ascertain that it is their professional obligation to become more informed about and supportive of improvements in the system of care. While services and supports for parents with disabilities need to be tailored to meet the needs on an individual basis, training and support must also be provided for professionals to help them recognize those needs and how to negotiate support systems to ensure those needs are met.

Experiences of Parents with Disabilities Receiving Child Protective Services

Child protective services did not have an immediate or overwhelming presence in the current life situations of either of the families involved in this study. While there were "hot points" of involvement with the child protective service system in the early histories of both families, and an ongoing connection to the system, parents interviewed did not have strong opinions about their relationship with the current services they receive. Although, in discussing parenting histories with the Schultz and the Beckers, both families described periods of time when they felt that the presence of child protective services caused significant and long-term harm. The strong language used by both families describing their earliest involvement indicates that the families may have become immune to the overall impact child protective services has had on their lives. The Beckers for example were suspicious of my visit. Sheila Schultz wishes there were a way for her to have legal custody of her daughter Ava. While the current involvement with services offered through child protective services might seem either insignificant or even helpful, the long-term impact of suspicion and guilt are hardly inconsequential outcomes.

<u>Summary of Parent Experiences</u> The Becker family and the Schultz family represent very different constellations. These differences include developmental disabilities vs. mental illness, urban vs. semi-rural, single parent living with an extended family vs. two-parent home. Despite these differences, many similarities in their connections to child protective services exist. These similarities include:

1) Neither family was referred to child protective services nor any other parent support service by a pre or postnatal care provider during their earliest stages of parenting.
2) Initial referrals to child protective services <u>did not</u> address their needs as parents in ways described helpful by the families.

3) Parent training programs available as a result of their connections to child protective services were considered essential to the well being of both families.

Ways in Which Parents with Disabilities Involved in the Case Study Perceive they have Encountered Discrimination as Parents because of their Disability

Of the two families involved in this case study, only the Becker family used the language of discrimination to describe their experiences as parents. The pointed question, "Did you ever feel discriminated against as a parent because you have a disability? If so, can you tell me about those experiences?" was asked of both families. Sheila Schultz was unable to recall incidents or describe perceptions of discrimination. The Beckers, on the other hand, felt very strongly that they have and continue to experience discrimination because of their disabilities. Discriminatory practices were evident from Amy's earliest point of pregnancy. At that time, it was recommended that she have an abortion because she was told by the mental health center's senior case manager that 'no two people with serious mental illness would ever last in a relationship' and that Amy would soon be a single mother. The Beckers also described their perceptions of involvement in the system of child protective services. They believe that they are on a child protective watch list because they are poor and have labels of mental illness.

> I never know if I am going to come home to a note on my door or Someone standing on my front steps because they think I don't take care of my children. Now we just call the lawyer when this happens because nobody has ever been able to prove anything.
> (Amy Becker)

There has never been an incident of serious concern with the Beckers other than the hot stove incident in their early days. The Beckers described their parenting style as one that relies on time outs and positive reinforcement – rather than disciplinary measures such as hitting, spanking, or other forms of physical abuse. In addition, the Beckers described parenting issues they are most concerned about as meeting the health, nutritional, and educational needs of their children.

Analysis of parental discrimination. While it was difficult for Sheila to clearly articulate feelings of discrimination, her history is rich with examples. Throughout her life she was denied access to typical opportunities and the supports necessary for her to benefit from these experiences. According to Catherine (Sheila's mother) Sheila was denied an adequate education because of her disability. She was relegated to a low paying job because of the lack of an appropriate education and the opportunity to learn meaningful skills and discover her talents. As a parent, the system of child protective services offered no alternative to Sheila other than to remove her daughter Ava from her home.

In light of these exclusionary experiences, disguised as supports and services for people with disabilities, the resignation that discrimination is a way of life appears to have subtly invaded Sheila's existence. More obvious discrimination is experienced by the Becker's such as when they were advised to have an abortion during the pregnancy of the first child and their sense of child protective services' ongoing surveillance following the incident with the malfunctioning stove. It is understandable that the Beckers live with a constant feeling of suspicion directed toward available supports and services. Even my visits initially concerned them because they said "the state doesn't trust us as parents."

Appropriate Supports and Services for Parents who have Disabilities

An analysis of the data gathered in this study offers a wealth of suggestions and concrete ideas directed toward developing more appropriate supports for parents who have disabilities. These suggestions range from strategies to improve the availability of supports for parents, recommendations for changes in systems of professional development for pre and postnatal care providers and child protective services workers to the development of state and national policies that recognize and support individuals with disabilities as parents. This chapter will address recommendations in the areas of family support for parents with disabilities and changes in the field of pre and postnatal care. Chapter Six will address the larger policy, societal, and advocacy issues as recommendations for further study.

Recommendations for Change and Improvements in the Field of Supporting Parents with Disabilities

Recommendations for changes and improvements in the field of supporting parents with disabilities naturally fall into two categories as a result of information learned directly from this study - new supports for families and new supports for pre and postnatal care professionals. These topic areas have emerged primarily through in-depth interviews with families and pre and postnatal care providers, and secondarily from survey information.

Improvement in the System of Family Supports for Parents with Disabilities

Unfortunately, the supports and services parents with disabilities and others describe as helpful in maintaining the integrity and well-being of families are the supports that are the most difficult to obtain. And, as evidenced by the statements below, accessing support is predicated by the assumption that parents are first neglectful or abusive toward their children and second, eligible for support.

> Family support is not allowed in unless it is a child protective services case. The system is flawed by the need to identify parents as neglectful or abusive before necessary services can be made available. (visiting nurse)

> It would be great if there were an agency or statewide program to help parents that didn't give off negative feelings of punishment for parents rather than help. And if there were an agency outside of visiting nurses, then I wouldn't know what it is. (pediatrician)

Families, pre and post natal care providers, and the literature define helpful supports and services as individualized to the needs of the family, directed by the family, holistic in their approach, and collaborative among various systems to achieve common family dreams. For example, the Schultz family is engaged with a myriad of supports and services to meet their needs; but the needs that they defined as most pressing, housing and employment, are not being addressed. The scrutiny experienced by the Beckers might have been resolved if the system had been able to help find adequate housing or repair the faulty stove. Instead, the lives of these families are defined by the existing services rather than services being defined by the needs and desires of families.

The usual familiar and traditional concept of family should be questioned. Families can no longer be examined from an "ideal" family point of reference. As evidenced from the families involved in this study, family configurations may be intact, healthy, and loving without being a traditional two-parent related group. The Beckers have been together for nine years although are they are not legally married. The Schultz family configuration is a single mother of two living with her own mother and stepfather who have legal custody of one of their granddaughters. Families have to be understood as they are and as they perceive themselves to be. Lest we not forget the different cultural interpretations of family, many are more congruent with the needs and desires of parents with disabilities. Rather than judging family life in relation to perceived ideals, researchers, service providers, and policymakers must ask questions about family roles and positions within communities and society. This study affirms the need for policymakers and practitioners to take into account family relationships and preferred family styles to develop responsive support strategies that reflect these individualized preferences.

Obviously, a major improvement in the system of family support for parents with disabilities would be to recognize that individuals with disabilities define the goal of parenting as achievable and desirable at the same rate and in the same terms as individuals without disabilities. Individuals with disabilities are parents, and the systems supporting people with disabilities need to recognize this within their repertoire of available supports and services. Concomitantly, generic systems of family support need to recognize that the families they support WILL include parents with disabilities. Generic family support programs can no longer offer generic supports and services directed primarily to parents without disabilities. Supports and services must be culturally competent as well as recognize the variety of diverse learning styles represented by the families they serve. The generic system of family support may be in denial given the high rate of disability among its clientele. Possibly, organizations like child protective services need to employ and/or organize advisory structures that include parents with disabilities

One of the primary sources of support for families, identified in all aspects of this study, is the parent program that by design offers one-on-one support tailored by the family to meet their unique issues. Although both families were participating in group, center-based parenting programs, these were not the supports families described as most helpful. These programs may have met a need for social connection, but they did not meet the immediate needs defined by the families. Families defined these needs to be a more flexible service delivery model to address the issues of healthcare, housing, employment, and access to available benefits and services to promote economic enhancement.

Changes in Systems of Professional Development for Pre and Postnatal Care Providers At this point, it should go without saying, that parents with disabilities and their children would benefit from improvements in training for pre and postnatal care providers. The majority of pre and postnatal care providers described an absence of training on the topic of disability. Additionally, in-depth interviews suggested the need for more training in the areas of preconceptual issues and parenting in general. Professionals in the fields of pre and postnatal care were very articulate in defining recommendations for better supports and services - in particular – defining needs for families in which parenting with a disability was a presiding factor.

Training and information about the lives of people with disabilities should be provided at all stages of the development of such professionals. Training should focus not only on the health and medical issues associated with disability; but on the possibilities and supports available for people with disabilities to live full and equal lives, which may include parenting. This responsibility includes specialized training to recognize the needs of parents with disabilities and make appropriate referrals to the growing array of programs and services designed to meet the unique circumstances of these parents. According to the findings of this study the service delivery system for parents with disabilities meets the needs of the consumer only 19 percent of the time. Imagine a service delivery system in another field (dental care, education, highway safety) meeting the needs of their constituents only 19 percent of the time? This finding alone, should be a call for improvements in a system that is sorely lacking. Research findings support the need to expand and/or revise preservice professional training experiences to include new understandings of the variety of constellations of families in today's society. Training should move beyond the medical implications of parenting with a disability to include the relevance and importance of understanding and providing supports to ensure that parents with disabilities are understood and supported in their desire to have and raise their children.

Returning to the Assumptions of this Research

This research was guided by a set of assumptions based on my own experiences and biases. These assumptions led to a comprehensive review of the literature, the development of research questions, and an approach to address my questions and form new implications and potential hypotheses regarding parenting with a disability. Did the data and my analysis reinforce or refute my assumptions? The importance of research is to answer this question and develop new avenues of inquiry.

Assumption 1 *The factors that influence out-of-home placement recommendations for children of parents with disabilities are based on societal biases and a medical model approach and in existence prior to the birth of a child. The data and analysis that emerged from this study does not support my assumption.* Although anecdotal evidence suggests pre and postnatal care providers are responsible for referrals to child protective services at the earliest stages of the life, the data and analyses did not conclusively support this.

Assumption 2 *Pre and postnatal care professionals are unfamiliar with the myriad of supports that may be available for parents with disabilities.* Data and analyses from this study reinforced this assumption and ideally will result in improvements in professional understanding of supports and services and noticeable improvements for families.

Assumption 3 *Formal systems of support for parents with disabilities do not collaborate in the best interest of children and families.* Data and analyses from this study reinforced this belief. Formal systems of support do not collaborate in the best interest of families. Families were able to clearly articulate their needs and desires, yet their life was defined by the services prescribed by the system. The two were not always compatible.

Assumption 4 *New systems of support merging parenting and disability supports will need to be developed to respond to the new family structures in today's society.* Data and analyses from this study reinforced this belief and defined new systems of support based on the needs defined by families. Traditional parent support programs and disability family support programs both need to recognize that parents with disabilities represent consumers of their services and need to change to reflect the range of family constellations that exist in today's society.

These biases and assumptions will influence the formulation of theory (Glaser & Strauss, 1967) in the field of disability and family studies, professional decision making, and descriptive research. Chapter Six will provide additional insight, final conclusions, and recommendations for improvements in the fields of family support and parenting with a disability.

CHAPTER 6

CONCLUSION, APPLICATIONS, AND RECOMMENDATIONS FOR FURTHER STUDY

This Study's Ability to Improve Practice and/or Policy

In this study, I have explored and documented the views of pre and postnatal care providers about their attitudes and experiences dealing with parents with disabilities, and I have spoken with and observed parents with disabilities with an eye toward understanding their experience and perceptions regarding the system of support. The findings of this research contribute to the theory building related to parenting with a disability in the following ways. For professionals, the findings highlight the nature of these relationships and the importance of increasing their knowledge about parenting with a disability. For parents with disabilities, the findings suggest the need to increase their ability to describe and direct the formal and informal supports and services necessary to prevent neglect or abuse of their children.

This study, being the first of its kind, has generated insight and information concerning the experiences, attitudes, and demographics of pre-and postnatal care professionals and parents with disabilities. Additionally, it has resulted in an emerging understanding of the experiences of parents with disabilities and their connections to formal and informal support systems. While a growing number of studies have asked the question "Can parents with significant disabilities be effective parents?" and others have focused on the services parents with disabilities receive, no one has interpreted the findings in a way that assesses the responsibility of the service delivery system to develop new supports for parents with disabilities. With this insight, strategies may be developed and disseminated to professionals caring for these parents. This new knowledge may have a profound impact on services and supports provided to parents with disabilities. Ultimately, one hopes that these research outcomes positively influence state and federal policy development and direct practice in the areas of children's wellness and family support. Policy recommendations will be put forth in this chapter to assist professionals to provide better support to and appropriate referrals for parents with disabilities. In addition, I hope to impact parent training and support programs to expand their ability to provide appropriate services to families where one or both of the parents' experiences a disability.

Theory Building and Parents with Disabilities

New theories related to parenting with a disability and the delivery of supports and services to these parents is a focus of the outcomes of this research. New theories are relate to the improvement of safety, permanence, and the well-being of children; society and the roles of professionals to support vulnerable members; the role of natural family supports and parents with disabilities; leadership and self-advocacy training for parents with disabilities; and theories related to the allocation of resources toward parents with disabilities through policy development.

Improvement of Safety, Permanence and Well-Being of Children

In many respects, individuals with disabilities who have who not been adequately supported in their parenting roles should be treated like other parents. Children born into these families have a right to reasonable safety, and those rights should be protected if and when they are threatened. By identifying the supports needed for pre and postnatal care professionals to make appropriate early referrals to family support agencies, encouraging family support agencies' abilities to expand services for parents with disabilities, and supporting families to define the supports and services they receive the number of parents with disabilities who are engaged in, or considered more likely to engage in, abuse and/or neglect of their children will ultimately decrease.

It is essential however, that a child's safety is not assumed to be at risk merely because of a parent's disability. As evidenced in the case study examples of the Schultz and Becker families, parents with disabilities can and do benefit from family support and training programs. Parents with disabilities have a legally protected right to experience these training programs if needed to provide a safe and nurturing life for their family. These supports need not be presented as a punitive measure, following perceptions or evidence of neglect but rather at the earliest stage of pre and postnatal care. Parent support and training programs should be offered as soon as the need for such programs is identified , be modeled after programs noted for their success in maintaining the health and well-being of families while attending to the needs identified by families, and should be defined by the people in need of such programs. The Family Circles program described earlier is a notable example of a parenting program that achieves positive family outcomes. These outcomes can be attributed to professionals working in partnership with families and all possible available resources to support parents with disabilities and their children. Concomitantly, pre and postnatal care professionals have an obligation to receive appropriate training and information and a responsibility to support all families in their care.

Parenting with a disability needs to move beyond the narrow niche it currently occupies into the mainstream of professional development. Resources for parents with disabilities can be found through a variety of well-organized disabilities groups; yet, general medical and human service practitioners are unaware of their existence. Awareness about parenting with a disability is being increased thanks to a limited number of conferences and pop culture productions such as films and books. The annual conference sponsored by Through the Looking Glass, an organization devoted to parenting with a disability, draws over a thousand participants each year to learn about new research, innovations, and resources related to parenting with a disability. Hollywood produced a recent movie on the topic called *I Am Sam*, starring Sean Penn. Many children's books such as Momma Zooms are published on topics related to new family configurations including parenting with a disability. At the same time that American culture is wrestling with this subject matter through books and film, changes in society relating to new family structures ought to be mirrored within all professional development programs which by their design are intended to support the health and well-being of all families.

Society and the Role of Professionals While this research study was not designed to identify or account for differences between pre and postnatal care professionals and families receiving their care, there were undeniable and uncomfortable intellectual, familial, status, and educational differences between the two groups. People who provide services represent wealth, control, and power. People who receive services represent poverty, vulnerability, and submission to those in power. This is especially true for parents with disabilities because of the additional real and/or perceived discrimination they face because they participate in a social role (parenting) that isn't supported, valued, or recommended by society. The disparity that exists between these two groups should be examined and better understood in order to identify improvements in the way people deliver and receive services. There is no simple answer, conclusion, or recommendation to address these differences but one important step is to acknowledge that we exist in a society with clear differentiation and treatment among classes of people who are defined by their perceived abilities. While relationships among poverty, disability, and referral to child protective services were not deeply explored in this study, one must acknowledge that the majority of people with disabilities live in poverty and the majority of families referred to child protective services are of low income status. If we can begin to address the existing economic disparities by supporting the economic development of parents with disabilities connected to child protective services, we may begin to see a reduction in child neglect and abuse.

If those in positions of power do not have the knowledge of what is needed by those who require services, then services will not be provided in the best interest of the recipient, and the likelihood of an individual benefiting from services is low. Bridging the gap between what is needed and what is offered is critically important. This should be done by more closely aligning the abilities of families to define their own needs and increasing the knowledge level of professionals about available resources for support. This may reduce the likelihood that parents with disabilities will neglect or abuse their children. For example, by supporting parents to decide what supports and services they need at the earliest stage of parenting, parents interviewed suggest that they will experience less stress and an increased ability to concentrate on the needs and well-being of their children and family. Areas identified by families included access to better housing and employment opportunities instead of weekly visits from a parent trainer, budget case manager, and nutrition consultant. The services they received (but didn't request) were mandated by child protective services to prevent child placement in foster care. Understandably, parents participated in these unrequested services in order to keep their children.

According to John McKnight, author of the Careless Society (1995), the assumption of need and prescribed solutions by professionals creates disabling effects. The need itself is translated into a deficiency; and at the same time professionals compartmentalize these "deficiencies" into prescribed responses. The central assumption is that the service is a unilateral response. "I, the professional produce. You, the client, consume" (pg. 46). McKnight goes on to say that professionals take the liberty to define problems and remedies, and that the self-determination aspect of citizenship no longer exists. Additionally, professionals claim the ability to decide whether their "help" is effective. For parents with disabilities this cycle is obvious. Parents with disabilities are determined "deficient" by professionals because of the need for support to maintain their families' well-being. Professionals determine the response to this "deficiency" and evaluate the effectiveness thus reinforcing the notion that parents are "deficient" and cannot determine what they need or whether it has been helpful. Supporting families to have an active role in defining their needs and the services they receive as well as evaluating the effectiveness of these services, and concomitantly educating professionals about this shift in control, may in fact result in healthier and more positively understood family circumstances when parenting with a disability is a factor. Policymakers should be alarmed by the fact that families report that the support available can actually be a constraint and that one of the primary roles of the service delivery is to perpetuate its very existence through the identification of needs and responses.

<u>Natural Family Support and Parents with Disabilities</u> Parenting with a disability is not a solo activity anymore than is parenting without a disability. The nature of parenting is one of interdependent relationships. These relationships can complement or deter from the health and well being of a family. Relationships include other close family members and relatives, neighbors, teachers, professionals, and others. Policymakers and service providers must learn to assess family structures on an individual basis rather than assume that parents can, should, and want to call on family members to provide parenting support. Rather, it behooves service providers to individually assess the natural support available to parents and take into account the parents' views of this support as promoting or inhibiting their competence as parents. While both Sheila and Catherine positively expressed their opinion that Catherine gained legal custody over Ava, it was not until the system stepped in to remove Ava from her home that natural family support was encouraged. The Beckers predicted that their children would be in foster care if it were not for the assistance of family

members finding them a new home. The Beckers rely on their neighbors for childcare in exchange for snow shoveling and lawn care. Therefore, for some families, natural family support may be available to prevent the possibility of abuse and/or neglect of their children; but for others it may not be. There can be no single recommendation regarding the utilization or reliance on natural family supports. Diversity of family structures, available supports, and needs are important factors one must take into consideration when developing appropriate supports for parents with disabilities.

Leadership and Self-Advocacy Training for Families As previously stated, parents with disabilities should be in the position of directing the supports and services necessary to maintain the health and well being of their family. Being able to direct one's own services through self-determination, self-advocacy, and personal leadership are not skills inherently developed through the experience of growing up with a disability or parenting with a disability. These are skills to learn and skills to practice. Leadership and self-advocacy will develop more easily following deliberate opportunities to realize one's success as a leader. In New Hampshire, and nationally, there are a plethora of well-organized leadership training programs for individuals with disabilities and their family members. Most notably, the Partners in Policymaking program is a comprehensive leadership building course available in almost every state. In addition, the national self-advocacy programs People First, and Self-Advocates Becoming Empowered (SABE) are two initiatives designed to support individuals with disabilities to advocate for themselves. These programs are designed to train participants about self-advocacy, community organizing, and how to use the legislative process to create change. Program content promotes individuals with disabilities to determine the course of their own lives and recruit the supports necessary to stay on course. The curriculum is tailored to meet the individual support needs of participants, including participants with cognitive disabilities and mental illness. Support is provided in order that all members of these programs can actively participate. Support can include interpreters, modified materials, transportation, childcare expenses, technical assistance to complete fieldwork assignments, and the like. For parents with disabilities, leadership development programs could be essential not only to support their own family's well being but also to change policies and practices in the area of family preservation and support to address the unique needs of parents with disabilities.

Policy Recommendations

Policy recommendations resulting from this study fall into two primary categories. The first recommendation addresses the need for an expanded system of data collection within the system of child protective services. Recommendation two is related to federal and state resources available for the prevention of neglect and abuse, particularly within recognized populations at risk.

Expanded System of Data Collection State child protective service systems collect data on the perpetrators of child abuse and neglect – the people who have abused or neglected children or allowed children in their care to be maltreated. Characteristics reported on these individuals include age, sex, and relationship to their victim (NCANDS, 2001). While individual states may report additional characteristics on the perpetrators, the reporting systems do not require it. Adding new mandated characteristic categories to the data base on perpetrators can only assist in determining the predominant risk factors associated with the neglect and abuse of children. Categories should include variables such as parental disability, substance abuse, educational level, and socioeconomic status. By gaining a better understanding of the vulnerabilities experienced by families involved in the system of child protective services, arguments can be made to allocate resources toward the prevention of child maltreatment within populations who might benefit from early family supports and services.

Allocation of Resources Policy makers, educators, statisticians, human service workers, communities, and families have recognized the tragic effects of neglect and abuse on children for years. Innumerable scientific studies have documented links between the abuse and neglect of children and a wide range of medical, emotional, psychological, behavioral, and educational problems. Conservative estimates (Fromm, 2001) are believed to be $92 billion per year in direct costs associated with the neglect and/or abuse of children. Cost figures include hospitalization, chronic health problems, mental health care, child welfare, law enforcement, and the judicial system. Yet, only six percent of the overall New Hampshire state budget for child protective services is spent on prevention when even the most sorely underfunded efforts are able to document success in preventing child abuse and neglect. National and state policy leaders in the area of child welfare and child protection need to closely examine the relationship between the outcomes of child neglect and abuse prevention programs for at risk populations and the experiences of at risk families who are not connected to programs. Resources should be redirected toward populations who are most at risk for the neglect and abuse of children and strategies that are known to support families and prevent the neglect and/or abuse of children.

In a preliminary review of national programs available for states to address the neglect and abuse of children and family support, there is a dearth of resources available to address the needs of families when parenting with a disability is a factor. For example, in 2000, important new regulations were announced by the Department of Health and Human Services to improve outcomes for children who are neglected and abused, children in foster care, and children awaiting adoption. These regulations hold states accountable for services to at-risk children, with a results-oriented approach in the federal monitoring of state child welfare programs. For the first time, states are being measured on the quality of services provided to, and outcome results for, children who are at risk. While this regulation puts the emphasis where it belongs, on safety and permanent homes for families, parents with disabilities experience significant disadvantages. The following five programs administered through the Administration on Children and Families through the Department of Health and Human Services, all relate to improvements in child welfare systems with the goal of keeping families together and permanency planning efforts for children: Child Welfare Services, Title IV-B; Promoting Safe and Stable Families, Title IV-B; CAPTA State Grants, Community-Based Family Resource Program Grants; and the Children's Justice Act. New Hampshire is probably not unique in the fact that over 60 percent of families involved in the system of child protective services experience a label of disability. Despite New Hampshire's high participation rate of parents with disabilities (and probably most states) child welfare services offer no recognition that families involved in these systems may in fact include parents with disabilities. New program components do address issues related to children with disabilities, but parents with disabilities are noticeably absent.

A primary policy recommendation directed toward improvements in supports and services available to keep families together would be for programs and policies to recognize that parents identified for supports and services include parents with disabilities (at a potentially higher rate than parents without disabilities). While there is no single recommendation to solve this dilemma of exclusionary practices related to parents with disabilities a first step is to identify the absence of the population who are potentially most in need of services and supports to keep their families together. Only then can federal and state programs begin to be revised to address the unique but growing needs of these families. As mentioned in Chapter Two, and strongly reinforced throughout this study, Preston and Jackobsen (1997) of the National Task Force on Parents with Disabilities and their Families identified the following priorities and strategies: Parents with disabilities and their families need to be recognized and included within mainstream and disability organizations directed at families and adults with disabilities. Regional and national policies which address the needs of families in which one or both parents experience a disability need to be promoted through changes in child protective service regulations, greater flexibility of personal assistance routines, Fair Housing Laws, changes in transportation policies, equal access to adoption services, and financial mechanisms to enable parents to purchase services and equipment to raise their children. There needs to be increased access to services appropriate for parents with disabilities through parent and professional training, resource libraries, and accessible childcare sites. The availability and development of adaptive parenting equipment and assistive technologies for families needs to be expanded and more widely accessible. Parents with disabilities and their families need to speak for themselves and advocate for parents with disabilities across all disability categories, across all ethnic groups, and across all family constellations.

While these strategies suggest positive outcomes for parents with disabilities and their children, they are not widely recognized or implemented within the fields of child protection services and disabilities.

The Need for Further Research

Limited research findings from this study suggest that parents with disabilities are receptive to supports and services that will enhance the health and well-being of their family, but systems are not equipped to address their unique needs. In light of the stories portrayed in this study, parents with disabilities experience obvious and subtle forms of discrimination throughout their lives. Services and supports for parents with disabilities have not been individualized according to the needs and desires defined by families. In addition, pre and postnatal care professionals do not have adequate information and training on topics related to supporting families. Additionally, there is a significant need to better understand the relationships and influences among poverty, disability, and connections to the system of child protective services.

Limitations of the Study. Obvious limitations exist within this study. The first limitation was the use of survey research to attempt to capture deeply ingrained perceptions and attitudes of pre and postnatal care professionals toward people with disabilities. The ability to probe during the in-depth interviews resulted in richer findings. A second limitation was the case study approach. While the case study findings add tremendous life to this topic, one can not make confident generalizations from the experiences of only two families. A third limitation is the single-state context of this study. Finally, because the survey was newly designed, it lacked established validity.

Emerging Hypotheses Two hypotheses in particular emerged from the study that warrant further research. One could hypothesize that an increase in the knowledge base of professionals of the services available to support parents with disabilities would result in a decrease in referrals to child protective services and an increase in referrals to more appropriate systems of support. In achieving this, one could further hypothesize that when families receive services they identify as necessary for the well being of their family, child neglect and abuse will decrease and the societal standing of parents with disabilities will increase.

New studies, both quantitative and qualitative are needed to better understand the experiences of parents with disabilities and their connections to formal and informal systems of support. Understanding the primary sources of parent referral to systems of support and to child protective services begs for further inquiry. Larger scale case studies of family experiences are needed to more fully understand the needs and perceptions of these families. National research in the form of a meta analysis needs to be conducted to learn more about the inclusion of parents with disabilities in all aspects of state and federal child protective service and family support program guidelines and practices and to provide adequate recommendations for change.

Contribution to Research and Theory-Building

This research is intended to enlarge the knowledge base and understanding of an otherwise neglected area of study - parents with disabilities. Additionally, this study advances the fields of qualitative and quantitative research by bringing together elements of each discipline in order to organize a holistic set of data responsive to pressing societal concerns and the generation of responses. This study asked a set of questions that have not yet been asked within an academic, scientific framework. The methods used to gather information and develop hypotheses are methods that have not yet been used to directly address the issue of parents with disabilities and their earliest connections to systems of pre and postnatal care. Ultimately, it is hoped that this research will contribute to a new theoretical understanding of family systems when one or both parents experience a disability and the professional decision making process of pre and postnatal care professionals involved in the lives of these presently underserved and vulnerable families. The strands that make up the fabric of community will be strengthened and brighter through the inclusion of people with disabilities as parents.

REFERENCES

Andron, L., & Sturm, M. (1973). Is "I do" in the repertoire of the retarded? A study of the functioning of married retarded couples. Mental retardation, 11 (1), 31-34.

Auliff, L,. (2001). Bringing up baby. WeMedia, 5 (1), 66-69.

Banks, M., (1999). Patients' physical disability may influence doctors' perceptions of suitability for risk assessment of coronary heart disease. British Medical Journal, Letter to the Editor. November 6.

Barker, L.T. & Maralani, V., (1997). Challenges and strategies of disabled parents: findings from a national survey of parents with disabilities, Final Report. Through the Looking Glass: National Resource Center for Parents with Disabilities, Berkeley, CA.

Bell, J., (1995). A review of family preservation and family reunification programs. Office of the Assistant Secretary for Planning and Evaluation. U.S. Department of Health and Human Services.

Berry, M., (1992). An evaluation of family preservation services: fitting agency services to family needs. Social Work, 37 (4), 314-322.

Booth, T., & Booth, W., (2000). Against the odds: growing up with parents who have learning difficulties. Mental Retardation, 38 (1), 1-14.

Blanch, A. K. & Nicholson, J. (1994). Parents with severe mental illness and their children. The need for human service integration. Journal of Mental Health Administration, 2 (4), 388-396.

Braddock, D., Hemp, R., Parish, S., & Westrich, J., (1998). The state of the state in developmental disabilities. Washington, DC: American Association on Mental Retardation.

Califano, J. A., (1999). The least among us children of substance abusing parents. America, 180 (14), 10-12.

Culley L., Genders, N., (1999). Parenting by people with learning disabilities: the educational needs of the community nurse. Nurse Education Today, 19 (6). 502-508.

Dillman, D. A., (1978). Mail and telephone surveys. New York: David Wiley & Sons.

Dillman, D.A., (2000). Mail and internet surveys: the tailored design method. New York: David Wiley & Sons.

Espe-Sherwindt, M., (1991). The IFSP and parents with special needs/mental retardation. Topics in Early Childhood Special Education, 11 (3), 107-121.

Estrada, M., (1996). California adoption agencies: how do they assess parents with disabilities? Through the Looking Glass: National Resource Center for Parents with Disabilities, Berkeley, CA.

Fromm, S., (2001). Total estimated cost of child abuse and neglect in United States: statistical evidence. Prevent Child Abuse America, Edna McConnell Clark Foundation.

Glaser, B.G. & Strauss, A.L., (1967). The discovery of grounded theory: strategies for qualitative research. New York: Alpine Publishing Company.

Greene, B.F., Norman, R., Seattle, M.S., Daniels, M., & Lubeck, R. C., (1995). Child abuse and neglect by parents with disabilities: a tale of two families. Journal of Applied Behavior Analysis, 28 (4) 417-434.

Hughes, R. C. & Rycus, J. S., (1998). Developmental disabilities and child welfare. Washington, DC: Child Welfare League of America, Inc.

Kennedy, R., & Garbus, L. (Producers & Directors), (1999). Different Moms [Film]. (Available from Lifetime Home Videos, www.lifetimetv.com).

Kirshbaum, M., (2000). A disability culture perspective on early intervention with parents with physical or cognitive disabilities and their infants. Infants and Young Children, 13 (2) 9-20.

Llewellyn, G., (1995). Relationships and social support: views of parents with mental retardation/intellectual disability. Mental retardation. 33 (6), 349-363.

Mental Illness Education Project. (1999). I love you like crazy: being a parent with mental illness. Massachusetts Department of Mental Health. Brookline, MA.

McConnell, D., & Llewellyn, G., (2000). Disability and discrimination in statutory child protection proceedings. Disability and Society 15 (6) 883-895.

McConnell, D., & Llewellyn, G., (1998). Parental disability and the threat of child removal. Family Matters 2 (51) 33-37.

McConnell, D., & Llewellyn, G., (1997). Providing services for parents with intellectual disability: parent needs and service constraints. Journal of Intellectual and Developmental Disability, 22 (1) pp. 5-28.

McKnight, J., (1995). The Careless Society: community and its counterfeits., New York, NY: Basic Books.

Miller, W., (1994, April 10,11,12) The Spokesman Review, Spokane, Washington.

National Child Abuse and Neglect Data System (NCANDS, 2001). Ten years or reporting: child maltreatment 1999. U.S. Department of Health and Human Services, Administration on Children, Youth, and Families. Washington, DC: U.S. Government Printing Office.

National Committee to Prevent Child Abuse. (1999). Current trends in child abuse reporting and fatalities: the results of the 1998 annual national fifty-state survey. Chicago, IL: National Committee to Prevent Child Abuse.

National Committee to Prevent Child Abuse. (2000). Current trends in child abuse reporting and fatalities: the results of the 2000 annual national fifty-state survey. Chicago, IL: National Committee to Prevent Child Abuse.

Pomerantz, P., & Pomerantz, D. J., (1990). A case study: service delivery and parents with disabilities. Child Welfare, 69 (1), 65 -72.

Portney, L. G. & Watkins, M. P., (1993). Foundations of clinical research: applications to practice. Norwalk, CN: Appleton and Lange.

Preston, P., & Jakobsen, M, (1997). Keeping our families together: a report of the national task force on parents with disabilities and their families. Through the Looking Glass: National Resource Center for Parents with Disabilities, Berkeley, CA.

Pugach, M.C. (2001). The stories we choose to tell: fulfilling the promise of qualitative research for special education. Exceptional Children, 67 (4), 439-453.

Ray, N. K., & Rubenstein, H. (1994) Understanding the parents who are mentally retarded. Guidelines for family preservation programs. Child Welfare, 73 (6), 725-743.

Report on Child Abuse and Neglect (1993). National Academy of Science.

Reppucci, N.D., Britner, P.A. & Woolard, J.L., (1997). Preventing child abuse and neglect through parent education. Baltimore, MD: Paul H. Brookes.

Reischel, T., (1999). Survey of New Hampshire Regional Coordinators on the Involvement of Parents with Disabilities in Child Protective Services.

Revised Statutes Annotated 171-A2, State of New Hampshire.

Ronai, R. C., (1997). On loving and hating my mentally retarded mother. Mental Retardation. 35 (6), 417-432.

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

Sobsey, R., (1999). Report on Abuse and Neglect and People with Disabilities. UNH Institute on Abuse and Neglect, Durham, NH.

Stein, K., (1999). Cross sectional survey of cervical cancer screening in women with learning disabilities. British Medical Journal. March 6. British Medical Association.

Toub, D.B., (2000). Gynecological care of women with developmental disabilities and other special needs. OBGYN.net Publications.

Taylor, S., J., & Bogdan, R. (1984). Introduction to qualitative research methods: the search for meaning (2nd ed.). New York: David Wiley & Sons.

Taylor, S. J., (1995). Children's division is coming to take pictures: family life and parenting in a family with disabilities. In Noelle, S. J., Bogdan, R., & Lutfiyya, Z. M., (eds.). The variety of community experience: qualitative studies of family and community life. Baltimore, MD: Paul H. Brookes.

Taylor, S.J., (2000). "You're not a retard, you're just wise." disability, social identity, and family networks. Journal of Contemporary Ethnography, 29 (10) 58-92.

Tymchuk, A.J. (2001). Family life: experiences of people with mild cognitive limitations. In Tymchuk, A.J., Lakin, C. L., & Luckasson, R., (eds.). The forgotten generation. Baltimore, MD: Paul H. Brookes.

Tymchuk, A. J., (1999). Moving towards integration of services for parents with intellectual disabilities. Journal of Intellectual and Developmental Disability, 24 (1),59-72.

Tymchuk, A. J., Llewellyn, G., & Feldman, M., (1999). Parenting by persons with intellectual disabilities: a timely international perspective. Journal of Intellectual and Developmental Disability 24 (1) 3-6.

Tymchuk, A.J., (1992). Predicting adequacy of parenting by people with mental retardation. Child Abuse and Neglect, 16, 165-178.

Tymchuk, A.J., & Andron, L., (1990). Mothers with mental retardation who do not abuse or neglect their children. Child Abuse and Neglect, 14 313-323.

Tymchuk, A.J., (1990a). Parents with mental retardation: A national strategy. Journal of Disability Policy Studies, 1, 44-56.

Whitman, B. Y., & Accardo, P. J. (1987). When a parent is mentally retarded. Baltimore, MD: Paul H. Brookes.

World Health Organization, WHO, (2002). International classification of functioning and disability. Draft for Field Trials. Geneva Switzerland.

APPENDIX A

IRB APPROVAL

UNIVERSITY OF NEW HAMPSHIRE

ice of Sponsored Research
Service Building
51 College Road
Durham, New Hampshire 03824-3585
(603) 862-3564 FAX

LAST NAME	[redacted]	**FIRST NAME**	[redacted]
DEPT	UNH Institute on Disability, Leavitt Center, Durham	**APP'L DATE**	[redacted]
OFF-CAMPUS ADDRESS (If applicable)	UNH Institute on Disability Leavitt Center Durham, NH 03824	**IRB #**	2487
		REVIEW LEVEL	FULL
	[redacted]	**DATE OF NOTICE**	3/12/2001
PROJECT TITLE	[redacted]		

The Institutional Review Board (IRB) for the Protection of Human Subjects in Research reviewed and approved the protocol for your project with the following contingencies:

- *Receipt of letter in support of study from DCYF.*

Approval is granted for one year from the approval date above. At the end of the approval period you will be asked to submit a project report with regard to the involvement of human subjects. If your project is still active, you may apply for extension of IRB approval through this office. **Changes in your protocol must be submitted to the IRB for review prior to their implementation; you must receive written, unconditional approval from the IRB before implementing them.**

The protection of human subjects in your study is an ongoing process for which you hold primary responsibility. In receiving IRB approval for your protocol, you agree to conduct the project in accordance with the ethical principles and guidelines for the protection of human subjects in research, as described in the following three reports: Belmont Report; Title 45, Code of Federal Regulations, Part 46; and UNH's Multiple Project Assurance of Compliance. The full text of these documents is available on the OSR information server at http://www.unh.edu/osr/compliance/Regulatory_Compliance.html and by request from the Office of Sponsored Research.

If you have questions or concerns about your project or this approval, please feel free to contact our office directly at 862-2003.

For the IRB,

Julie F. Simpson

Julie F. Simpson
Regulatory Compliance Manager
Office of Sponsored Research

cc: File
Bruce Mallory

APPENDIX B

SURVEY

UNIVERSITY *of* NEW HAMPSHIRE

March 19, 2001

Dear Colleague:

I am writing to ask your help in a research project about the experiences and attitudes of pre-and post-natal care professionals caring for *parents who have disabilities*. This study, a collaborative project with the Dartmouth Medical School, Center for Genetics and Child Development, and New Hampshire Health and Human Services is part of an effort to understand how these parents become connected to formal systems of support.

It is my understanding, that you are a professional practicing in pre-or post-natal care. Since this is a census survey, I am making every attempt to contact all professionals in this category. By understanding your professions' personnel preparation practices, experiences with disability, and current practices and opinions related to *parents with disabilities*, policymakers can begin to address the critical issues facing new *parents with disabilities* and the service systems of support.

Your answers are completely confidential and will be released only as summaries in which no individual's answer can be identified. When you return the postcard acknowledging your completion of the survey, your name will be deleted from the mailing list and never be connected to your answers in any way.

If you have any comments about this study, I would be happy to talk with you via e-mail or telephone, 228-2084. My e-mail address is mcschuh@cisunix.unh.edu. In addition, if you have any questions about your rights as a research participant, you may contact Julie Simpson in the University of New Hampshire Office of Sponsored Research at 603-862-2003.

Thank you very much for helping with this important study.

Sincerely,

Mary Schuh, Ph.D. Candidate
Institute on Disability/UAP
University of New Hampshire

John Moeschler, MD
Center for Genetics and Child Development
Dartmouth Medical School

Donald Shumway, Commissioner
State of New Hampshire
Health and Human Services

Enclosure: survey and return postcard

Institute on Disability/UAP
The Concord Center, Suite 317 10 Ferry Street, Unit #14 Concord, New Hampshire 03301-5019 603-228-2084 v/TDD 603-228-3270 fax

UNIVERSITY OF NEW HAMPSHIRE

Institute on Disability
A University Affiliated Program
7 Leavitt Lane, Suite 101
Durham, New Hampshire 03824-3522

(603) 862-4320 (tel/tdd)
(603) 862-0555 (fax)
http://iod.unh.edu (internet)
institute.disability@unh.edu (email)

August 15, 2001

Dear Colleague,

In the spring I sent a survey to you that asked about your experiences as a pre/post natal care professional. To the best of our knowledge, it's not yet been returned.

The comments and responses of people who have responded include a wide variety of referral practices for new parents. Many have described their experiences, both challenging and rewarding, regarding parents who have disabilities. We think the results are going to be very useful in developing policies and practices to better support all families.

We are writing again because of the importance that your survey has for helping to get accurate results. Although we sent surveys to all pre and post natal care professionals in New Hampshire, *it's only by hearing from nearly everyone that we can be sure the results are truly representative.*

We hope that you will fill out and return the survey today, but if for any reason you prefer not to answer it, please let us know by returning a note or blank questionnaire in the enclosed stamped envelope. Your answers are completely confidential and will be released only as summaries in which no individual's answer can be identified. When you return the postcard acknowledging your completion of the survey, your name will be deleted from the mailing list and never be connected to your answers in any way.

If you have any comments about this study, I would be happy to talk with you via e-mail or telephone, 228-2084. My e-mail address is mcschuh@cisunix.unh.edu. In addition, if you have any questions about your rights as a research participant, you may contact Julie Simpson in the University of New Hampshire Office of Sponsored Research at 603-862-2003.

Thank you very much for helping with this important study.

Sincerely,

Mary C. Schuh

Mary Schuh, Ph.D. Candidate
Institute on Disability/UAP
University of New Hampshire

Cc: John Moeshler, MD, Dartmouth Medical School
Donald L. Shumway, Commissioner, NH Department of Health and Human Services

Enclosure: survey and return postcard

A University Affiliated Program in Collaboration with:

Center for Genetics and Child Development
Dartmouth-Hitchcock Medical Center
One Medical Center Drive
Lebanon, NH 03756

The Hood Center for Children and Families
Dartmouth-Hitchcock Medical Center
One Medical Center Drive
Lebanon, NH 03756

Institute for Health, Law and Ethics
Franklin Pierce Law Center
Two White Street
Concord, NH 03301

Survey of Pre- and/or Post-Natal Care Professional Referral Process

This survey is designed to provide a better understanding of the referral practices of pre and post natal care professionals caring for PARENTS who experience a disability. The results will be used to help policy makers, medical professionals, and agencies providing supports and services address critical issues facing parents with disabilities.

Please take a moment to complete and return the survey in the enclosed envelope. In order to maintain confidentiality and delete your name from the mailing list for follow up correspondence a postcard is enclosed for you to complete and return. Thank you for taking the time to complete and return by **April 19, 2001.**

U.S. Census Definition of Disability: [illegible] Long-time use of mobility device such as a wheelchair or cane; difficulty with seeing, hearing, speaking, walking, using stairs, lifting; difficulty with activities of daily living such as getting out of bed, dressing, bathing, eating; difficulty with instrumental activities such as personal finances, preparing meals, light housework, taking medications as prescribed; specified condition such as learning disability, development disability, dementia, mental or emotional disability; limits in the ability to work and receiving federal benefits based on the inability to work [illegible]

1) Professional title: ____________________

2) Years of experience within your title: ____ 2a) Year you received your last degree: ____

Please circle the number of the response that best reflects your answer.

3) Do you spend 1 <u>more</u> or 2 <u>less</u> (circle one) than 50% of your time providing direct patient care?

4) In your training as a pre-and/or post-natal care professional, did you receive training and information about parents with disabilities?
1 yes 2 no

4a) If yes, please describe.

5) Please check and identify your personal experience living with a disability.

1 physical disabilities (cerebral palsy, spinal cord injury)
2 mental retardation, traumatic brain injury
3 mental illness or emotional disabilities
4 sensory disabilities (deafness, blindness)
5 multiple disabilities (combination of two or more)

Indicate type from list above.

☐ I have a disability. ____
☐ I have a child with a disability. ____
☐ I have a sibling with a disability. ____
☐ I have a spouse with a disability. ____
☐ I have a parent with a disability. ____
☐ I have a close friend with a disability. ____
☐ I have a coworker with a disability. ____
☐ I attended school with students with disabilities in my classes. ____
☐ Some of my neighbors and acquaintances have disabilities. ____
☐ No personal experience living with a disability. ____

6) In your experience as a pre and/or post-natal care professional, have you ever treated a parent with a known disability?
1 yes 2 no

7) Approximately how many parents have you cared for who have a disability? ____

8) What types of disabilities have you encountered in your professional care of parents with disabilities.

Please circle all that apply.

1 physical disabilities (cerebral palsy, spinal cord injury)
2 cognitive disabilities (mental retardation)
3 mental illness or emotional disabilities
4 sensory disabilities (deafness, blindness)
5 multiple disabilities (combination of two or more)

9) Have you ever treated a baby born to a parent with a known disability? 1 yes 2 no

10) Do you follow any specific guidelines on caring for babies who have parents with a known disability? 1 yes 2 no

11) If yes, briefly describe these guidelines:

12) Which of these discharge services do you recommend to <u>any new parent</u>. Circle the number that represents the frequency of referral.

	always	often	sometimes	rarely	never
home visiting services	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
foster care placement services	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
referral to child protective services	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
referral to the local area agency for developmental services	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
referral to Granite State Independent Living	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
referral to welfare agencies	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
other, (please describe)________________________	1	2	3	4	5

13) In your treatment and care for families when a <u>parent has a disability</u>, what discharge information and services do you recommend. Circle the number that represents the frequency of referral.

	always	often	sometimes	rarely	never
home visiting services	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
foster care placement services	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
referral to child protective services	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
referral to the local area agency for developmental services	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
referral to Granite State Independent Living	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
referral to welfare agencies	1	2	3	4	5
[illegible]	[illegible]	[illegible]	[illegible]	[illegible]	[illegible]
other, (please describe)________________________	1	2	3	4	5

14) Have you ever made a referral to child protective services for a family in your care when one or both of the parents experience a disability? 1 yes 2 no

15) Your most frequent reason for referral to child protective services is:
1 perceived risk for child abuse and/or neglect
2 evidence of child abuse and/or neglect
3 other (please describe) ____________________

16) Please circle the intended outcome for making a referral to child protective services:
1 access to parent training programs
2 in-home family support
3 removal of child from family
4 other (please describe) ____________________

17) In your opinion, are parents with certain types of disabilities more likely to be referred for child protective services?
1 yes 2 no

18) If yes, please circle type of disability of parents most likely to be referred to child protective services. Circle all that apply.
1 physical disabilities (cerebral palsy, spinal cord injury)
2 cognitive disabilities (mental retardation)
3 mental illness or emotional disabilities
4 sensory disabilities (deafness, blindness)
5 multiple disabilities (combination of two or more)

19) Please describe programs you are aware of noted for their involvement with parents with disabilities.

Please read through the following scenarios and circle all services you would most likely recommend to these families:

20) Jane is the 34 year old mother of two. She has just delivered an 8lb. 7oz. baby girl at the local hospital. Her pregnancy and delivery were uneventful and she plans on returning home following a 48 hour stay. Her husband Mike is out of work and struggling to meet all the financial needs of his family and afford the repairs on the mobile home that they own in rural NH. His unemployment funds will be ending soon.

1 home visiting services
2 adoption placement services
3 foster care placement services
4 referral to parent training programs
5 referral to child protective services
6 referral to the early intervention services
7 other, (please describe) ____________________
8 referral to the local area agency
9 referral to the mental health center
10 referral to Granite State Independent Living
11 referral to the Disability Rights Center
12 referral to welfare agencies
13 referral to housing agencies

21) Emily has cerebral palsy and uses a motorized wheelchair to get around. She and her husband have just become the parents of a 6lb. 4oz. healthy baby girl. Their home is fully accessible and both parents have full-time jobs with the local university.

1 home visiting services
2 adoption placement services
3 foster care placement services
4 referral to parent training programs
5 referral to child protective services
6 referral to the early intervention services
7 other, (please describe) ____________________
8 referral to the local area agency
9 referral to the mental health center
10 referral to Granite State Independent Living
11 referral to the Disability Rights Center
12 referral to welfare agencies
13 referral to housing agencies

22) Jessa is single and works for the local transportation authority as a dispatcher. She is blind and has a guide dog as a companion. Her former boyfriend is the father of her newborn son, although his where abouts are unknown.

1 home visiting services
2 adoption placement services
3 foster care placement services
4 referral to parent training programs
5 referral to child protective services
6 referral to the early intervention services
7 other, (please describe) ____________________
8 referral to the local area agency
9 referral to the mental health center
10 referral to Granite State Independent Living
11 referral to the Disability Rights Center
12 referral to welfare agencies
13 referral to housing agencies

23) Sarah is the [illegible] year old mother of two with an IQ of 70. She has just delivered a 8lb 9oz baby boy at the local hospital. Her pregnancy and delivery were uneventful and she plans on returning home following a 48 hour stay. Her husband Greg, who has a label of schizophrenia, is out of work and struggling to meet all the financial needs of his family and afford the repairs on the mobile home that they own in rural NH. His unemployment funds will be ending soon.

1 home visiting services
2 adoption placement services
3 foster care placement services
4 referral to parent training programs
5 referral to child protective services
6 referral to the early intervention services
7 other, (please describe)____
8 referral to the local area agency
9 referral to the mental health center
10 referral to Granite State Independent Living
11 referral to the Disability Rights Center
12 referral to welfare agencies
13 referral to housing agencies

24) Elisa, a recent high school graduate, and newlywed is attending the local technical college to become a computer technician. She and her husband Jack are expecting their first child. Jack currently receives disability benefits because he is on a leave of absence from his job in order to get his severe mental illness under control.

1 home visiting services
2 adoption placement services
3 foster care placement services
4 referral to parent training programs
5 referral to child protective services
6 referral to the early intervention services
7 other, (please describe)____
8 referral to the local area agency
9 referral to the mental health center
10 referral to Granite State Independent Living
11 referral to the Disability Rights Center
12 referral to welfare agencies
13 referral to housing agencies

25) In your opinion, does the service delivery system offer appropriate supports for parents with disabilities?

1 - always 2 - often 3 - sometimes 4 - rarely 5 - never

Personal Information

26) Gender: 1 (M) 2 (F) Age: ______

27) Marital Status: 1 single 2 married 3 divorced 4 partner 5 widowed

28) Are you a parent/guardian? 1 yes 2 no 29) If yes, how many children? _____

30) Geographical location of the majority of your patients? 1 rural 2 suburban 3 urban

31) Are you available to participate in an in-depth interview (30 min) regarding the issue of parents with disabilities?

1 Yes 2 No

If yes, please provide your name, telephone number, and e-mail address. Thank you.

Name:____
Telephone: _____________________________________ (best time of the day to call)_______
E-mail address_________________________________

Thank you for completing and returning this survey by April 19, 2001.
A self-addressed stamped envelope is enclosed for your convenience.
Please call 228-2084 or e-mail mcschuh@cisunix.unh.edu with any questions.

Mary Schuh
Institute on Disability/UAP
The Concord Center, 10 Ferry Street, #14
Concord, NH 03301-5019

APPENDIX C

SURVEY QUESTIONS 20-24
SIGNIFICANCE TESTS

Crosstabs

professional title * 20 home visiting

Crosstab

Count

		20 home visiting		
		yes	no	Total
professional title	RN	71	19	90
	OB-GYN	34	9	43
	midwife	6	2	8
	Pediatrician	63	11	74
	Birth Coor	14	2	16
Total		188	43	231

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.819[a]	4	.769
Likelihood Ratio	1.867	4	.760
Linear-by-Linear Association	1.425	1	.233
N of Valid Cases	231		

a. 2 cells (20.0%) have expected count less than 5. The minimum expected count is 1.49.

professional title * 20 child protective services

Crosstab

Count

		20 child protective services	
		no	Total
professional title	RN	90	90
	OB-GYN	43	43
	midwife	8	8
	Pediatrician	74	74
	Birth Coor	16	16
Total		231	231

Chi-Square Tests

	Value
Pearson Chi-Square	.[a]
N of Valid Cases	231

a. No statistics are computed because 20 child protective services is a constant.

professional title * 20 local area agency

Crosstab

Count

		20 local area agency		Total
		yes	no	
professional title	RN	35	55	90
	OB-GYN	22	21	43
	midwife	4	4	8
	Pediatrician	23	51	74
	Birth Coor	9	7	16
Total		93	138	231

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	6.804[a]	4	.147
Likelihood Ratio	6.796	4	.147
Linear-by-Linear Association	.130	1	.718
N of Valid Cases	231		

a. 2 cells (20.0%) have expected count less than 5. The minimum expected count is 3.22.

professional title * 20 mental health center

Crosstab

Count

		20 mental health center		Total
		yes	no	
professional title	RN	7	83	90
	OB-GYN	2	41	43
	midwife		8	8
	Pediatrician	2	72	74
	Birth Coor		16	16
Total		11	220	231

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	3.698[a]	4	.448
Likelihood Ratio	4.685	4	.321
Linear-by-Linear Association	3.238	1	.072
N of Valid Cases	231		

a. 5 cells (50.0%) have expected count less than 5. The minimum expected count is .38.

Crosstabs

professional title * 21 home visiting

Crosstab

Count

		21 home visiting		Total
		yes	no	
professional title	RN	74	12	86
	OB-GYN	37	6	43
	midwife	7	1	8
	Pediatrician	66	5	71
	Birth Coor	16		16
Total		200	24	224

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	4.362[a]	4	.359
Likelihood Ratio	6.081	4	.193
Linear-by-Linear Association	3.774	1	.052
N of Valid Cases	224		

[a] 3 cells (30.0%) have expected count less than 5. The minimum expected count is .86.

professional title * 21 child protective services

Crosstab

Count

		21 child protective services	Total
		no	
professional title	RN	86	86
	OB-GYN	43	43
	midwife	8	8
	Pediatrician	71	71
	Birth Coor	16	16
Total		224	224

Chi-Square Tests

	Value
Pearson Chi-Square	.[a]
N of Valid Cases	224

[a] No statistics are computed because 21 child protective services is a constant.

professional title * 21 local area agency

Crosstab

Count

		21 local area agency		Total
		yes	no	
professional title	RN	10	76	86
	OB-GYN	6	37	43
	midwife	2	6	8
	Pediatrician	4	67	71
	Birth Coor	3	13	16
Total		25	199	224

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	5.019[a]	4	.285
Likelihood Ratio	4.938	4	.294
Linear-by-Linear Association	.264	1	.607
N of Valid Cases	224		

a. 3 cells (30.0%) have expected count less than 5. The minimum expected count is .89.

professional title * 21 mental health center

Crosstab

Count

		21 mental health center			Total
		yes	no	22	
professional title	RN	1	85		86
	OB-GYN	1	41	1	43
	midwife		8		8
	Pediatrician		70		70
	Birth Coor		16		16
Total		2	220	1	223

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	6.141[a]	8	.631
Likelihood Ratio	5.783	8	.672
Linear-by-Linear Association	.074	1	.785
N of Valid Cases	223		

a. 10 cells (66.7%) have expected count less than 5. The minimum expected count is .04.

Crosstabs

professional title * 22 home visiting

Crosstab

Count

		22 home visiting		
		yes	no	Total
professional title	RN	84	7	91
	OB-GYN	36	7	43
	midwife	8		8
	Pediatrician	74		74
	Birth Coor	16		16
Total		218	14	232

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	14.693[a]	4	.005
Likelihood Ratio	18.189	4	.001
Linear-by-Linear Association	6.929	1	.008
N of Valid Cases	232		

a. 4 cells (40.0%) have expected count less than 5. The minimum expected count is .48.

professional title * 22 child protective services

Crosstab

Count

		22 child protective services		
		yes	no	Total
professional title	RN	4	87	91
	OB-GYN	3	40	43
	midwife		8	8
	Pediatrician	3	71	74
	Birth Coor	1	15	16
Total		11	221	232

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.056[a]	4	.901
Likelihood Ratio	1.375	4	.849
Linear-by-Linear Association	.006	1	.939
N of Valid Cases	232		

a. 5 cells (50.0%) have expected count less than 5. The minimum expected count is .38.

professional title * 22 local area agency

Crosstab

Count

		22 local area agency		Total
		yes	no	
professional title	RN	36	55	91
	OB-GYN	20	23	43
	midwife	3	5	8
	Pediatrician	27	47	74
	Birth Coor	10	6	16
Total		96	136	232

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	4.313[a]	4	.365
Likelihood Ratio	4.264	4	.371
Linear-by-Linear Association	.153	1	.696
N of Valid Cases	232		

a. 2 cells (20.0%) have expected count less than 5. The minimum expected count is 3.31.

professional title * 22 mental health center

Crosstab

Count

		22 mental health center		Total
		yes	no	
professional title	RN	5	86	91
	OB-GYN	2	41	43
	midwife		8	8
	Pediatrician	2	72	74
	Birth Coor		16	16
Total		9	223	232

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.949[a]	4	.745
Likelihood Ratio	2.836	4	.586
Linear-by-Linear Association	1.599	1	.206
N of Valid Cases	232		

a. 5 cells (50.0%) have expected count less than 5. The minimum expected count is .31.

Crosstabs

professional title * 23 home visiting

Crosstab

Count

		23 home visiting		
		yes	no	Total
professional title	RN	86	5	91
	OB-GYN	40	1	41
	midwife	8		8
	Pediatrician	71	3	74
	Birth Coor	16		16
Total		221	9	230

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.824[a]	4	.768
Likelihood Ratio	2.732	4	.604
Linear-by-Linear Association	.641	1	.423
N of Valid Cases	230		

a. 5 cells (50.0%) have expected count less than 5. The minimum expected count is .31.

professional title * 23 child protective services

Crosstab

Count

		23 child protective services		
		yes	no	Total
professional title	RN	16	75	91
	OB-GYN	13	28	41
	midwife	2	6	8
	Pediatrician	18	56	74
	Birth Coor	1	15	16
Total		50	180	230

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	5.916[a]	4	.206
Likelihood Ratio	6.411	4	.170
Linear-by-Linear Association	.002	1	.962
N of Valid Cases	230		

a. 2 cells (20.0%) have expected count less than 5. The minimum expected count is 1.74.

professional title * 23 local area agency

Crosstab

Count

		23 local area agency		
		yes	no	Total
professional title	RN	49	42	91
	OB-GYN	27	14	41
	midwife	5	3	8
	Pediatrician	36	38	74
	Birth Coor	11	5	16
Total		128	102	230

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	4.584[a]	4	.333
Likelihood Ratio	4.653	4	.325
Linear-by-Linear Association	.030	1	.863
N of Valid Cases	230		

[a] 2 cells (20.0%) have expected count less than 5. The minimum expected count is 3.55.

professional title * 23 mental health center

Crosstab

Count

		23 mental health center		
		yes	no	Total
professional title	RN	55	36	91
	OB-GYN	24	17	41
	midwife	6	2	8
	Pediatrician	31	43	74
	Birth Coor	11	5	16
Total		127	103	230

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	8.951[a]	4	.062
Likelihood Ratio	9.042	4	.060
Linear-by-Linear Association	2.239	1	.135
N of Valid Cases	230		

[a] 2 cells (20.0%) have expected count less than 5. The minimum expected count is 3.58.

Crosstabs

professional title * 24 home visiting

Crosstab

Count

		24 home visiting		Total
		yes	no	
professional title	RN	63	26	89
	OB-GYN	29	10	39
	midwife	6	2	8
	Pediatrician	58	13	71
	Birth Coor	14	2	16
Total		170	53	223

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	3.828[a]	4	.430
Likelihood Ratio	3.997	4	.406
Linear-by-Linear Association	3.735	1	.053
N of Valid Cases	223		

[a] 2 cells (20.0%) have expected count less than 5. The minimum expected count is 1.90.

professional title * 24 child protective services

Crosstab

Count

		24 child protective services		Total
		yes	no	
professional title	RN	1	88	89
	OB-GYN	3	36	39
	midwife		8	8
	Pediatrician	4	67	71
	Birth Coor		16	16
Total		8	215	223

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	5.215[a]	4	.266
Likelihood Ratio	6.053	4	.195
Linear-by-Linear Association	.582	1	.445
N of Valid Cases	223		

[a] 5 cells (50.0%) have expected count less than 5. The minimum expected count is .29.

professional title * 24 local area agency

Crosstab

Count

		24 local area agency		Total
		yes	no	
professional title	RN	33	56	89
	OB-GYN	18	21	39
	midwife	4	4	8
	Pediatrician	21	50	71
	Birth Coor	4	12	16
Total		80	143	223

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	4.588[a]	4	.332
Likelihood Ratio	4.585	4	.333
Linear-by-Linear Association	1.825	1	.177
N of Valid Cases	223		

a. 1 cells (10.0%) have expected count less than 5. The minimum expected count is 2.87.

professional title * 24 mental health center

Crosstab

Count

		24 mental health center		Total
		yes	no	
professional title	RN	67	22	89
	OB-GYN	22	17	39
	midwife	5	3	8
	Pediatrician	36	35	71
	Birth Coor	10	6	16
Total		140	83	223

Chi-Square Tests

	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	11.061[a]	4	.026
Likelihood Ratio	11.278	4	.024
Linear-by-Linear Association	7.300	1	.007
N of Valid Cases	223		

a. 1 cells (10.0%) have expected count less than 5. The minimum expected count is 2.98.