

BARRIERS TO SUCCESSFUL PARENTING: IDENTIFYING THE NEEDS OF
PARENTS WITH DEVELOPMENTAL DISABILITIES

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by

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Division of Social Work

Abstract

of

BARRIERS TO SUCCESSFUL PARENTING: IDENTIFYING THE NEEDS OF
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by

Jaime Zehner

Parents with developmental disabilities face a number of challenges in performing parental duties in accordance with current child welfare policies, which allow for the termination of parental rights on the basis of disability. The purpose of this research is to examine the barriers to successful parenting amongst persons with developmental disabilities; and to identify best service practices for addressing parent needs. The literature review utilized peer reviewed journal articles, and policies to examine the challenges faced by families with parental disability. This research study examined the needs of 48 parents with developmental disabilities in Sacramento County. Findings indicate that the primary barriers were insufficient social supports and reduced ability to support child education. An overwhelming majority of participants were involved with Child Protective Services and requested professional supports in providing an adequate standard of care for their families.

_____, Committee Chair
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Date

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Chapter 1

STATEMENT OF THE PROBLEM

In 2006, the United Nations signed the resolution of the Convention on the Rights of Persons with Disabilities (CRPD), recognizing the equality of all persons, regardless of physical or developmental disability. Article 23 of CRPD, Respect for Home and the Family, states that all persons with disabilities, being of legal age to consent, have the right to marry and to form a family consisting of any chosen number of children (United Nations, 2006). Further, the resolution grants disabled parents access to the necessary education and supports required to achieve their familial and reproductive rights.

Despite global efforts to improve familial rights—such as the United Nations’ CRPD resolution, the involvement of child welfare services amongst families with parents known to have a developmental disability is an issue which persists across both developed and under-developed nations. In 1994, an analysis of the National Health Interview Survey in the United States identified that 49 percent of non-institutionalized parents with intellectual disabilities were separated from their children (Larson, Lakin, Anderson, & Kwak, 2001). Studies conducted on the prevalence of developmental disability in child welfare court cases in the United States, England, and Australia found similar concerns “that children of parents with intellectual disabilities were more likely than any other group, including children of parents with mental illness and/or drug and alcohol issues, to be permanently placed away from their family home” (Llewellyn, Traustadottir, McConnell, Siquirjonsdottir, & Taylor, 2010, p. 250).

In her line of professional duties, the author of this Master's Thesis Project, has repeatedly observed this gross representation in the child welfare system amongst parents with developmental disabilities in Sacramento County. She has provided various services and support to parents with developmental disabilities through independent living skills training programs designed to facilitate successful community integration and sustainability. Among the families served, many gain services as a result of family crisis, particularly from those attempting to navigate the child welfare system in order to regain or maintain custody of minor children. Parents often express feelings of misrepresentation of their abilities and a general lack of understanding of why their children are removed from the home. The author has witnessed family court proceedings in which the parent has met every case plan requirement, yet the parent loses parental rights on the basis of disability. Still other cases demonstrate areas in which vital parental abilities are insufficient to meet the emotional and developmental needs of the child within the limitations of the parent's disability.

There exists little research in the United States on the ability of parents with developmental disabilities to reach self-efficacy in parenting; and even less research upon which to justify of the termination of parental rights on the grounds of disability. These conflicting experiential realities and anecdotal observations have led the author to seek research in the challenges, necessary supports and evidence-based findings on the experiences of child rearing by developmentally disabled parents.

Background of the Problem

In the United States today, estimates of the number of parents with disabilities vary between 4.1 million to 9 million (Through the Looking Glass, 2012a). These parents face unwavering scrutiny in the community and in the institutional practices which govern familial rights. The assumption that parental disability leads to the abuse or neglect of a child is sanctioned by the use of developmental disability as grounds for the termination of parental rights through legal statutes across the United States. In 2010, Lightfoot, Hill and LaLiberte researched child protective laws in the United States, including the District of Columbia; and found that 37 states include parental rights termination on the grounds of disability, while the remaining 14 states authorize termination where child neglect may be attributed to disability. Parenting deficiencies are further attributed to disability in legal precedence when the use of Intellectual Quotients (IQ) determines parenting ability in developed countries (McConnell, Llewellyn, & Ferronato, 2000).

Fracturing the families of persons with developmental disabilities demonstrates negative outcomes for child and parent well-being. DePanfilis and Salus (2003) state that when children are removed from their homes and placed in foster care, they encounter high levels of stress and suffer a significant loss of self-esteem. Young children, in particular, experience emotional trauma which can stunt development and lead to behavioral problems (Silver et al, 1999).

Booth and Booth (2005) conducted a qualitative study of 24 parents with intellectual disabilities, in which at least one child had been the subject of a child protective court case. Booth and Booth's study found that of those who had their children removed, many continued to experience extreme grief years afterward and suffered from severe depression, while others reported incidences of self-harm. They concluded that the majority of parents expressed concerns with the care of their children and maintained that no other family placement could love the child as much as they did.

Even still, the challenges faced by parents with developmental disabilities may lead to adverse effects on their children. Feldman and Walton-Allen (1997) studied low-income children of developmentally disabled parents aged 6-12 to determine if there was a significant difference in intellectual and behavioral development as compared to low-income children from the same neighborhood whose parents did not have a disability. Feldman and Walton-Allen's study showed that on average, their performance on measures of IQ, reading, spelling and math was poorer than the comparison group, and more behavior problems were observed.

Children of parents with developmental disability may not only experience intellectual challenges, but social challenges, as well. The International Association for the Scientific Study of Intellectual Disabilities (IASSID) (2008) reported that, in general, children describe having experienced stressful childhoods. These stressful childhood experiences include being bullied, ostracized and rejected by other children, attributed in part to the stigma of having a mother with disability.

In recognizing family and childhood issues correlated with the challenges faced by parents with developmental disabilities, it becomes important to explore the nature of these challenges to provide guidelines for intervention. Identifying prominent barriers to successful parenting is the first step in preventing unnecessary harm to the children of these families, and the removal of the children from the home.

Statement of the Research Problem

Despite legal precedence which authorizes the disruption of the family system on the basis of disability, congruent evidence to support this internationally recognized intervention is insufficient. Aspects of family dysfunction leading to cessation of parental rights are largely attributed to the presence of disability; with vacillating consideration for the contributions of unrelated factors. In conducting this study the author aims to examine the barriers experienced by parents with developmental disabilities in childrearing; to examine those factors which contribute to successful parenting among persons with developmental disabilities; and to identify professional service practices which promote successful parenting strategies for persons with developmental disabilities.

Study purpose. The purpose of this research is to identify the various barriers faced by parents with developmental disabilities utilizing existing literature and an exploratory study of parents that are representative of the population. In examining the challenges of the population, the author hopes to subsequently identify factors which lend to success and resilience in parenting. Understanding the needs of the population through

exploratory research is a significant factor in identifying best practice strategies which seek to address the aforementioned issues effecting both the child and family system.

Theoretical framework. This Master's Thesis Project utilized the ecological systems theory (as cited by Shriver, 2010). The tendency to focus on the disabled parent as the sole care-giver and the single risk-factor in childrearing can be reframed within the ecological systems perspective. This perspective allows the author to understand the parent, child, and family as being effected by multivariate institutions. In addition to cognitive functioning, an ecological assessment of parenting capacity considers the multifarious relationship between children and their parents, family, friends, culture, resources, personal histories, and professional institutions, such as schools and social welfare agencies (IASSID, 2008). "Each of the systems along this continuum from small to large presents risks and opportunities for individuals at each stage of their development" (Schriver, 2010, p. 209). Thus, when examining the challenges and needs of the developmentally disabled parent, the author can shift focus to include social and institutional supports, rather than intellectual barriers alone.

In addition, the family-centered approach enhanced the author's understanding in regard to the nature and function of the family system. Family-centered practice theory incorporates an understanding that the family has the ability to grow and change for the better, and that policy should be formulated in support of strengthening the family. Perhaps one of the most relevant features of this framework is the underlying concept of family preservation. Schriver (2010) notes that people of all ages can best develop and

their lives be enhanced, with few exceptions, by remaining with their family or relying on their family as an important resource.

In context of families identified as having a developmentally disabled parent, this theory highlights the importance of recognizing the family members as the experts who, in collaboration with professional interventions, are capable of adapting and functioning in a mutually beneficial system. As mentioned above, family-centered theory holds family preservation as the driving force for policy and practice—a contradiction to current practices in addressing the challenges of developmentally disabled parents.

Social work research justification. The values embedded within this research are the fundamental human right to reproduce and maintain a family, to be governed by policies which advocate for equality, and freedom of individual choice. The disabled population is largely characterized by an inability to gain equal access to informed reproductive healthcare and family planning, housing, education, employment, and adequate wages. Recent and various political enactments have been written into law with the goal of securing equal rights and opportunities for persons with disabilities, including reproductive rights.

In the 1977 United States Supreme Court case, *Carey v. Population Services*, the Court stated that: “The decision whether or not to beget or bear a child is at the very heart of [the] cluster of constitutionally protected choices” (Field & Sanchez, 1999, p. 16), upholding an individual’s constitutional right to reproductive freedom. However, the right to raise ones’ own children and to preserve the family fails to gain political clarity.

Substantive increases in research and services have not taken place in response to the unregulated and diverse responses of child welfare services in addressing the families of parents with developmental disabilities. This gap in research and policy leads to a large number of families being forced apart unnecessarily.

The social work profession seeks to advocate for the equal rights and protections of vulnerable populations such as the disabled. The National Association of Social Workers (2008) requires in the Code of Ethics that “social workers strive to ensure access to needed information, services, and resources; equality of opportunity; and meaningful participation in decision making for all people” (para. 16). As such, social workers must be cognizant of the social injustices surrounding the political and personal challenges of parents with developmental disabilities. Furthermore, social workers must be at the forefront of cutting edge research in the issue, in order to guide best practice in working with these families and to advocate for the population within multivariate institutional arenas.

Assumptions. The author postulates several assumptions regarding the factors identified as challenges to successful parenting. The first of these assumptions is that lack of consistent and competent support systems, both professional and familial, will be identified as a primary barrier. People with developmental disabilities require long-term, repetitive intervention planning which provides support throughout changing developmental processes and events. The author also assumes that other barriers will

include: limitations of disability, limited availability to or existence of resources, poverty, and stigma and prejudice attached to persons with developmental disabilities.

Definition of terms. The summary of terms and phrases outlined in this section is important in developing an understanding of the study and in reviewing the literary references provided in Chapter 2. The author compiled the definition of terms using professional research and legal terminology which exist to classify persons with disabilities.

Developmental Disability: The United States Developmental Disabilities Assistance and Bill of Rights Act defines a developmental disability as one which “originated at birth or during childhood; is expected to continue indefinitely; and substantially restricts the individuals’ functioning in several major life activities” (Department of Health and Human Services, 2000). It is the term generally accepted and utilized in the United States when referring to a person who meets the above criteria. Developmental disabilities can be both intellectual and physical in nature. Some examples of developmental disability include, but are not limited to: autism, mild, moderate or severe mental retardation, down syndrome, and cerebral palsy.

Intellectual Disability: The American Association on Intellectual and Developmental Disabilities (AAIDD) defines an “intellectual disability [as] a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical

skills” (para. 1). This form of disability is diagnosed in childhood and is included under the more general spectrum of developmental disabilities.

Mental Retardation: Mental retardation is a medical term used to describe persons with developmental and intellectual disabilities and is guided by practices of diagnosis.

Diagnosis can range from mild, moderate, and severe mental retardation. The criteria for a diagnosis of mental retardation are: (1) the person’s IQ level of functioning must be below 75; (2) he or she must have significant limitations in two or more adaptive skill areas; and (3) the condition must manifest itself during the childhood years—before the subject is 18 years old (Field & Sanchez, 1999).

Limitations of Disability: The limitations of disability are defined as those which significantly and chronically impair functioning in major areas of living. Persons with developmental disability may be impaired in the following functions: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living and economic self-sufficiency (Department of Health and Human Services, 2000).

While much of the international literature available references the term intellectual disability, for the purpose of this study, the research will utilize the term developmental disability. This blanket term recognizes and is inclusive of all forms of early-onset and genetic disabilities related to impairments in cognitive functioning. Further, the absence of an internationally accepted definition allows for the terms to be used interchangeably in literature.

Chapter 2

REVIEW OF LITERATURE

The review of the literature pertaining to parents with developmental disabilities intends to appraise professional knowledge used to understand the history of societal measures which sought to address the problem and the primary barriers to self-efficacy in parenting. The review of the literature will reflect on the history of disabled parents within society, with particular attention to the genesis of stigmatization resulting in systematic isolation and discrimination of individuals through early institutions. This brief history of time will segue into current child welfare statutes in the United States, followed by an in depth look into the struggles of parents with disabilities as they attempt to integrate into modern Western culture. Specifically, the author will discuss factors of social support and isolation, prevalence and effects of poverty, limitations of disability and access to community resources. After investigating the various factors which lend to impediments in parenting ability, the author will address the role of the social work profession in attending to the problem, through the exploration of currently accepted, evidence-based intervention models, designed specifically for the needs of this unique population.

History of Disabled Parents within Society

The history of parents with developmental disability in Western culture is important to examine in order to understand the impact of research assumptions and professional practice on the formulation of public policy. Early policies were derived

from limited medical research and public opinion, leading to the nationwide implementation of eugenics-based customs which sought to separate persons with disabilities from society, rather than meet the needs of these individuals through community integration. Modern standards of care for individuals with disability and the right to receive reasonable accommodations in order to actively participate in all aspects of society still reflect a miscellany of past eugenics-based assumptions, particularly in child welfare statutes.

The Eugenics Movement

As reported by Field and Sanchez (1999), the Eugenics Movement arose in the United States in the late nineteenth and early twentieth centuries under the ideals of removing human characteristics deemed unfavorable, such as race, disability, and criminality. Following several research findings regarding the competency of disabled individuals to parent children, states began a steady implementation of institutionalization and sterilization practices accomplished through legislation. Such research, since determined to be junk science, found that persons with disabilities were incompetent parents, would pass genetic deficiencies to their children, and would subsequently abuse their children (Field & Sanchez).

According to Field and Sanchez (1999), by 1917, 31 states passed laws mandating the institutionalization of individuals labeled retarded, mentally ill or epileptic. They explain that these persons were removed from their homes, communities and families to be placed in medical facilities which would isolate them from society. This shift in

disability treatment practices saw nearly 60 thousand individuals relocated to state institutions between 1900 and 1930. Within the confines of these sexually segregated facilities, sterilization became a routine practice which would ensure that persons with disabilities could not procreate.

Methods to deter persons with disabilities from having children quickly became adopted outside of state institutions. Legal marriage bans were enforced across the states, disallowing disabled persons from marrying. Connecticut set the legal precedence for marriage bans in 1896, leading to 39 states adopting similar marriage bans and provisions for annulment based upon existence of mental disability (Field & Sanchez, 1999). Further, a majority of states adopted legislation allowing for the sterilization of persons diagnosed as mentally retarded. Field and Sanchez stated that the advent of the eugenics movement and the development of relatively simple surgical techniques for sterilization gave impetus to compulsory sterilization. In 1907, Indiana was the first state to successfully pass such a law without nullification on the grounds of unconstitutional practice.

Today, the practice of eugenics among persons with disabilities is less palpable. Medical advances in birth control allow families of persons with disabilities to inhibit unwanted pregnancies without necessitating invasive surgical procedures. Even still, modern eugenics exist in medical procedures such as amniocentesis, providing assessment for genetic anomalies and disabilities before the child is full term. Genetic testing can be performed during family planning stages, prior to conception, for parents

with sufficient financial resources. Such tests render a medical practitioner capable of reducing or eradicating the identified condition, and a woman able to decide whether or not to continue the pregnancy after she has conceived (Field & Sanchez, 1999).

Current Child Welfare Statutes in the United States

Involvement of the child welfare system in the case of parents with developmental disability is high, considering the power of states to use disability as a factor in determining a parent's ability to care for a child. In 1997, the Clinton Administration released the *Guidelines for Public Policy and State Legislation Governing Permanence for Children*, recommending state inclusion of parental disability as sufficient grounds for the termination of parental rights. The Research and Training Center of Community Living (RTTCL) at the University of Minnesota (2006) reports that more than two-thirds of states now include parental disability as grounds for termination of parental rights. Child welfare statutes detail intellectual and developmental disabilities as either mental deficiency or mental retardation, terms that have become unpopular in recent decades pursuant to the implementation of the American's with Disabilities Act (ADA) of 1990.

It is estimated that only 51 percent of parents with disabilities in the United States continue to reside with their children, with reunification rates considered indeterminable (RTTCL, 2006). The tendency of the child welfare system to determine that removal of the child from the home of a disabled parent is in the best interest of the child, in lieu of family-sustainability, may be attributed to the inability of service workers to understand and accommodate the unique needs of the population.

The RTTCL (2006) finds child welfare systems across the United States are ill-equipped to provide services to parents with disabilities and their families and, as an inherent result of ineptitude, concentrate on the disability of the parent. The singular focus on the limitations of a parent's disability repudiates the parent's capacity to care for a child within the confines of their disability. The notion that persons with disabilities are incapable of learning new skills, including parenting skills, and are more likely to neglect or abuse their children defies consistent research findings to the contrary. The International Association for the Scientific Study of Intellectual Disabilities (IASSID) (2008) maintains that the assumption of parental intellectual disability as indisputable evidence of risk of harm to a child and the assumption of parenting deficiencies being irreversible are incorrect and invalid.

It can be argued that to pursue termination of a parent's rights on the grounds of disability is contradictory to the protections provided in federal legislation under the ADA. ADA laws prevent discrimination against persons with disabilities and require public services to enact reasonable accommodations which would render services accessible (United States Department of Justice, 2009). Child welfare systems are public services contracted by the state to protect vulnerable children, by providing support and intervention to at-risk families. Arkansas and Idaho have both recognized this connection in child welfare statutes prohibiting the termination of parental rights without first satisfying every reasonable effort to support the disabled parent in accordance with ADA regulations (RTTCL, 2006).

Alternatively, proponents for denying ADA rights within the context of the child welfare system argue that this legislation is irrelevant due to the failure of the ADA to include parental rights termination in the bill language. Opposition also finds ADA laws to be immaterial due to the supposition that child welfare systems are designed to protect the welfare of the child rather than the parent (RTTCL, 2006).

Disability Policies and Protections

There exist a number of disability rights policies in the United States which address various issues pertaining to protections against discriminatory and exclusory practices in public agencies. This section will describe federal and state policies specific to the rights of parents with disabilities in accessing public entities such as the child welfare system, as well as contemporary policy efforts to implement comprehensive disability rights.

Federal Civil Rights Laws

The breadth of disability rights remains inconsistent from state-to-state due to speculative interpretation and subjective implementation of federal statutes. When examining the role of federal rights laws in the child welfare and family court systems, one finds the statements of protection are far reaching, yet indeterminately obscure.

Rehabilitation Act of 1973. The civil rights movements saw advancements in integrative practices and anti-discrimination laws across the United States. For citizens with disabilities, the first of these rights was enacted under the Rehabilitation Act of 1973. Section 504 of this important legislation declares that no person “shall, solely by

reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance”. This protection is extended to include social service agencies such as the child welfare department; and would therefore call into question state policies and practices which allow discrimination against parents based on the presence of disability.

Americans with Disabilities Act, Title II. The Americans with Disabilities Act was enacted in 1990 by President George Bush after Congress heard a number of personal testimonies as to the extent of discrimination experienced by persons with disabilities (National Council on Disability, 2012). Among these testimonies were the voices of parents with disabilities who were stripped of their parental rights or denied the opportunity to adopt children (National Council on Disability). Title II of the ADA provides protections similar to those found in Section 504 of the Rehabilitation Act. The primary difference between these two policies is that ADA extends its antidiscrimination laws to all public entities, regardless of federal financial aid (Americans with Disabilities Act of 1990). Accountable agencies include child welfare systems and family court systems, requiring the modification of policies, practices and procedures in order to allow equal opportunity to access and participate in services (National Council on Disability). While such regulations afford necessary protections in all arenas, the ill-defined intentions of the federal legislature leave each individual state to interpret the law and design implementation strategies accordingly.

California State Disability Policies

California has enacted few laws under the Welfare and Institutions Code in order to define disability rights in state institutions. These laws were not intended to speak to the power of the child welfare department in revoking parental rights based on a medical diagnosis of intellectual disability; however, each law does express the right of the disabled to bear children, retain custody and receive services which would allow them to be successful in parenting.

SB 1188 Child Custody: Disabled Parent. The California Supreme Court ruled *In re Marriage of Carney* (1979) that the “mere fact of the disability of a parent is not a proper basis upon which to make a determination regarding custody or visitation”. In 2010, California Senator Roderick Wright introduced SB 1188, an amendment to California Family Code Section 3049, in order to sanction the intentions of the Supreme Court through the legislative process. This amendment provides that a parent’s disability may not be considered in custody or visitation proceedings unless the accusing party can provide sufficient evidence that the child’s health, safety or welfare are at risk (S. 1188, 2010).

This law attempts to protect the rights of parents with disabilities from being discriminated against in the California family court system. However, the case of *In re Marriage of Carney* (1979) was brought about through a marital dissolution custody suit and took up the issue of physical disability, rather than a cognitive disability. As such, the

precedence set by this important bill perpetuates the inconsistency of legal determinations in regards to the rights of parent with disabilities.

The Lanterman Developmental Disabilities Services Act. In 1965 a pilot program was launched in San Francisco and Los Angeles to provide a continuum of care for persons with disabilities in California (Alta California Regional Center, 2008). These pilot projects were later expanded into a statewide program under the Lanterman Developmental Disabilities Services Act of 1969 (California Department of Developmental Services, 2013). The goal of the policy was to maximize the functioning of individuals diagnosed with mental retardation and to develop alternatives to in-patient care in Development Centers (Alta California Regional Center).

The Lanterman Act was later amended in 1974 to expand service provisions for individuals diagnosed with cerebral palsy, epilepsy, autism, and other developmental conditions related to mental retardation (Alta California Regional Center, 2008). This law defines the rights of all persons with developmental disabilities, having been diagnosed before the age of 18, to receive services which allow them to live under the same conditions and freedoms of those without disabilities. Notably, this right to service includes parent training and family planning (California Department of Developmental Services, 2001). Presently, there are 22 Regional Centers available to provide case management services across the state, with approximately 180,000 clients served annually (Alta California Regional Center).

Modern Perspectives on Disability Rights

In 2009, President Barack Obama signed the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the first human rights treaty of the 21st century. Article 23 of this important treaty states that persons with disabilities have the right to bear children; and that children may not be separated from the parent on the basis of a parent's disability (United Nations, 2006). This treaty also states that programs must be made available to persons with disabilities to provide assistance in performing parent responsibilities (United Nations). By signing this treaty, the United States agreed under Article 4 to change or remove all policies and practices which allow for the discrimination of persons with disabilities (United Nations).

If implemented, this important piece of legislation would change disability rights on both federal and state levels. However, in December 2012, the United States Congress failed to reach the two-third majority vote needed to ratify the protections of the CRPD, with 38 Republican senators refusing to implement the terms of the treaty (Jacobson, 2012). Reasons provided ranged from concerns with the promotion of reproductive rights, including abortion, state involvement in child education, and refusal to permit international suppositions in American policies (Jacobson, 2012).

Limitations of Disability

The definition of adequate and competent child care is defined subjectively in literature based on researchers' operational purposes or not defined at all. Assumptions are made largely based on Western cultural norms and individual opinions based on

personal experiential realities. Llewellyn, Traustadottir, McConnell, Siquirjonsdottir and Taylor (2010) define adequate parenting as the provision of a safe, clean environment, nutrition, stimulation and the ability to keep a child out of harm's way. Greenspan and Budd (1986) describe successful parenting as the promotion of child socialization such that the child develops into his or her role as an adult and a member of society.

Persons with developmental disabilities have varying levels of cognitive impairments, from mild to severe. The AAIDD (2011) defines an intellectual disability as one characterized by significant limitations in intellectual functioning and adaptive behavior as expressed in conceptual, social and practical adaptive skills. Mild cognitive limitations are marked by lower than average abilities to learn and understand, with decreased levels of judgment (Tymchuk, Lakin, & Luckasson, 2001). Research suggests that it is primarily in relation to parents with an IQ of 60 or below that parenting skill deficits are more likely to arise (Coren, Thomae, & Hutchfield, 2011). These limitations are the basis for the question of whether or not a developmentally disabled individual is capable of caring for a child; however variables of undesirable parenting behavior were not found to be well-defined or documented in reviewing the literature. The National Council on Disability (2012) recognizes that "contextual problems—such as poverty and a lack of adequate supports—are frequently ignored, so any problems found by researchers end up being attributed to disability".

Research does support the impression that limitations in cognitive functioning can be circumvented with ample supports. Llewellyn, Traustadottir, McConnell,

Sigurjonsdottir and Taylor (2010) find that parents with developmental disabilities have the capacity to learn new skills and apply their knowledge to practical circumstances. Parent education programs are frequently designed based upon this conclusion, implementing individualized, home-based, behavioral instruction educating parents in practical child-rearing responsibilities (Llewellyn, Traustadottir, McConnell, Sigurjonsdottir, & Taylor). Training programs utilize repetition and simplified, step-by-step tasks to facilitate learning and retention of new skills.

Social Support and Isolation

Support networks remain an important factor in successful childrearing for persons with or without disabilities. Support may come in many forms, such as family, friends, community organizations and professional institutions, including social service workers. Some of the support provided to a parent may include financial assistance, emotional support, trainings in necessary life skills, parenting advice, child care, and respite (Mayes, Llewellyn, & McConnell, 2008), all of which are important components of healthy parenting. Meeting the supportive needs for parents with developmental disabilities is vital in ensuring proper behavior modeling and skills learning for adhering to basic child care demands (Llewellyn, Traustadottir, McConnell, Sigurjonsdottir & Taylor, 2010).

Still research demonstrates that these parents remain without substantial social or professional support networks. Mayes, Llewellyn, and McConnell (2008) conducted a study that involved 70 women with developmental disabilities, each having a child

younger than six years of age, to examine the type of social supports available to them. The primary source of support named by the women was family members, with whom they felt most comfortable asking for assistance. The second source of support reported by the women was service providers, from whom they reported feeling uncomfortable seeking assistance. They also found that an alarming 25 percent of mothers did not have any support from friends or neighbors.

Kroese, Hussein, Clifford, and Ahmed (2002) reported similar findings in their study of 15 mothers with developmental disabilities and their social support networks. On average, the women in the authors' study were able to name only five, decidedly helpful social supports, through which only half of the women received support on a once-weekly basis. Also similar to the study by Mayes, Llewellyn, and McConnell (2008), was the finding that less than 35 percent of the participants reported the existence of supportive friendships (Kroese, Hussein, Clifford, & Ahmed).

Research has not provided substantial evidence as to why parents with developmental disabilities lack effective support systems. The author assumes the barrier to support attainment is a combination of factors, such as prejudice within the culture and society toward persons with disabilities, fear of losing power and being perceived as incompetent, and lack of knowledge on how to advocate for and access help.

Whatever the cause of this social deficit the need remains prevalent. Traustadottir and Sigurjonsdottir (2008) write that good support positively affects the parents' ability and competence in child rearing, and provides protection against parental breakdown and

child maltreatment. Essentially, supportive roles have the necessary function of protecting against potential risk-factors associated with the limitations of parent disability and stress. Alternatively, lack of support is correlated with the removal of children from the home (Traustadottir & Sigurjonsdottir), a prominent barrier to family preservation as described in the goals of the ecological systems perspective.

Prevalence and Effects of Poverty

Insufficient income. Parents with developmental disabilities have disproportionate access to financial resources required to sustain a family. The National Council on Disability (2012) reports that the number of people with disabilities who live in poverty is three times the number of people without disabilities. In the United States alone, nearly eight million persons with disabilities receive Supplemental Security Income (SSI), a government insurance program designed to meet the basic living needs of the disabled, such as food, clothing, and housing (Technical Assistance Collaborative [TAC], 2011). Despite heavy reliance on government insurance sources, the average SSI benefit award is still only \$8,436 each year—over 20 percent below national poverty levels in 2010 (TAC, 2011). This grossly inadequate financial assistance is the primary barrier to obtaining sufficient life-sustaining resources.

Housing Disparities. Among the most significant problems which exists in the United States is income-based housing discrimination experienced by the disabled community. Factors which contribute to the problem of income-based housing

discrimination include: limited income, lack of affordable housing subsidies and regulations, and minimum income requirements for housing applications.

Disabled adults commonly suffer from extreme poverty, characterized by an inability to access affordable, independent, and safe housing (National Council on Disability, 2012). The national standard for affordable housing details that no more than 30 percent of an individual's income should be utilized to satisfy housing costs. The Consortium for Citizens with Disabilities (CCD) (1999) states that when using current Housing and Urban Development (HUD) Fair Market Rents as the standard for modest rental housing costs, nowhere in the United States can a disabled SSI beneficiary rent a one-bedroom apartment for less than 50 percent of his or her income. Subsequently, individuals with disabilities must either relinquish independence, living in care homes, group homes, or with aging relatives; or forgo personal safety, becoming homeless, or residing in substandard housing units.

Limited income is an obvious economical barrier to the allocation of vital housing resources. The disabled are often dependent upon social insurance and social welfare programs to provide the income necessary for living expenses (National Council on Disability, 2012). However, as previously mentioned, these benefits exist well below the national earned-income average. For example, individual benefits received from SSI can be represented as an hourly wage of \$3.22—less than half the federal minimum wage standard (CCD, 1999).

Barriers to private housing. Government programs which provide affordable housing subsidies for the poor are limited in number and are insufficient in providing services to all qualifying applicants, due to deficiencies in funding. Unable to access these programs, disabled applicants must look to the private housing market. These property companies lawfully discriminate against disabled applicants based on limitations of income, by imposing unwavering minimum income requirements. According to CCD (1999), there is not a single housing market area in the United States where a person with a disability receiving SSI benefits can afford to rent a modest efficiency apartment.

Insufficient housing supports. In addition to an inability to afford standard housing, programs implemented to offset this challenge consistently fail to meet the needs of the disabled population. Supportive Housing for Persons with Disabilities is a dedicated housing program in the United States under Housing and Urban Development assistance, which provides services in accordance with its namesake. Currently, this program has only 30,000 units nationwide, with millions unable to access benefits (TAC, 2011).

Public Housing and Section 8 Housing Choice Voucher programs also provide housing assistance to low-income individuals, and tend to favor servicing the elderly and disabled (National Coalition for the Homeless, 2007). HUD guidelines for the Housing Choice Voucher program maintain that applicants should be placed on a waiting list for no more than 24 months (HUD, 2001). However, average wait list times have risen significantly in recent years to 33 months for public housing and 28 months for a housing

voucher (HUD, 1999). Larger cities experience much longer wait times in both assistance programs. HUD reports show that the waiting period for a housing voucher in Los Angeles is ten years; eight years in New York City, seven years in Houston; and five years in Chicago (HUD, 1999).

Effects of poverty on parenting. Limitations of disability are consistently held culpable for the failure to provide adequate care for a child. This focus negates additional factors which influence parenting in abled and disabled parents alike, particularly the challenges which arise from low socioeconomic status. In fact, research indicates that stress factors outside of impairment create more obstacles to successful parenting than the impairment itself (Llewellyn, Traustadottir, McConnell, Siquijonsdottir, & Taylor, 2010). Income inequalities lead to housing disparities, lack of proficient child care and education resources, and an inability to meet basic needs such as nutritious foods. Not surprisingly, low socioeconomic status is attributed to higher rates of stress and depression in developmentally disabled parents struggling to meet the demands of the family (Mayes & Llewellyn, 2009).

Accessing and Understanding Community Services

Limitations of disability lend to difficulties in accessing community services, actively participating in services and in understanding the intricacies of services. With modern advances in technology, many people are able to access resource and educational information through the use of the internet and print media. More and more, information is being provided solely through the use of technology. In 2000, the Department of

Commerce conducted a study that found that individuals with disabilities are half as likely to have internet access as those without disabilities; while close to 60 percent of individuals with disabilities have never even used a personal computer.

This shift toward the use of technology has become an exclusory practice for persons with developmental disabilities, when they are unable to afford or utilize such technologies without the assistance of a secondary party. For individuals relying on the support of Social Security to provide for daily needs, income is not only significantly insufficient, but is restricted to the singular purchase of life-sustaining products such as food, clothing and shelter (Social Security Administration, 2012). In the absence of personal and social resources for accessing information, society utilizes professional resources. Yet the majority of professional agencies are not equipped to meet the needs of individuals and mothers with developmental disabilities (Llewellyn, Traustadottir, McConnell, Sigurjonsdottir, & Taylor, 2010).

Active and informed participation in services is questionable given limitations in understanding due to cognitive impairments. While involved in agency processes, such as the child welfare system, parents are asked to make life-altering decisions with little to no support in understanding the questions being asked of them and the events taking place around them (Llewellyn, Traustadottir, McConnell, Sigurjonsdottir, & Taylor, 2010). This calls into question whether these parents can be considered satisfactorily informed of their rights, responsibilities and the consequences of their decisions.

Barriers within the child welfare system. Research demonstrates that the current child welfare system is designed in such a way as to present natural barriers for parents with disabilities while navigating child protective services. The challenge begins with the assessment process and the multiple institutional failures to adequately assess parenting ability. Parent assessments are often conducted in professional offices, without consideration for adaptations to the setting; whereby the “functioning of parents with intellectual or other cognitive disabilities can be compromised in an unfamiliar setting owing to memory and organization issues” (National Council on Disability, 2012). McConnell, Llewellyn and Ferranato (2000) find that stress and confusion stimulated by child welfare proceedings and the threat of permanent separation from the child may undermine the mental state of the parent and consequently impair or diminish their performance during evaluation. Failures may also be reflected in the subjective methodology utilized in the reunification process for these families (Child Welfare Information Gateway, 2011). According to a study by Hess, Folaron and Jefferson (1992) investigating the effectiveness of reunification services, poor assessment or decision-making by the caseworker or service provider was a factor in 42 of the 62 cases assessed.

Booth and Booth (2005) conducted a study to examine the experiences and attitudes of 24 parents with developmental disabilities after having been involved in the child welfare system. Participants of the study reported difficulty in understanding correspondence from and meetings with child welfare representatives, due to the use of

“big words, written papers, fast talk, jargon, unfamiliar rules of procedure and nerves” (p. 118). McConnell, Llewellyn and Ferronato (2000) state that within the child welfare process, imperative negotiations are conducted in a manner incomprehensible to many parents; particularly to parents with intellectual disability. Similarly, three-quarters of the participants interviewed by Booth and Booth reported that false information was reported regarding their circumstances—demonstrating the complex nature of facilitating efficient communications between parents with developmental disabilities and resource personnel.

Tarleton (2007) conducted a study examining the perceptions and experiences of parents within two specialist parent advocacy services supporting parents with learning disabilities during child protection proceedings. Tarleton’s study found that, prior to receiving advocacy services, parents often felt they were not listened to and that information reported about their parenting was inaccurate. They had difficulty following and understanding meetings and court proceedings and felt embarrassed and scared during these meetings (Tarleton). After receiving assistance from the parent advocacy worker, the parents reported feeling more confident in participating in their case and had an increased understanding in the proceedings. They also reported a perceived change in the manner in which they were treated by the child welfare social workers, including a decrease in derogatory language use and an increased attempt to share information with the parent.

Community Based Intervention Strategies

The National Council on Disability (2012) finds that parent ability cannot be determined until individualized adaptations catering to the functioning needs of the parent are provided. Individualized, home-based parent training that practices repetition of lesson plans and provides adaptive services, have been shown effective in educating parents with developmental disabilities (National Council on Disability). Conversely, generalized parent supports are offered in child welfare cases and termination of parental rights is sought when the parent fails to demonstrate marked improvements within these confines. According to the IASSID (2008) “support which is competence-promoting helps parents to learn and achieve by themselves; however, support can also be competence-inhibiting when others criticize or do-for the parents, thus undermining the parent’s confidence and denying them opportunities to learn” (p. 3).

Parent Training Program Models

Through the Looking Glass (TLG) is a nationally recognized organization providing competent services to parents with developmental disabilities in Berkeley, California. Parents who receive services at TLG boast a lower rate of child removal from the home, at 7 percent—compared to nearly 50 percent nationally (National Council on Disability, 2012). The assessment process takes place within the family home, where observations of parent-child interactions and relationships occur in a natural setting, conducted by qualified occupational therapists and mental health professionals (TLG, 2012b). Parent support and education is individualized, home-based and implemented

through high-frequency and long duration sessions. Repetition and practice is a key component to service provision, allowing for the development of habitual behaviors and memory retention. Services at TLG aim to provide early intervention child mental health, child development and educational supports, safety training and parent support groups (TLG, 2012b). Case management, functional adaptations and disability resources are also available to parents.

Similarly, the Arc's Positive Parenting Resource Center, in Greenfield, Massachusetts—a chapter of the national disability rights advocacy group—is acclaimed for its development and implementation of a home-based parent education and skills training program. Parent education and support groups “focus on child development, communication, health and wellness, family literacy, basic household and financial stability, positive discipline and limit setting, safety factors, prevention of abuse and neglect, and access of community resources” (National Council on Disability. 2012).

Components of Effective Program Design

The success of parent training programs is attributed to specific components and methodologies utilized in service delivery as opposed to generalized skill development practices. Coren, Thomaes and Hutchfield (2011) studied three parent training programs designed to improve outcomes for families with parental disability, wherein one or more of the children were under the age of 18. The researchers maintain that training successful interventions are skill-focused and use behavioral teaching strategies, such as modeling, practice, feedback, praise and tangible reinforcement.

Home-based interventions also demonstrated more successful outcomes. A home-based program focused on child safety training discovered statistical significance in areas of parent ability to recognize household dangers and precautions, and to maintain child medical appointments. The second home-based program analyzed by Coren, Thomae and Hutchfield (2011) addressed daily infant care training, with a 20 percent increase in post-test improvement, and a 90 percent retention rate in follow-up studies. The study also found that parent skills were more likely to be improved in program designs that used visual aids and deconstructed parenting tasks into smaller steps, taught individually.

The Center for Disease Control (2009) conducted a meta-analysis of 77 comparable parent training programs for children between the ages of zero and seven, to determine program designs proven to be successful for this age group. In the variable of acquiring parental skills, teaching parents emotional communication and positive parent-child interactions, while practicing with the child were the three facets of skill development determined most effective. The study defines emotional communication as active listening and the identification and expression of feelings. Positive parent-child interaction can be defined as the understanding of appropriate recreational activities, and the enthusiastic participation of activities with the child. The Centers for Disease Control (2009) emphasize the importance of hands-on interactive training with the parent and child, in order to insure proper implementation of skills and to allow the parent-trainer the ability to provide immediate feedback.

The meta-analysis also identified the areas deemed successful in decreasing maladaptive child behaviors, including aggression, hyperactivity and non-compliance (Centers for Disease Control, 2009). The appropriate use of time-out as part of a disciplinary system, and consistency of disciplinary expectations and consequences were key training areas of parent training which showed signs of alleviating unwanted child behaviors. In addition to promoting the development of parenting skills, positive parent-child interactions and trainings involving the child prove to be valuable tools for addressing externalized child behaviors.

The National Council on Disability (2012) states that:

Despite the lack of appropriate resources for most disabled parents and their children as well as persistent negative assumptions about these families, the vast majority of children of disabled parents have been shown to have typical development and functioning and often enhanced life perspectives and skills. (p. 230)

The study also finds that children of parents with disabilities adapt their behaviors to that of the disabled parent in order to successfully function within the family system. No research was discovered pertaining to the potential for positive outcomes for children raised by adults with developmental disabilities; nor is there research available as to the positive attributes of parents with disabilities. There remains insufficient evidence to uphold the termination of parental rights based on disability alone. However, the research indicates that there exists a correlation between social-contextual barriers and parenting ability among persons with developmental disabilities.

Chapter 3

METHODS

The purpose of this Master's Thesis Project is to identify the needs of adult parents with developmental disabilities in Sacramento County, California. It is hoped that this study will provide additional information that could help identify the needs of this unique and understudied parent population and assist service agencies in assessment, intervention planning and advocacy efforts for new and increased services. This chapter will discuss the exploratory study design, sampling procedures for participant recruitment, data collection procedures, instrumentation and data analysis and the process for the protection of human subjects.

Study Design

The study utilized a quantitative, non-probability purposive sampling procedure. A quantitative design was selected in order to assess the data using simple statistical analysis; and to succinctly identify factors which present as barriers to successful parenting among parents with developmental disabilities. Purposive sampling was necessary to be able to collect sufficient data from a small population that is difficult to access within the community and to insure each respondent possessed the necessary qualifying factors in order to participate (Yegidis, Weinbach, & Myers, 2012). The study was also designed to be exploratory in nature, due to the fact that very little research is currently available to assist service providers in understanding the population, with a notably large research deficit existing in the United States.

Sampling Procedures

The participants in this study were adults 21 years and older, who have been diagnosed with a developmental disability and who are the parent to one or more children. This study surveyed 48 participants. Even though they have been diagnosed with a developmental disability, each participant was required to have the ability to understand and respond to simple questions, as determined by the originating agency. Participants were recruited through a developmental disability service provider located in Sacramento County. The mission of the agency is to provide independent and supported living services to adults with developmental disabilities and their families. The researcher was an employee and student intern of the service agency at the time the study was conducted. The researcher approached the executive director and gained written permission to conduct the research through the agency.

Once access was granted, the agency participated by notifying service staff of the study using an open, written invitation produced by the researcher. Service staff was responsible for identifying qualified candidates among their clientele and providing these candidates with both verbal and written invitations to participate. Respondents were given the option to contact the researcher directly using the information provided on the written invitation, or to give verbal consent to agency staff to release contact information to the researcher.

Each parent participant was entered into a random drawing for a 50 dollar Walmart gift card. The potential for monetary inducement was advertised on open

invitation letters and disclosed within the participant consent form. The drawing took place at the agency upon completion of all questionnaires. The winning participant was notified by phone and the gift card was delivered to the participant's home by their support staff. Inducement was funded in its entirety by the researcher.

Data Collection Procedures

The research was conducted in the participants' homes or in a private location of the participants' choosing. Once the recruited parents orally agreed to serve as a respondent, an appointment was scheduled to go over the research objectives in detail and to discuss the informed consent form, as well as the voluntary nature of participation. When the subject signed the consent form, the researcher administered the questionnaire as an in-person interview, wherein each question was read to the parent and the answers recorded on the form by the researcher. Completion of the questionnaire took between 20 minutes to an hour, and was dependent upon the participants' level of cognitive functioning. No research was conducted until the proposed researched methods were approved by the Human Subjects Review Committee at the Division of Social Work, California State University Sacramento.

While in-person interviews are often not the primary method of data collection in quantitative studies, these interviews are considered best practice when the participant population includes people with learning disabilities or limited literacy skills. This type of data collection procedure also demonstrates the advantage of having a higher completion rate, as compared to mail-in, internet or phone interviews. It is important to

note that one of the disadvantages of in-person interviews is the likelihood that the respondent will provide answers deemed either socially desirable or answers which would please the interviewer, called the expectancy effect (Yegidis, Weinbach, & Myers, 2012).

The completed questionnaires were filed in separate envelopes to insure the confidentiality of each respondent. Prior to data entry, each participant was assigned a pseudonym on the top of the survey for identification purposes. None of the surveys listed the identity, home address or social security number of the participant anywhere on the form. Hardcopies of data were destroyed upon completion of data input. Electronic data was stored using a flash drive and was not saved to any public computers. Consent forms remain secured in the researcher's home office for three years as dictated by the regulations of the Internal Review Board.

Instruments

Data was collected in a 62 question, three-part survey, which included (a) participant demographics, a (b) 5-point Likert Scale needs assessment and a (c) felt needs assessment (see Appendix A). Demographic questions included variables such as age, gender, relationship status and number of children. Additional demographic questions were posited in regards to previous involvement with Child Protective Services or a Parent Training program. This section also sought to identify socioeconomic variables such as source of income and educational attainment.

The Likert-Scale needs assessment posed 23 statements to which the participant responded on a five-point scale of 1-“Never”, 2-“Rarely”, 3-“Sometimes”, 4-“Often” and 5-“Always”. Examples of such statements include: “I have enough money to provide food for my family each day”; “I know where to find help when I feel overwhelmed”; and “My child participates in social activities outside the home”. The third section consisted of a felt needs assessment which measured the participants’ opinion of what they need support with in regards to parenting, and how they would prefer to receive that support, in a simple “Yes” or “No” format.

Surveys are ideal for conducting quantitative research and for measuring the “demographic characteristics of people along with their opinions, preferences and beliefs” (Yegidis, Weinbach, & Myers, 2012). Since the study was exploratory and there are presently no standardized instruments to assess the needs of parents with disabilities specifically, the survey questions were constructed by the researcher. The questions were not able to be pretested for reliability or validity in measurement due to limited time and resources.

In a manual constructed for the United States Department of Health and Human Services, as a guide for caseworkers within Child Protective Services, DePanfilis and Salus (2003) dictate that a safe home for a child is one in which the parent adequately provides for the physical, mental, emotional, educational and medical needs of the child. The authors also identified key components for the assessment of child neglect or abuse. Some of these variables included whether the parent provides a stable home environment,

access to medical care for illness or injury, nutritious meals, appropriate clothing. Additionally, the authors state that social isolation, age appropriate educational support, expectations and discipline, as well as quality of relationships outside the home should be assessed when evaluating the competency of a parent.

Using these guidelines for parental assessment, each section of the survey included questions designed to assess the needs of the parent in five areas: support networks, financial support, child health and development, nurturing, and child education. Support networks insure the family has access to community programs, education, and peer and family support, all of which can assist a parent in reducing stress and preventing family crisis. Financial support is a basic measure which may help to identify gaps in community, state and federal resources, to identify a need to bolster resource development efforts, or to simply bridge the gap between existing resources and parent access. Assessing a parent's ability to understand and attend to normal child development processes is a key factor in promoting the health and well-being of the child. Similarly, nurturing is an important aspect of child health and well-being that may be hindered by symptoms of certain developmental disabilities. Finally, child education is necessary for successful navigation of the education system and to promote successful advancement into adulthood. Educational support may present as a need due to a parent's inability to comprehend or to teach depending on the parent's level of disability.

Data Analysis

Data recorded on the hardcopy surveys were transcribed into a statistical analysis software program called SPSS. The hardcopies were destroyed upon data entry. The data were analyzed in such a way as to identify the primary barriers experienced by parent participants, the self-reported assessment of needs expressed by the parents, and the preferred methods of service provision to meet their needs. Responses were coded for quantitative analysis. Each of the Likert-scaled questions was also coded into one of the five intended variables of measurement: (a) support networks, (b) financial support, (c) child health and development, (d) nurturing, and (e) child education. Frequency tables were developed to report the level of need measured in each variable. Correlation data was used to determine the relationship between measured need and expressed need, as well as any significant relationship between variables, with statistical significance identified as $p < 0.05$.

Protection of Human Subjects

The Human Subjects Application was submitted to the Division of Social Work Committee for the Protection of Human Subjects at the California State University of Sacramento. The proposed research questions, consent form and an agency participation letter were also submitted with the application. All documents were reviewed by the researcher's faculty advisor prior to submission. The committee approved the research proposal with the condition that the questionnaire be modified to exclude or justify questions referring to the ages of the respondents' children. These demographic

questions were deemed immaterial for the purposes of this Master's Project and were removed from the survey accordingly. Upon resubmission of the application with the requested modification, the researcher received notification via email on November 30, 2012 approving the research as exempt with approval number 12-13-028, and expired November 30, 2013.

Concerns about the participants' ability to provide consent due to developmental disability were navigated appropriately through the following factors: (1) Participants must be 21 years of age or older to provide consent to participate; (2) Participants must demonstrate ability to understand and respond to simple questions, as determined in the participant screening process by the originating service agency; (3) Participants were read the consent form and given the opportunity to ask any questions regarding the research process prior to signing the form; and (4) Participants were notified of their right to discontinue participation at any point during the research process.

Identifying information, such as name, address and social security number were not requested on the questionnaire. Pseudonyms were assigned to each participant to maintain anonymity and results were reported as a group.

The survey posed a minimal risk for participant discomfort as a result of the in-person interview process, through which the researcher read each question and records each answer. However, this process is necessary for insuring appropriate responses are given, despite a participant's inability to read or to comprehend the reading due to disability. Participants were also advised to notify their support staff and to seek mental

health support from one of three local agencies should they experience any undue emotional distress as a result of research procedures. The researcher provided contact information for the following three agencies: Turning Point North Transitional Support Services, The Effort, or the Sacramento County Mental Health Access team.

At the time of participant recruitment, the researcher was a support employee at the agency targeted for participation. In order to prevent perceived conflicts of interest, the researcher did not recruit client participants directly. The researcher also declined the use of her employee email or phone as contact information on research documents, including recruitment and consent forms. Parents were recruited by management or other support staff using verbal and written invitations provided by the researcher. When subjects orally agreed to participate in the proposed research, the researcher was permitted to contact the respondent and schedule an appointment to provide more detail about the research, to review the consent form and to conduct the questionnaire.

Chapter 4

STUDY FINDINGS AND DISCUSSIONS

This section examines data obtained from administered questionnaires regarding the parenting needs of adults with developmental disabilities in Sacramento County, California. The analysis focuses on the addressing the research purposes described in chapter one: 1) identify barriers experienced by parents with developmental disabilities in childrearing; 2) identify factors which contribute to successful parenting among persons with developmental disabilities; and 3) identify professional service practices which promote successful parenting strategies for persons with developmental disabilities.

This research study examined a total of 64 variables (see Appendix #). The presentation of the findings is divided into three sections. The first section describes the overall findings of the study, which includes the demographic characteristics of participant gender, age, relationship status, educational attainment, primary source of income, number of children and level of involvement with Child Protective Services. The second section examines the specific findings associated with the aims of the research project. The variables outlined in this section seek to measure the abilities and needs of participants in the parenting areas of finances, support networks, education, nurturing, and child development. This section also measured the desired frequencies of variables of service delivery in parenting support programs. The last section interprets these findings by correlating variables which represent parenting barriers in relation to involvement with Child Protective Services, as well as comparisons between variables

which measure parenting barriers and those that measure self-expressed needs in the provision of support services.

Overall Findings

A total of 48 persons with disabilities participated in this study. Of the total participants, a majority of the respondents (83.3%, n=40) were female, with only 16.7% (n=8) male respondents (see Table 1). Participants' ages ranged from 21 years to 51 and older. Nearly half of the participants were between the ages of 21 and 30 (43.8%, n=21); 33.3% (n=16) were between the ages of 31 and 40; 20.8% (n=10) were 41 to 50, and only 2.1% (n=1) were 51 or older (see Table 2).

Table 1

Gender of Respondent

		Frequency	Percent
Valid	Male	8	16.7
	Female	40	83.3
	Total	48	100.0

Table 2

Age of Respondent

		Frequency	Percent
Valid	21-30	21	43.8
	31-40	16	33.3
	41-50	10	20.8
	51 and older	1	2.1
	Total	48	100.0

Many of the participants identified their relationship status as single (60.4%, n=29) (see Table 3). An equal number of participants were married (14.6%, n=7) or cohabiting (14.6%, n=7) with partners (see Table 3). The remaining 10.5% of participants were either divorced (6.3%, n=3) or separated (4.2%, n=2) (see Table 3).

Table 3

Relationship Status of Respondent

		Frequency	Percent
Valid	Single	29	60.4
	Married	7	14.6
	Divorced	3	6.3
	Separated	2	4.2
	Co-habiting	7	14.6
	Total	48	100.0

Table 4

Educational Attainment of Respondent

		Frequency	Percent
Valid	Did not finish high school	19	39.6
	High school graduate	18	37.5
	Some college	8	16.7
	College graduate	3	6.3
	Total	48	100.0

The educational attainment of the respondents varied from no high school diploma to college graduates. Most of the participants (77.1%, n=37) had less than a high school education, with 39.6% (n=19) having not completed high school and 37.5% (n=18) having completed high school (see Table 4). The remaining participants had either some college education (16.7%, n=8) or were college graduates (6.3%, n=3).

The primary source of income for the overwhelming majority (91.7%, n=44) of respondents was Supplemental Security Income (see Table 5). A much smaller percentage (6.3%, n=3) of respondents declared their primary source of income to be employment; while the remaining 2.1% (n=1) listed their primary source of income as county benefits (see Table 5). Only 18.8% (n=8) received a housing subsidy to aid in housing costs (see Table 6).

Table 5

Primary Source of Income

		Frequency	Percent
Valid	Supplemental Security Income	44	91.7
	Employment	3	6.3
	County Benefits	1	2.1
	Total	48	100.0

Table 6

Receipt of Housing Subsidy

		Frequency	Percent
Valid	Yes	9	18.8
	No	39	81.3
	Total	48	100.0

Table 7

Number of Children

		Frequency	Percent
Valid	1-2 children	34	70.8
	3-4 children	10	20.8
	5 or more children	4	8.3
	Total	48	100.0

Each of the participants was parent to one or more children. Of all participants, 70.8% (n=34) had one or two children, 20.8% (n=10) had three or four children, and 8.3% (n=4) had five or more children (see Table 7). Prior involvement with Child Protective Services (CPS) was measured with an alarming 81.8% (n=39) of participants reporting having some CPS involvement (see Table 8.1). Further, more than half 52.1% (n=25) of all participants had their children removed from the home by CPS (see Table 8.2).

Table 8.1

Involvement of Child Protective Services

		Frequency	Percent
Valid	Yes	39	81.3
	No	9	18.8
	Total	48	100.0

Table 8.2

Removal of Children by Child Protective Services

		Frequency	Percent
Valid	Yes	25	52.1
	No	14	29.2
	Not Applicable	9	18.8
	Total	48	100.0

Participation in a parent training program was also measured. More than half of the respondents (56.3%, n=27) had participated in a parent training program (see Table 9.1). Of all respondents, 45.8% (n=22) perceived themselves as having benefited from

participation in a parent training program, while 10.4% (n=5) did not benefit, and 43.8% (n=21) had never participated (see Table 9.2).

Table 9.1

Participation in Parent Training Program

		Frequency	Percent
Valid	Yes	27	56.3
	No	21	43.8
	Total	48	100.0

Table 9.2

Perceived Benefit of Parent Training Program

		Frequency	Percent
Valid	Yes	22	45.8
	No	5	10.4
	Not Applicable	21	43.8
	Total	48	100.0

Specific Findings

The data collection instrument solicited responses to questions which reflected the areas of finances, support networks, education, nurturing and child development. The subsequent data summaries are thusly divided. There are 23 ordinal variables which measure experiential barriers to parenting, 22 variables stating self-expressed parenting support needs, and five variables representing participant preferences for support service methods.

Measurements of Financial Barriers

Participants responded to a series of questions regarding financial barriers to parenting on a scale of “Always” to “Never”. In regards to having enough money to pay for housing consistently each month, only 45.8% (n=22) reported always having enough finances. (see Table 10.1). An equal number of participants (45.8%, n=22) reported having enough money to pay for housing “Sometimes” to “Never” (see Table 10.1).

Table 10.1

Enough Money to Pay for Housing

		Frequency	Percent
Valid	Never	3	6.3
	Rarely	7	14.6
	Sometimes	12	25.0
	Often	4	8.3
	Always	22	45.8
	Total	48	100.0

Table 10.2

Enough Money for Food

		Frequency	Percent
Valid	Never	1	2.1
	Rarely	1	2.1
	Sometimes	20	41.7
	Often	5	10.4
	Always	21	43.8
	Total	48	100.0

Table 10.3***Enough Money for Clothing***

		Frequency	Percent
Valid	Never	2	4.2
	Sometimes	2	4.2
	Often	2	4.2
	Always	42	87.5
	Total	48	100.0

When asked if they were able to purchase enough food for each day, participant responses were most significant in the “Sometimes” (41.7%, n=20) and “Always” (43.8%, n=21) categories (see Table 10.2). Alternatively, 87.5% (n=42) of participants reported “Always” having enough money for weather appropriate clothing each season, while the remaining 12.5% (n=6) were able to provide clothing “Often” (4.2%, n=2), “Sometimes” (4.2%, n=2), or “Never” (4.2%, n=2) (see Table 10.3). A surprising 52.1% stated they were able to budget their finances effectively to provide for their child’s needs “Always” (27.1%, n=13) or “Often” (25%, n=12) (see Table 10.3).

Table 10.4***Able to Budget Finances***

		Frequency	Percent
Valid	Never	1	2.1
	Rarely	3	6.3
	Sometimes	19	39.6
	Often	12	25.0
	Always	13	27.1
	Total	48	100.0

Measurements of Support Network Barriers

Variables which measured support networks presented with large deficits in supports across all variables. Participants reported their awareness of social supports when they became overwhelmed at a total rate of 75.0% (n=36) in the categories of “Never” (16.7%, n=8), “Rarely” (37.5%, n=18) or only “Sometimes” (20.8%, n=10) (see Table 11.1). The remaining participants reported having supports “Always” (18.8%, n=9) or “Often” (6.3%, n=3) (see Table 11.1).

Table 11.1

Awareness of Social Supports when Overwhelmed

		Frequency	Percent
Valid	Never	8	16.7
	Rarely	18	37.5
	Sometimes	10	20.8
	Often	3	6.3
	Always	9	18.8
	Total	48	100.0

Table 11.2

Family Assistance with Childcare

		Frequency	Percent
Valid	Never	18	37.5
	Rarely	10	20.8
	Sometimes	8	16.7
	Often	3	6.3
	Always	9	18.8
	Total	48	100.0

Table 11.3*Family Support in Meeting Child Needs*

		Frequency	Percent
Valid	Never	20	41.7
	Rarely	11	22.9
	Sometimes	5	10.4
	Often	4	8.3
	Always	8	16.7
	Total	48	100.0

Support from family was reported at a rate even lower than support of friends, although both subsets of support networks were lacking. Family support with childcare was found to be 75.0% (n=36) overall on a scale of “Never” to “Sometimes” (see Table 11.2); only 18.8% (n=9) “Always” had family child care support; 6.3% (n=3) “Often” had family childcare support (see Table 11.3). Similarly, only 16.7% (n=8) “Always” had general familial support in meeting their children’s needs; 75.0% (n=36) had familial support “Never” (41.7%, n=20), “Rarely” (22.9%, n=11), or “Sometimes” (10.4%, n=5) (see Table 11.3). Participants also reported having little support from friends, with 66.7% (n=31) having support “Never” to “Sometimes” and 33.3% (n=16) participants having support “Often” to “Always” (see Table 11.4). Participation in social activities outside the home was significantly low with 85.4% (n=41) participating in activities “Never” to “Sometimes”; and 14.6% (n=7) participating in activities “Often” to “Always” (see Table 11.5).

Table 11.4***Reliable Friends to Provide Support***

		Frequency	Percent
Valid	Never	19	39.6
	Rarely	4	8.3
	Sometimes	9	18.8
	Often	5	10.4
	Always	11	22.9
	Total	48	100.0

Table 11.5***Participation in Social Activities in the Community***

		Frequency	Percent
Valid	Never	24	50.0
	Rarely	8	16.7
	Sometimes	9	18.8
	Often	2	4.2
	Always	5	10.4
	Total	48	100.0

Measurements of Educational Barriers

Barriers to child education were measured in five variables. Of all participants, 25.0% (n=12) reported “Always” being aware of educational programs available to their child; 4.2% (n=2) were “Often” aware; 25.0% (n=12) were “Sometimes” aware; 35.4% (n=17) were “Rarely” aware; and 10.4% (n=5) were “Never” aware (see Table 12.1). In regards to assisting children with school assignments, the majority of participants responded “Sometimes” (31.3%, n=15) or “Not Applicable” (31.3%, n=15) (see Table 12.2). Participants also reported that their children were “Never” or “Rarely” late for

school at 43.7% (n=21); 29.2% (n=14) of participant's children were late for school "Sometimes" to "Always"; and the remaining 27.1% (n=13) responded "Not Applicable" (see Table 12.3).

Table 12.1

Awareness of Educational Programs

		Frequency	Percent
Valid	Never	5	10.4
	Rarely	17	35.4
	Sometimes	12	25.0
	Often	2	4.2
	Always	12	25.0
	Total	48	100.0

Table 12.2

Ability to Assist with School Assignments

		Frequency	Percent
Valid	Not Applicable	15	31.3
	Never	2	4.2
	Rarely	3	6.3
	Sometimes	15	31.3
	Often	5	10.4
	Always	8	16.7
	Total	48	100.0

Table 12.3***Child is Tardy for School***

		Frequency	Percent
	Not Applicable	13	27.1
	Never	11	22.9
	Rarely	10	20.8
Valid	Sometimes	11	22.9
	Often	2	4.2
	Always	1	2.1
	Total	48	100.0

Of all participants, an overwhelming 50.0% (n=24) of parents stated their children did not participate in activities outside of the home; 20.8% (n=10) participated in activities “Sometimes”; and 10.4% (n=5) “Always” participated in activities. Finally, 20.8% (n=10) of participants “Always” read books to their child; 45.8% (n=22) “Sometimes” read books to their child; and 27.1% (n=13) read books to their child “Never” or “Rarely” (see Table 12.5).

Table 12.4***Child Participates in Social Activities Outside of Home***

		Frequency	Percent
	Never	24	50.0
	Rarely	5	10.4
Valid	Sometimes	10	20.8
	Often	4	8.3
	Always	5	10.4
	Total	48	100.0

Table 12.5***Reads Books to Child***

		Frequency	Percent
Valid	Never	3	6.3
	Rarely	10	20.8
	Sometimes	22	45.8
	Often	3	6.3
	Always	10	20.8
	Total	48	100.0

Measurements of Nurturing Barriers

Variables which measure barriers to nurturing remain low, with the majority of respondents reporting little to no barriers. Of all participants, 81.3% (n=38) “Always” found it important to spend time with their child (see Table 13.1); 77.1% (n=37) “Always” felt they had a good relationship with their child (see Table 13.2); 75.0% (n=36) “Always” enjoy being a parent (see Table 13.5). Variables which reflected the highest degree of nurturing barriers included setting clear boundaries for children with a majority of respondents stating they were able to do so “Sometimes” (56.3%, n=27) (see Table 13.3); and praising children for their achievements, with 47.9% (n=23) reporting they “Always” provide praise (see Table 13.4).

Table 13.1*Spends Time with Child*

		Frequency	Percent
Valid	Sometimes	5	10.4
	Often	4	8.3
	Always	39	81.3
	Total	48	100.0

Table 13.2*Good Relationship with Child*

		Frequency	Percent
Valid	Rarely	1	2.1
	Sometimes	5	10.4
	Often	5	10.4
	Always	37	77.1
	Total	48	100.0

Table 13.3*Sets Clear Boundaries for Child*

		Frequency	Percent
Valid	Never	1	2.1
	Rarely	5	10.4
	Sometimes	27	56.3
	Often	6	12.5
	Always	9	18.8
	Total	48	100.0

Table 13.4***Praises Child for Achievements***

		Frequency	Percent
Valid	Rarely	2	4.2
	Sometimes	10	20.8
	Often	13	27.1
	Always	23	47.9
	Total	48	100.0

Table 13.5***Enjoys Being a Parent***

		Frequency	Percent
Valid	Rarely	1	2.1
	Sometimes	5	10.4
	Often	6	12.5
	Always	36	75.0
	Total	48	100.0

Measurements of Child Development Barriers

Child Development barriers were measured in four variables: understanding childhood development, providing nutritional meals, ability to respond to medical needs and following medical recommendations from medical providers. Of all developmental barriers, understanding childhood development was reported as the primary barrier, with the majority of participants understanding their child's development "Sometimes" (60.4%, n=29) (see Table 14.1). Participants reported "Always" (54.2%, n=26) or "Sometimes" (25.0%, n=12) providing nutritional meals (see Table 14.2); "Always"

68.8% (n=33) being able to respond to a child's injury or illness (see Table 14.3); and "Always" 95.8% (n=46) following medical recommendations (see Table 14.4).

Table 14.1

Understanding of Childhood Development

		Frequency	Percent
Valid	Never	2	4.2
	Rarely	3	6.3
	Sometimes	29	60.4
	Often	5	10.4
	Always	9	18.8
	Total	48	100.0

Table 14.2

Provides Nutritional Meals

		Frequency	Percent
Valid	Rarely	1	2.1
	Sometimes	12	25.0
	Often	9	18.8
	Always	26	54.2
	Total	48	100.0

Table 14.3

Awareness of Medical Responses to Child Injury or Illness

		Frequency	Percent
Valid	Rarely	1	2.1
	Sometimes	7	14.6
	Often	7	14.6
	Always	33	68.8
	Total	48	100.0

Table 14.4***Follows Medical Recommendations from Child Physicians***

		Frequency	Percent
Valid	Sometimes	2	4.2
	Always	46	95.8
	Total	48	100.0

Self-Expressed Service Needs

The third segment of the data collection instrument measured self-expressed needs in regards to parenting support services. These variables were also categorized by finances, support networks, education, nurturing and child development. This section will examine the frequencies at which these variables occurred.

Financial support. All three financial supports identified in this section were reported as needed by the majority of participants. The need for support in locating and accessing affordable housing was reported by 70.8% (n=34) of participants (see Table 15.1); 89.6% (n=43) need support locating and accessing financial resources (see Table 15.2); and a smaller percent (60.4%, n=29) need support managing their budget to provide for their child's needs (see Table 15.3).

Table 15.1***Needs Support Locating and Accessing Affordable Housing***

		Frequency	Percent
Valid	Yes	34	70.8
	No	14	29.2
	Total	48	100.0

Table 15.2*Needs Support Locating and Accessing Financial Resources*

		Frequency	Percent
Valid	Yes	43	89.6
	No	5	10.4
	Total	48	100.0

Table 15.3*Needs Support Managing Budget to Provide for Child*

		Frequency	Percent
Valid	Yes	29	60.4
	No	19	39.6
	Total	48	100.0

Building support networks. Desired support in developing support networks varied from needing support to not needing any support. The two variables most requested were support in locating and accessing family resources (77.1%, n=27) (see Table 16.1) and locating and accessing affordable child care (64.6%, n=31) (see Table 16.2). Variables least desired were communicating with a partner (35.4%, n=17) (see Table 16.3) and communicating with family members (47.9%, n=23) (see Table 16.4).

Table 16.1*Needs Support Locating and Accessing Family Resources*

		Frequency	Percent
Valid	Yes	37	77.1
	No	11	22.9
	Total	48	100.0

Table 16.2*Needs Support Locating and Accessing Affordable Child Care*

		Frequency	Percent
Valid	Yes	31	64.6
	No	17	35.4
	Total	48	100.0

Table 16.3*Needs Support Communicating with Partner*

		Frequency	Percent
Valid	Yes	17	35.4
	No	31	64.6
	Total	48	100.0

Table 16.4*Needs Support Communicating with Family*

		Frequency	Percent
Valid	Yes	23	47.9
	No	25	52.1
	Total	48	100.0

Educational support. A majority of participants reported needing support in meeting the educational needs of children in all variables measured. In regards to locating educational and recreational programs, 83.3% (n=40) of respondents needed support (see Table 17.1); 66.7% (n=32) of participants reported needing support understanding child educational development (see Table 17.2); 72.9% (n=35) needed support developing age-appropriate educational lessons at home; 64.6% (n=31) (see

Table 17.4) and 62.5% (n=30) (see Table 17.5) needed support communicating with school staff and understanding school expectations respectively.

Table 17.1

Needs Support Locating Educational and Recreational Programs

		Frequency	Percent
Valid	Yes	40	83.3
	No	8	16.7
	Total	48	100.0

Table 17.2

Needs Support Understanding Child Educational Development

		Frequency	Percent
Valid	Yes	32	66.7
	No	16	33.3
	Total	48	100.0

Table 17.3

Needs Support Developing Educational Lessons

		Frequency	Percent
Valid	Yes	35	72.9
	No	13	27.1
	Total	48	100.0

Table 17.4*Needs Support Communicating with School Staff*

		Frequency	Percent
Valid	Yes	31	64.6
	No	17	35.4
	Total	48	100.0

Table 17.5*Needs Support Understanding School Expectations*

		Frequency	Percent
Valid	Yes	30	62.5
	No	18	37.5
	Total	48	100.0

Nurturing support. Support was requested by the majority of participants in the variables of developing and implementing daily routines 58.3% (n=28) (see Table 18.1); 68.8% (n=33) need support understanding and responding to child behaviors (see Table 18.2); 77.1% (n=37) need support developing disciplinary strategies (see Table 18.3); and 62.5% (n=30) need support communicating with their child (see Table 18.6). Also among these variables, 64.6% (n=31) of participants did not feel they needed support understanding or responding to emotional needs (see Table 18.4) or developing their child's self-esteem (see Table 18.5).

Table 18.1*Needs Support Developing and Implementing Routines*

		Frequency	Percent
Valid	Yes	28	58.3
	No	20	41.7
Total		48	100.0

Table 18.2*Needs Support Understanding and Responding to Child Behavior*

		Frequency	Percent
Valid	Yes	33	68.8
	No	15	31.3
Total		48	100.0

Table 18.3*Needs Support Developing Age Appropriate Discipline Strategies*

		Frequency	Percent
Valid	Yes	37	77.1
	No	11	22.9
Total		48	100.0

Table 18.4*Needs Support Understanding and Responding to Emotional Needs*

		Frequency	Percent
Valid	Yes	17	35.4
	No	31	64.6
Total		48	100.0

Table 18.5***Needs Support Developing Child Self-Esteem***

		Frequency	Percent
Valid	Yes	17	35.4
	No	31	64.6
	Total	48	100.0

Table 18.6***Needs Support Communicating with Child***

		Frequency	Percent
Valid	Yes	30	62.5
	No	18	37.5
	Total	48	100.0

Supporting child development. The last category of needs assessment measured self-expressed need in the area of child development. Variables identified as needing support included locating medical resources (56.3%, n=27) (see Table 19.1) and understanding stages of childhood development (60.4%, n=29) (see Table 19.3). Participants reported the remaining areas of support as not needed, with 52.1% (n=21) not needing support scheduling and maintaining child medical appointments (see Table 19.2) and 60.4% (n=29) not needing support assessing the home for safety hazards (see Table 19.4).

Table 19.1*Needs Support Locating Medical Resources*

		Frequency	Percent
Valid	Yes	27	56.3
	No	21	43.8
	Total	48	100.0

Table 19.2*Needs Support Scheduling and Maintaining Child Medical Care*

		Frequency	Percent
Valid	Yes	23	47.9
	No	25	52.1
	Total	48	100.0

Table 19.3*Needs Support Understanding Stages of Child Development*

		Frequency	Percent
Valid	Yes	29	60.4
	No	19	39.6
	Total	48	100.0

Table 19.4*Needs Support Assessing Home for Safety*

		Frequency	Percent
Valid	Yes	19	39.6
	No	29	60.4
	Total	48	100.0

Methods of Intervention

The final section of the research study examined the methods of support service interventions participants would be most interested in receiving. The three most requested intervention methods were written materials (75.0%, n=36) (see Table 20.1), media materials (77.1%, n=37) (see Table 20.2), and in-home parent trainers (70.8%, n=34) (see Table 20.3). A smaller majority of participants were interested in parent support groups (56.3%, n=27) (see Table 20.4). The least requested method of intervention was parent trainings in a group setting, with only 31.3% (n=15) of participants interested in this type of service (see Table 20.5).

Table 20.1

Interested in Educational Written Materials

		Frequency	Percent
Valid	Yes	36	75.0
	No	12	25.0
	Total	48	100.0

Table 20.2

Interested in Educational Media Materials

		Frequency	Percent
Valid	Yes	37	77.1
	No	11	22.9
	Total	48	100.0

Table 20.3***Interested in an In-Home Parent Trainer***

		Frequency	Percent
Valid	Yes	34	70.8
	No	14	29.2
	Total	48	100.0

Table 20.4***Interested in Parent Support Groups***

		Frequency	Percent
Valid	Yes	27	56.3
	No	21	43.8
	Total	48	100.0

Table 20.5***Interested in Parent Training in Group Settings***

		Frequency	Percent
Valid	Yes	15	31.3
	No	33	68.8
	Total	48	100.0

Interpretations to the Findings

The primary barriers identified by the research study were lack of support networks and the understanding of and ability to support the child's education. The overwhelming lack of natural supports demonstrated by the participants of this study are reflected in the second section of the data collection instrument which sought to measure barriers of parenting based on participant's opinions of their own experiential realities.

Most of the parent participants were single, divorced or separated (70.9%, n=34) (see Table 3); reported having little-to-no family support (75.0%, n=31) (see Table 11.3), reliable friends (66.7%, n=32) (see Table 11.4), or participation in activities which would integrate them into the community and assist in developing support networks (85.4%, n=41) (see Table 11.5).

The chi-square test of independence was performed to examine the relationship between participating in social activities and expressed need for support locating and accessing family resources. Participant responses of “Never” and “Rarely” participating in activities were recoded into the variable “No”; participant responses of “Sometimes” to “Always” participating in activities were recoded into the variable “Yes”. The chi-square test found that there was a significant association between the variables ($X^2=5.897$, $df=1$, $p=.015$) (see Table 21.1). Participants who requested support locating community resources were less likely to be involved in community activities (77.08% vs. 22.92%).

Table 21.1***Cross Tabulation of Community Activities and Expressed Need for Family Resources***

	Needs support locating family resources		Total		
	No	Yes			
Community Activities	No	28	32		
	Yes	9	16		
Total		37	48		
	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	5.897 ^a	1	.015		
Continuity Correction ^b	4.260	1	.039		
Likelihood Ratio	5.630	1	.018		
Fisher's Exact Test				.027	.021
N of Valid Cases	48				

a. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 3.67.

b. Computed only for a 2x2 table

The study found that education was also a primary barrier to successful parenting among respondents. Awareness of educational programs, ability to assist with school assignments, reading books to children, and participation in children's activities outside the home were low. The chi-square test of independence was utilized to determine the relation between awareness of educational programs and the expressed need for support in understanding school programs. Participant responses of "Never" and "Rarely" aware of educational programs were recoded into the variable "No"; participant responses of "Sometimes" to "Always" aware of educational programs were recoded into the variable "Yes". The chi-square test shows that there was a significant association between the variables ($X^2=6.467$, $df=1$, $p=.01$) (see Table 21.2). As shown in Table 21.2, participants

that requested support understanding the expectations of the school program also reported limited awareness of educational programs (62.5% vs. 37.5%).

Table 21.2

Cross Tabulation of Awareness of Education Programs and Need for Support

	Needs support understanding school expectations		Total		
	Yes	No			
Awareness of Education Programs	No	18	4	22	
	Yes	12	14	26	
Total		30	18	48	
	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	6.467 ^a	1	.011		
Continuity Correction ^b	5.035	1	.025		
Likelihood Ratio	6.758	1	.009		
Fisher's Exact Test				.017	.011
N of Valid Cases	48				

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 8.25.

b. Computed only for a 2x2 table

While nearly all of the parent participants (91.7%, n=44) were dependent upon Supplemental Security Income (see Table 5) and did not receive housing assistance (81.3%, n=39) (see Table 6), this study did not find that parents reported a significant financial struggle in providing for the basic needs of their children. This finding is further confused by the self-expressed needs of the participants, the majority of which reported needing financial support (89.6%, n=46) (see Table 15.2). The chi-square test examined the relationship between ability to budget and the need for budgeting support. Participant responses of “Never” and “Rarely” able to budget were recoded into the variable “No”; participant responses of “Sometimes” to “Always” able to budget were

recoded into the variable “Yes”. The chi-square test shows that there was no significant association between the variables ($X^2=.198$, $df=1$, $p=.66$) (see Table 21.3). Participants who requested support in budgeting were not more likely to report limitations in budgeting for the child’s needs (60.42% vs. 39.58%).

Table 21.3

Cross Tabulation of Budgeting Barriers and Expressed Need of Budgeting Support

	Needs support managing budget to provide for child		Total		
	Yes	No			
Budgets for Child's Needs	No	2	4		
	Yes	27	44		
Total		29	48		
	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.198 ^a	1	.656		
Continuity Correction ^b	.000	1	1.000		
Likelihood Ratio	.194	1	.660		
Fisher's Exact Test				1.000	.521
N of Valid Cases	48				

a. 2 cells (50.0%) have expected count less than 5. The minimum expected count is 1.58.

b. Computed only for a 2x2 table

Child Protective Services and Social Support

The purpose of this research study was to identify the barriers to parenting and to determine the best practices for intervention. This study was able to measure the rate of involvement of Child Protective Services in the participants’ homes, as well as the rate of child removal from the home. A shocking majority (81.3%, $n=39$) of respondents reported CPS involvement (see Table 8.1); with more than half (52.1, $n=25$) also having their children removed from the home (see Table 8.2).

The chi-square test of independence was conducted to examine the relation between CPS child removal and the most prominently reported barrier of family support in caring for the child. Participant responses of “Never” and “Rarely” having family support were recoded into the variable “No”; participant responses of “Sometimes” to “Always” having family support were recoded into the variable “Yes”. The chi-square test shows that there was a significant association between the variables ($X^2=9.416$, $df=1$, $p=.002$) (see Table 22.1). Table 22.1 shows that those who had their children removed from the home had less family support (66.67% vs. 33.33%). Similarly, a chi-square test of independence examined the relation between CPS child removal and parent awareness of supports when overwhelmed. The chi-square test found that there is a significant association between the variables ($X^2=24.251$, $df=1$, $p=.00$) (see Table 22.2). Table 22.2 shows that respondents who had their children removed had less access to supports when overwhelmed (58.97% vs. 41.03%).

Table 22.1***Cross Tabulation of CPS Child Removal and Familial Support***

		Family Support in Caring for the Child		Total	
		No	Yes		
CPS Removal from Home	Yes	21	4	25	
	No	5	9	14	
Total		26	13	39	
	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square		9.416 ^a	1	.002	
Continuity Correction ^b		7.368	1	.007	
Likelihood Ratio		9.415	1	.002	
Fisher's Exact Test				.004	.003
N of Valid Cases		39			

a. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 4.67.

b. Computed only for a 2x2 table

Table 22.2***Cross Tabulation of Child Removal and Awareness of Supports When Overwhelmed***

		Supports When Overwhelmed		Total	
		No	Yes		
CPS Removal from Home	Yes	22	3	25	
	No	1	13	14	
Total		23	16	39	
	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square		24.251 ^a	1	.000	
Continuity Correction ^b		21.024	1	.000	
Likelihood Ratio		27.251	1	.000	
Fisher's Exact Test				.000	.000
N of Valid Cases		39			

a. 0 cells (0.0%) have expected count less than 5. The minimum expected count is 5.74.

b. Computed only for a 2x2 table

Of the 39 participants who reported having had a CPS case opened for their families, 21 had participated in a parent training program (see Table 22.3). The chi-square test was performed to determine the relationship between CPS involvement and participation in a parent training program and it was found to be insignificant ($X^2=.488$, $df=1$, $p=.49$) (see Table 22.3). Table 22.3 demonstrates that participants who participated in a parent training program were not more likely to be involved with Child Protective Services (56.25% vs. 43.75%).

Table 22.3

Cross Tabulation of CPS Involvement and Participation in Parent Training Program

		Participation in parent training program		Total
		Yes	No	
CPS Involvement	Yes	21	18	39
	No	6	3	9
Total		27	21	48

	Value	df	Asymp. Sig. (2-sided)	Exact Sig. (2-sided)	Exact Sig. (1-sided)
Pearson Chi-Square	.488 ^a	1	.485		
Continuity Correction ^b	.106	1	.744		
Likelihood Ratio	.498	1	.480		
Fisher's Exact Test				.712	.377
N of Valid Cases	48				

a. 1 cells (25.0%) have expected count less than 5. The minimum expected count is 3.94.

b. Computed only for a 2x2 table

Summary

This study examined the barriers to successful parenting, the needs of parent participants in addressing these barriers and the preferred methods of service delivery in providing parenting supports. Most of the participants were from single parent homes (70.9%, n=34), received Supplemental Security Income (91.7%, n=44) and had one or two children (70.8%, n=34). This research study concluded that the variable most participants identified as a barrier to parenting was lack of a reliable supports. This variable was also closely correlated to the removal of the child from the home by Child Protective Services. In addressing barriers to parenting nearly all supports were requested by the majority of participants. Participants predominantly requested supports in locating financial (89.6%, n=43), family (77.1%, n=37), and educational (83.3%, n=40) resources. Preferred methods of parent training included written (75.0%, n=36) and media materials (77.1%, n=37), as well as in-home parent trainers (70.8%, n=34).

Chapter 5

CONCLUSION, SUMMARY, AND RECOMMENDATIONS

This study examined the barriers to successful parenting as experienced by parents with developmental disabilities in Sacramento County. The aims of the study were to 1) identify the primary barriers to parenting among parents with developmental disabilities; 2) identify parenting strengths and resiliency factors; and 3) examine practice strategies which promote successful parenting. While the statistical findings of this study may not be generalized to parents with developmental disabilities outside of Sacramento County, it is hoped that the results may be utilized by local service agencies to develop program plans which seek to address the specific needs of this unique population. The summative findings of this Master's Thesis Project are described in the subsequent sections.

Summary of Study

The principle hypothesis of this Master's Thesis Project was that the primary barrier to successful parenting would be the lack of adequate and competent supports, both familial and professional. The findings of this study support this hypothesis, identifying the leading barrier reported by research participants as a lack of overall support. Participants reported their awareness of social supports when they became overwhelmed at a total rate of 75.0% (n=36) between the responses: "Never", "Rarely" and "Sometimes" (see Table 11.1). Family support with childcare was found to be 75.0% (n=36) overall on a scale of "Never" to "Sometimes" (see Table 11.2). Similarly, 75.0%

(n=36) had familial support “Never” (41.7%, n=20), “Rarely” (22.9%, n=11), or “Sometimes” (10.4%, n=5) (see Table 11.3). Participants also reported having little support from friends, with 66.7% (n=31) having support “Never” to “Sometimes” (see Table 11.4). Participation in social activities outside the home was significantly low with 85.4% (n=41) participating in activities “Never” to “Sometimes” (see Table 11.5).

Cross tabulations were used to examine the relationship between the foremost barrier of support networks and the removal of the child from the parent by Child Protective Services. Table 22.1 shows that the chi-square test of independence found those who had their children removed from the home were less likely to have family support in caring for the child (66.67% vs. 33.33%). An additional chi-square test of independence found that respondents who had their children removed from the home were less likely to have access to supports when overwhelmed (58.97% vs. 41.03%) (see Table 22.2). Conversely, these findings would suggest that those with greater supports are less likely to experience termination of parental rights.

The literature review also supports the hypothesis that social supports are a significant barrier to successful parenting. Kroese, Hussein, Clifford, and Ahmed (2002) found that less than 35 percent of mothers with developmental disabilities reported supportive friendships, with an average of only five identifiable and largely inconsistent persons available to provide support. Mayes, Llewellyn, and McConnell (2008) also found that among mothers with developmental disabilities, the main sources of social

support were family and social service workers, from whom they did not feel comfortable requesting support.

The secondary barrier identified by this study was parent ability to support child education. Awareness of educational programs (70.8%, n=34), reading books to the child (72.9%, n=35) and participation in children's activities outside the home (81.3%, n=39) were among the highest rated barriers. In accordance with the original hypothesis, the researcher postulates that this may be reflective of the limitations of disability, through which lower cognitive functioning of the parent would be related to a decreased ability to support the cognitive development of a child.

This study also sought to determine which factors would be identified as parent strengths. It is important to note that the only variables which demonstrated an overwhelming self-reported competency on a scale of "Always" to "Often" were the ability to provide adequate clothing to the child (91.7%, n=44), spending time with the child (89.6%, n=43), having a good relationship with the child (87.5%, n=42) and the overall enjoyment of being a parent (87.5%, n=42). These variables are reflective of the ability and desire of parent respondents to provide their children with the nurturing and affection necessary to support emotional development.

All other variables demonstrated some level of difficulty experienced by respondents, although to a lesser extent than those described above. The need for support in these lesser reported areas were accounted for in research measurements of self-expressed parent needs. The majority of participants requested all named service

supports, with the exception of communicating with partners (35.4%, n=17) and family (47.9%, n=23), responding to child emotional needs (35.4%, n=17), developing child self-esteem (35.4%, n=17), maintaining child medical care (47.9%, n=23), and household safety (39.6%, n=19).

Implications for Social Work

The protection of human rights and the provision of culturally competent social support services are at the forefront of social work ethics. Chapter 2 of this study discussed the revolutionary United Nations treaty the Convention on the Rights of Persons with Disabilities. This treaty is the single-most progressive disability rights campaign of the 21st century. Its' protections include the right to marry and have children, the right to services which assist in achieving parenting roles, the right to guardianship of a child, the right to family planning and education services, and the abolition of termination of parental rights on the basis of disability (United Nations, 2006). In 2006, the United States signed this treaty, but failed to ratify its' policies through Congress in the ensuing years (Jacobson, 2012).

It is the recommendation of the researcher that social workers advocate for the ratification of the Convention on the Rights of Persons with Disabilities, on the grounds that it insures vital protections for this vulnerable minority population and acts to sustain the rights of the family. Further, state family welfare policies which identify disability as the sole factor in justifying the termination of parental rights must be revoked. These practices demonstrate a unwavering bias and discrimination toward persons with

disabilities, while hiding behind the creed of child protection. The researcher contends that if a child is determined to be neglected or abused according to state statutes, the inclusion of parental disability becomes insignificant in justifying termination of parental rights.

Participants in this study reported an astoundingly high rate of CPS involvement (81.3%, n=39) and the removal of the child from the home (52.1%, n=25). This calls into question not only the policies which allow for the termination of parental rights on the basis of disability, but the practices and methodologies of local child welfare institutions in determining parent ability. The findings of the literature review support the recommendation that social workers must advocate for the training of Child Protective Services staff in the awareness and cultural competencies of disability; as well as the restructuring of the family assessment process to provide for the special needs of this population. The National Council on Disability (2012) maintains that the parent assessment processes of the child welfare system are designed in such a way as to guarantee the failure of parents with developmental disabilities. Booth and Booth (2005) found that parents with developmental disabilities report limited understanding of the process of child welfare investigations and communications with the child welfare agency.

Table 22.3 shows that parents who participated in a parent training program were not more likely to be involved with CPS (56.25% vs. 43.75%). This may signify that vital parent training resources available to persons with disabilities in California are not

being utilized effectively to assist in the sustainability of the family. Social workers must then work to build interagency connections between child welfare institutions and local disability support services. In building such collaborations, CPS social workers can cultivate competencies to assess and develop case plans for parents with disabilities.

This project also sought to identify best practice strategies for parent training programs designed specifically for parents with developmental disabilities. The study found that deficits in natural supports and parent ability to support child education were prominent barriers to successful parenting. Such barriers can be easily counteracted through accessing various social, emotional, educational and respite programs in the community, as well as supplemental educational programs for children. Parent training programs should focus on reducing social isolation and building support networks; increasing parent knowledge of local resources; and assisting parents with accessing these resources. The utilization of resources available to the children of parents with disabilities will also assist in offsetting areas of parent limitations.

Methods of service delivery were examined and found that participants preferred the use of in-home parent trainers (70.8%, n=34), providing both written (75.0%, n=36) and media (77.1%, n=37) materials as tools for parent education. A large percentage of parent participants (56.3%, n=27) also expressed interest in parent support groups, which could serve the dual function of delivering vital parent education, the promotion of social support networks and decreasing social isolation. The least desired method of service

delivery was parent trainings in group settings (31.3%, n=15), a common practice in generalized parent training services.

Recommendations for Future Research

In the process of completing this Master's Thesis Project, the researcher came upon many more questions than answers. While this study produced many valid research findings, each of these findings lead to the need for further research. The need to assess current parent training programs for persons with disabilities is the foremost research recommendation. When conducting the literature review, the researcher found little information regarding parent training programs for this minority population. Research should focus on contemporary program strategies and competencies, the utilization of interagency networks, and overall success rates in sustaining families with parental disability. Further research is also needed to identify program qualities which are most closely correlated with family sustainability in relation to the termination of parental rights.

The researcher also observed that many existing studies focus on the perceptions and experiences of parents with disabilities. Alternatively, research which examines the biases and competencies of child welfare social workers on the issue of parental disability would prove to be invaluable to effecting change. Such research could lead to practice recommendations in challenging public perceptions and training professional social workers who are responsible for making life-changing decisions for parents and children alike.

Limitations

The research presented was limited to a small sample size of 48 respondents due to the difficulties associated with accessing this minority population, and focused on the single geographic area of Sacramento County. Furthermore, participants were recruited from only one disability service agency within the county and were chosen based on specific, predetermined criteria. As such this sample was not randomized and the statistical analysis found within this study cannot be generalized to the larger population.

The methodology utilized in the study required in-person interviews to solicit responses to questions which were sensitive in nature. Yegidis, Weinbach, & Myers (2012) state that this type of research design is subject to the expectancy effect, which may cause the participant to provide responses considered socially desirable. Although the research design was quantitative in nature, participants often wanted to clarify and elaborate on their responses with the researcher, indicating that participant responses may have been compromised by the data collection process.

Conclusion

The researcher hopes that this Master's Thesis Project will prompt social workers to appraise their service methodologies and biases in regards to parents with developmental disabilities; and encourage providers to build cultural competency and humility when working with this population. The researcher also asserts that it is the responsibility of the social work profession to advocate for vulnerable populations when society fails to address rampant domestic injustices. This study should act as a catalyst

for policy advocacy in protecting basic human rights for persons with disabilities, which continue to be grossly inadequate in addressing matters of familial rights, service provision and policy implementation.

APPENDIX A

NEEDS ASSESMENT FOR PARENTS WITH DISABILITIES

Needs Assessment for Parents with Disabilities

PART 1 Demographics:

1. Gender of respondent

_____ Male

_____ Female

2. Age of the respondent

_____ years old

3. Relationship Status:

_____ Single

_____ Married

_____ Divorced

_____ Separated

_____ Co-habiting

_____ Widowed

4. Number of children _____

5. Has Child Protective Services ever been involved with any of the children in past years?

_____ Yes

_____ No

6. If yes, have any of the children ever been removed from the home in past years?

_____ Yes

_____ No

_____ Not applicable

7. Educational attainment of the respondent:

Did not finish high school

High school graduate

Some College

College graduate

8. Primary source of income

Supplemental Security Income

Employment

County Benefits

9. Do you receive a Housing Subsidy?

Yes

No

10. Are you currently, or have you ever, participated in a Parent Training program?

Yes

No

11. If yes, did you find the program beneficial?

Yes

No

Not applicable

PART 2 Likert-Scale Questions:

Instructions. The next set of questions will ask for your perception regarding your daily activities and experiences. I will read each statement to you. Please listen carefully to the statement and give me your response based on the following scale:

Never
Rarely
Sometimes
Often
Always
Not Applicable

_____ I have enough money to pay for housing each month.

_____ I am aware of educational programs available to my child.

_____ It is important to me to spend free time with my child.

_____ I have enough money to provide food for my family each day.

_____ My child has weather-appropriate clothing each season.

_____ I have a good relationship with my child.

_____ I am able to budget my money in order to provide for all of my child's needs.

_____ I know where to find help when I feel overwhelmed.

_____ My family assists me with childcare when I need help.

_____ I understand when my child is ready to learn new skills.

_____ I set clear boundaries for my child.

_____ My family assists me in providing for my child's needs.

_____ I have friends I can rely on.

_____ I participate in social activities within my community.

- _____ I am able to assist my school-age child with school assignments.
- _____ I am able to prepare nutritional meals for my child.
- _____ My child is tardy for school.
- _____ My child participates in social activities outside the home.
- _____ I read books to my child.
- _____ I praise my child when he or she does something well.
- _____ I enjoy being a parent.
- _____ I know what to do when my child is injured or ill.
- _____ I follow medical instructions for my child provided to me by the doctor.

PART 3 Parent Felt Needs (Attitude/Preferences) Assessment:

FINANCIAL

I need support with:

Locating and accessing affordable housing.

_____ Yes

_____ No

Locating and accessing local resources in my community.

_____ Yes

_____ No

Managing my budget to provide for my child's needs.

_____ Yes

_____ No

SUPPORT SYSTEM

I need support with:

Locating and accessing family resources within my community.

_____ Yes

_____ No

Locating and accessing adequate and affordable child care.

_____ Yes

_____ No

Communicating needs and expectations with my partner.

_____ Yes

_____ No

Communicating with family members.

_____ Yes

_____ No

EDUCATION

I need support with:

Locating educational and recreational programs in my community.

_____ Yes

_____ No

Understanding my child's educational development.

_____ Yes

_____ No

Developing age-appropriate educational lessons in the home.

_____ Yes

_____ No

Communicating with staff and educators at my child's school.

_____ Yes

_____ No

Understanding the expectations of my child's school or educational program.

_____ Yes

_____ No

NURTURING

I need support with:

Developing and implementing daily routines.

_____ Yes

_____ No

Understanding and responding to my child's behaviors.

_____ Yes

_____ No

Developing age-appropriate disciplinary strategies.

_____ Yes

_____ No

Understanding and responding to my child's emotional needs.

_____ Yes

_____No

Developing strategies which foster my child's self-esteem.

_____Yes

_____No

Developing strategies for communicating with my child.

_____Yes

_____No

HEALTH AND DEVELOPMENT

I need support with:

Locating medical resources in my community.

_____Yes

_____No

Scheduling and maintaining my child's doctor appointments.

_____Yes

_____No

Understanding my child's developmental stages.

_____Yes

_____No

Assessing my home for safety hazards and making necessary changes.

_____Yes

_____No

SERVICES I WOULD BE INTERESTED IN RECEIVING:

Written materials.

_____Yes

_____No

Media materials, such as videos and audio lessons.

_____Yes

_____No

In-home parent trainer.

_____Yes

_____No

Parenting support group.

_____Yes

_____No

Parent trainings in groups.

_____Yes

_____No

APPENDIX B
CONSENT TO PARTICIPATE IN RESEARCH

Consent to Participate in Research

You are being asked to participate in a research project which will be conducted by Jaime Zehner, a graduate student in Social Work at California State University, Sacramento. The study will investigate the support needs of parents with developmental disabilities. You will be asked to complete a questionnaire about your finances, support networks and normal activities with your family. The questionnaire will be read to you and your answers recorded by the researcher. The questionnaires may require up to an hour of your time. Some of the items in the questionnaires may seem personal, but you do not have to answer any question you feel uncomfortable with. You may not personally benefit from participating in this research. However, it is hoped that the results of the study will be beneficial for programs designed to support parents with similar situations as yours.

I want to assure you that your responses to the questionnaire will be confidential and your name will not be recorded or appear anywhere on the questionnaire. I also want to assure you that the questionnaire will be destroyed as soon as the data has been transcribed or entered into a computer in digital format. The paper form will not be kept for more than one year after the data have been recorded. No one but the researcher and her Project Advisor will have access to the data set. Finally, information provided by you and other respondents will be reported in aggregate format in the final product; therefore, no individual respondent will be identifiable in any shape or form.

As a research subject, you will not be compensated for participating in this study. However, if you would like a copy of the aggregate report, I would be happy to send you one. If after participating in this study you feel support is necessary, please contact your support agency or social worker. You may also contact any one of the following mental health agencies: (1) Turning Point North, Transitional Support Services at (916) 481-2328; (2) The Effort at (916) 737-5555; or the (3) Sacramento County Mental Health (916) 875-1000.

For general questions you may contact Jaime Zehner at (xxx) xxx-xxxx or by e-mail at xxxxxxxx@yahoo.com; or her Project Advisor, Dr. Serge Lee at (916) 278-5820 or by email at leesc@csus.edu.

Your participation in this research is entirely voluntary. You are free to decide not to participate without consequence. The researcher may also end your participation at any time. Your signature below indicates that you have read this page, understand the risks involved in this research and agree to participate in the research.

Signature of Participant

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