AN EXPLORATORY STUDY ON THE EDUCATIONAL EXPERIENCES OF CLIENTS WITH DEVELOPMENTAL DISABILITIES

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B.A., California State University, Sacramento, 2005

PROJECT

Submitted in partial satisfaction of the requirements for the degree of

MASTER OF SOCIAL WORK

at

CALIFORNIA STATE UNIVERSITY, SACRAMENTO

SPRING  
2010
AN EXPLORATORY STUDY ON THE EDUCATIONAL EXPERIENCES OF
CLIENTS WITH DEVELOPMENTAL DISABILITIES

A Project

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Division of Social Work
Abstract

of

AN EXPLORATORY STUDY ON THE EDUCATIONAL EXPERIENCES OF CLIENTS WITH DEVELOPMENTAL DISABILITIES

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There is limited information regarding the educational experiences and resilience of clients with developmental disabilities. To be able to provide adequate services and support to this population, it was crucial to hear parent stories first hand and give voice to those affected. This researcher’s sources of data included five families that met the criteria of having an adult child who was in special education with a developmental disability. The nature of parent support, parent involvement, and resilience were themes that emerged. Parents shared their children’s educational experiences and stressors they had faced. The parents identified the positive roles professionals played within this field.

_________________________, Committee Chair
Andrew Bein, PhD, LCSW

_________________________
Date

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ACKNOWLEDGMENTS

I would like to thank the families that participated in this study and allowed me into their lives. Without them this project would not have been possible. I feel extremely fortunate to have had Dr. Andrew Bein as my thesis advisor who offered support and encouragement in affirming the worth of this research project. I want to thank my supportive mother, Natividad and my hard working father, Rolando for all their infinite love and support. I am forever grateful. I would like to thank my grandparents, aunts, uncles, cousins, and friends who never stopped believing in me. For those who cannot be here with us: Nicolas “Tatang” Concepcion, Eulogio “Apong Yoyong” Quilacio, Julita “Apong Juling” Quilacio, and Aaron Bordeau. I’m deeply thankful for having you all in my life.
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Chapter 1

PROBLEM STATEMENT

Introduction

The focus of this study is to explore educational experiences of clients with developmental disabilities. The rationale for selecting this particular issue is to identify the experiences that a client goes through while in special education and also the experiences that the family has undergone or is going through.

This researcher has been working with clients with developmental disabilities for the past five years. In the last three years, while attending Individual Educational Planning meetings with the client, parents, and teachers, this researcher noticed that some parents were optimistic when it came to dealing with developmentally disabled son or daughter and some were pessimistic. This researcher wanted to further understand the special education system and the educational experiences of his clients. Despite having graduated with a Bachelor’s in Sociology and working with clients with developmental disabilities for several years, this researcher had never learned about the educational experiences of clients with developmental disabilities.

Background of the Problem

A developmental disability is a life-long, disability attributable to mental and/or physical impairments manifested prior to age 18. The term is used most commonly in the United States to refer to disabilities affecting daily functioning in three or more of the
following areas: capacity for independent living, economic self-sufficiency, learning, mobility, receptive and expressive language, self-care, and self-direction.

The term first appeared in U.S. law in 1970 when Congress, in its effort to improve conditions in dehumanizing facilities used the term to describe the population of individuals who had historically been placed in state institutions (P.L. 91-517, “The Developmental Disabilities Services and Facilities Construction Act of 1970”). The Lanterman Developmental Disabilities Act (AB 846), also known as the Lanterman Act, is a California law, initially proposed by Assembly member Frank D. Lanterman in 1973 and passed in 1977. This Act gave people with developmental disabilities the right to services and supports that enable them to live a more independent and normal life. The legislation significantly expanded upon its landmark predecessor, the Lanterman Mental Retardation Services Act (AB 225), initially proposed in 1969. The original act extended the state's existing regional center network of services for the developmentally disabled, while mandating provision of services and supports that meet both the needs and the choices of each individual (Department of Developmental Services, 2001).

The Lanterman Act declares that persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other persons by federal and state constitutions and laws, and charges the regional center with advocacy for, and protection of, these rights. The law has since been amended many times, and now calls for the full community inclusion and self-determination of people with developmental disabilities.
Frequently, people with mental retardation, cerebral palsy, autism spectrum disorder, various genetic and chromosomal disorders such as Down syndrome and Fragile X syndrome, and Fetal Alcohol Spectrum Disorder are described as having developmental disabilities. The inclusion of students with disabilities in the mainstream of general education remains one of the most contested topics in public education today. This qualitative study considered this issue from the perspective of included as well as excluded special education students over an extended period of time. More specifically, it sought to understand how 11 “developmentally handicapped” students made sense of their experience in a variety of inclusive and segregated classrooms in four urban school settings.

Statement of the Research Problem

There is a lack of information about experiences of client’s with developmental disabilities, the experiences their families go through, and how those with developmental disabilities feel about special education. Although, the United States has a motto of “no child left behind,” there is no evidence that shows students with developmental disabilities who are in special education are prepared to go to college or work out in the community. As we move toward a new approach to special education, it will be important for teachers and social workers to embrace the idea of helping those with special needs who are “left behind.”
Purpose of the Study

The purpose of this study is to provide a better understanding of the experiences of clients with developmental disabilities including parents that have a child that are developmentally disabled that is currently in and/or was in special education. In addition, to be able to provide adequate services and support to this population and give voice to those affected in order to identify the specific challenges this population faces. Findings must provide some insight into how well the upcoming teachers will be prepared to help working with students with developmental disabilities. The study must shed light on the stressor that occurs when having a child with a developmental disability and going through their educational experiences. A secondary purpose of this study is to provide local school districts with qualitative data that addresses how well their curriculum is addressing the issue of “no child left behind.” With the increase of youth dropping out of school and not being prepared for postsecondary school, this study serves the purpose of addressing a potential gap in special education.

Theoretical Framework

The ecological perspective provides the framework for this study. The ecological perspective is defined as: The need to view people and environments as a unitary system within a particular cultural and historic context. Both person and environment can be fully understood only in terms of their relationship, in which each continually influences the other within a particular context. Social workers have found that the ecological perspective allows them to be able to connect the individual’s behavior with that of both
social and environmental influences. This is important because it allows for several influences to help in explaining what impacts the development of children diagnosed with a developmental disability (Johnson & Rhodes, 2005).

This perspective “conceptualized the environment as “more than a static setting” for people’s lives” (Johnson & Rhodes, 2005). This statement allows the social worker to understand the stressors that may arise in families that have a child with a developmental disability; their constant struggle to keep up with society’s “norms” and “values” of how it should be in the home, school, and the community. This perspective permits social workers to be aware of what challenges or stressors families’ face both during the initial diagnosing of the child, and for the rest of their lives.

Definition of Terms

Developmental Disability

A term used in the United States to describe life-long, disabilities attributable to mental and/or physical or combination of mental and physical impairments manifested prior to age 18

Special Education

Education that is modified or particularized for those having singular needs or disabilities, as handicapped or maladjusted people, slow learners, or gifted children.
Stressors

A situation, occurrence, or factor causing physical, mental, or emotional strain or tension.

Assumptions

In this study, the overall assumption is that educational experiences of a son/daughter with a developmental disability affects a parent’s life because of stressors such as sacrifice, time, and patience.

Justification

This research is intended to benefit the teaching and social work profession in several ways. Within the Code of Ethics section regarding Service, it is absolutely necessary that “Social workers draw on their knowledge, values, and skills, to help people in need and to address social problems” (National Association of Social Worker [NASW], 1996, p. 2). Social workers are bound by ethics to determine and meet the needs of those who are underrepresented. Thus, it is crucial that social workers do their research and put to use their valuable knowledge to adequately serve their client(s).

The Code of Ethics section on Social Justice states that

Social workers pursue social change, particularly with and on behalf of vulnerable and oppressed individuals and groups of people. These activities seek to promote sensitivity to and knowledge about oppression and cultural ethnic diversity. Social workers strive to ensure access to needed information, services, and resources;
equality of opportunity; and meaningful participation in decision making for all people (NASW as cited in Reamer, n.d., ¶ 9).

This research will help to raise greater awareness for assisting parents who are raising a child with a developmental disability because these groups of people are often underrepresented, and may be oppressed, due to their developmental diagnosis.

The Code of Ethics also discusses the Dignity and Worth of the Person which states, “Social workers treat each person in a caring and respectful fashion, mindful of individual differences and cultural ethnic diversity” (NASW, 1996, p. 2). By allowing the subjects themselves to provide a descriptive narrative, all the while being the “expert” of their experiences and challenges, it sits the hopes of the researcher, is an affirming and empowering experience.

Limitations

This study utilizes a small sample that might not provide all the themes that a client with a developmental disability and his/her educational experiences may have. It is a convenience sample and may not be representative.

The only internal validity threat to the researcher’s study will be the selection of subjects. All of the subjects are currently receiving services from Alta California Regional Center in Sacramento.

Chapter 2 provides a literature review examining components involved in the developmentally disabled community. In this chapter, a definition of developmental disability diagnosis, special education, coping families, and stressors is discussed.
Chapter 2

LITERATURE REVIEW

Introduction

There are four themes that are addressed to aid the reader in developing a better understanding of clients with developmental disabilities and special education. The literature review begins with an overview of special education which will include information on the Individuals with Disabilities Education Act. The next section will discuss the developmental disability field. The third section will discuss Advocacy. The fourth topic discusses the different stages of grief and coping including the effects of respite care on parental stress.

Special Education

Special education is a fundamental part of our modern educational system. Prior to the 1970s, special education was not on the political radar. The understanding of special education as a civil right for disabled people largely stemmed from the efforts of disability rights advocates who worked to change the conception of disability in the United States. Through the early 1970s, disability policy adhered to the medical model of disability “in which people with disabilities were presumed unable to function independently in the mainstream of social, economic, and political life” (Phillips, 2008, p. 1809). The disability rights movement worked to shift public conceptions away from a medical model of disability, which locates symptoms of a perceived illness within a person and focuses on how to treat those symptoms, toward a social model of disability,
which “focuses on how existing social arrangements handicap individuals” (Phillips, 2008, p. 1809). This shift in awareness confronted physical and social barriers built by a majority that perceived human deviation as defective (Johnson & Rhoades, 2005).

One of the most important factors in mobilizing the disability rights and special education advocates was section 504 in the Rehabilitation Act of 1973, which prohibited any and all discrimination on the basis of disability within federally funded programs. Health, Education, and Welfare framed section 504 as a declaration of civil rights for disabled people. Section 504 fueled the way society viewed disability, which in turn led to a broad push for social accommodation. This development contributed to a realization that public school systems should accommodate disabled students and was a factor in the evolution of modern special education (Browder, 2008).

The Individuals with Disabilities Education Act (IDEA) has been widely celebrated for providing millions of disabled children with broader educational and life opportunities. In principle, the IDEA gives every qualified child in the United States access to special education. As with many government-provided services, however, individuals often must take action in order to receive program benefits. Special education, whose consumers are children, presents unique challenges with regard to asserting one's rights. Children do not have the capacity to identify a disability or understand that their educational needs differ from those of their classmates. They must rely on parents or teachers to recognize their special needs and provide appropriate evaluation. As the IDEA is currently structured, children who are entitled to special education depend upon
the school's provision of a free appropriate public education (FAPE), or, alternatively, their parents' willingness and ability to advocate for them (Trainor, 2008).

Because special education law today relies upon a system of procedural protections without detailed substantive requirements, schools can often make errors in judgment about the appropriate treatment plan for a disabled child. Such a formulation assigns parents to be the check on school systems, which is problematic in a system as complex and varied as special education.

The right to an adequate education has long been an issue of great importance for policymakers in this country, in part because the effects of education policy reach almost every family at some point in time. In passing the IDEA, Congress recognized that public education should not exclude children with disabilities, and thereby extended the benefits of free public education to a class of children who, prior to the 1970s, had been drastically underserved. Congress also recognized that advances in special education have vastly improved the educational prospects of children with disabilities. Without effective advocacy, however, the promise of special education for children with disabilities cannot be realized (Phillips, 2008).

The absolute necessity of successful special education programs is well established. The successes of the disability rights movement over the past few decades have resulted in the normalization of the movement's goals: accommodation of difference, preparation for independent living, and the right to work and participate fully in the community. For children with disabilities, full participation in the community is
largely achieved through special education. In 1970, studies showed that nearly two million children with disabilities were excluded entirely from public education. Today, no state allows public schools to exclude children, and as of 2003, 6.63 million American students received specialized services under the IDEA. Many disability rights advocates emphasize the economic sensibility of special education programs by stressing that integration and quality education will always be less expensive over time than the forced dependency of disabled people (Trainor, 2008).

Despite enormous gains in the area of special education over the last few decades, there is still much room for improvement in utilizing special education programs to expand community participation and opportunities for individuals with disabilities. Evidence suggests that in some instances identification under the IDEA has not seen sufficiently accurate. In addition, four times as many boys as girls are identified for special education (Phillips, 2008).

The most appropriate educational environment for students with disabilities has been an issue of intense public debate for several decades. While some continue to argue for the advantages of maintaining segregated special education settings, there is increasing recognition of the long-term social and academic cost of segregation as well as the benefits of full inclusion for all students (Freeman & Alkin, 2000). An aspect of this issue that is often overlooked is the perspective of special education students themselves.

The need for qualitative research in this area has been widely recognized. There are several recent studies related to how special education students understand segregated
and integrated educational placements. Although these studies reported various findings they differed from the research described here in that, for the most part, (1) they did not involve participant observation and multiple in-depth interviews across various segregated, traditionalist, and inclusive settings; (2) they did not consider changes in students’ self-understanding over an extended period of time; and (3) they did not interpret classroom teacher beliefs/ideology (traditionalist versus inclusive) in relation to students’ sense of self-worth and belonging (Fitch, 2003).

As a result, when integrated students became members of inclusive classroom communities, they constructed a relatively confident, hopeful sense of themselves as legitimate participants in the mainstream culture. However, even within what were termed inclusive schools, there were traditionalist classrooms that did not offer this sense of belonging. In this environment, students often expressed a sense of rejection, resignation, and a desire to escape to the safety of the education classroom as a sanctuary. As integrated students were eventually re-segregated into two local junior high schools, this former sense of confidence, hope, and sense of belonging disappeared (Fitch, 2003).

Among the segregated students, this degree of hope, confidence, and belonging never really emerged. In fact, the longer they remained within the special education classroom, the more they took on a kind of deviant sub-cultural identity as outsiders. Even as they professed a preference for the perceived safety and anonymity of the special education class, they admitted a secret sense of shame, embarrassment, and desire to eventually escape its confines. In a sense, the students in the study passively accepted a
deviant or subordinate status. Perhaps the most consistent pattern to emerge from the study was that the students moved in and out of inclusive, traditionalist, and segregated classes they presented a changing sense of themselves and social belonging that was closely tied to the structural and ideological elements of their school environment (Fitch, 2003).

In addition to special education mandates, the sixth amendment of the Constitution has long been interpreted to require the provision of counsel to criminal defendants who cannot afford a lawyer. It has become the norm for states to maintain a public defender’s office with full-time attorneys who represent indigent criminal defendants. A similar model could be applied to special education. According to Phillips (2008), each district could appoint a special advocate to every child being evaluated for special education services, and to those already receiving services. This advocate would be a full time employee paid by the state and would have pre-existing expertise in the area of special education. An ad hoc committee, which would accept complaints from students and parents receiving services, could act as an accountability mechanism to guarantee high quality advocacy (Phillips, 2008).

A full time advocate could be recruited from a number of different fields. One could imagine that the following people might be effective advocates: attorneys trained in education law, retired or former professionals in the education field, psychologists specializing in learning or other disabilities, literacy professionals, or psycho-educational consultants. A supplemental advocacy program could also enhance the advocates pre-
existing expertise by requiring that they completed a training course on special education advocacy. A number of non-profit organizations, such as the Federation of Children with Special Needs, the Council of Parent Advocates and Attorneys, and the Special Needs Advocacy Network currently offer such training.

Implementing this proposal would require policy makers to overcome some potential drawbacks. For example, the utilization of the child’s evaluation as an access point to the program does not address the concern that parents do not always make affirmative requests for evaluation when their children need it. In the United States approximately 14% of students end up receiving some form of special education (Phillips, 2008).

Developmental Disability

There are many social, environmental and physical causes of developmental disabilities, although for some a definitive cause may never be determined. Common factors causing developmental disabilities include: Brain injury or infection before, during or after birth, growth or nutrition problems, abnormalities of chromosomes and genes, prematurity, poor diet and health care, drug misuse during pregnancy, including alcohol intake and smoking, child abuse, which can severely affect a child's socio-emotional developmentally, and an autism spectrum disorder (Glidden & Jobe, 2006).

Developmental disabilities affect between 1% and 2% of the population in most western countries, although many government sources acknowledge that statistics are flawed. The worldwide proportion of people with developmental disabilities is believed
to be approximately 1.4%. It is twice as common in males as in females, and some researchers have found that the prevalence of mild developmental disabilities is likely to be higher in areas of poverty and deprivation, and among people of certain ethnicities.

Advocacy

In recent years, there has been a tremendous increase in the number of individuals diagnosed with a developmental disability. For this reason there is a greater need for resources and advocacy in this area. In this section, there will be a discussion of advocacy and resources available in the Sacramento region, in the state of California, and in the United States.

Sacramento is comprised of 99.2 square miles and a population of 407,018 as of the year 2000 (Sacramento, California, n.d.). In Sacramento, California there is an advocacy and resource center by the name of WarmLine Family Resource Center. This agency offers a variety of services and supports. One of the services offered is support for families of infants and young children with special needs (WarmLine Family Resource Center, 2000). This agency provides support for families with children diagnosed with a developmental disability. Parent(s) and other family members can call the WarmLine center and speak to someone that understands their feelings. WarmLine Family Resource Center was actually started by parents with children with special needs (WarmLine, n.d.). These parents felt that there was a need for an agency with positive peer support.

The WarmLine Family Resource Center provides a list of books, videos, and articles to aid families understand their child’s disability and other advocacy services and
supports available. The families can be connected to these other services and supports by the WarmLine Family Resource Center.

There have been numerous occasions when families needed assistance in advocating for their child at schools or in other agencies. The WarmLine Family Resource Center offers advocacy and support services. One way that WarmLine is able to advocate for all the families with children with special needs is through seminars and workshops that they hold (WarmLine, n.d.). WarmLine Family Resource Center utilizes Alta California Regional Center. Alta California Regional Center is a private non-profit organization corporation working under contract with the California Department of Developmental Services that currently serves 10 counties and close to 17,000 consumers (Alta California Regional Center, 2009).

California is a unique state because of the existence of the Lanterman Developmental Disabilities Act and related laws (Divisions 4.1, 4.5, and 4.7 of the Welfare and Institutions Code and Title 14 of the Government Code) (Department of Developmental Services, 2007). Frank D. Lanterman, an assembly member proposed the act in 1973 and it was passed in 1977 (Phillips, 2008). The Lanterman Act was the foundation that assisted the establishment of the 21 total Regional Centers in California. In the year 1977, the Lanterman Act was approved in hopes that individuals with developmental disabilities would be able to live in the community and lead their life to the fullest of their potential. The Lanterman Act defines a person with a developmental disability as one with the existence of a diagnosis prior to the age of 18. Qualifying
diagnoses are: mild to severe mental retardation, cerebral palsy, autism, epilepsy, as well as other conditions similar to what is needed for individuals with mental retardation (Alta California Regional Center, 2009).

Before 1977, many people with a developmental disability were being placed in institutions. Some of these developmental centers did not uphold the quality of life for the clients that were abused, considered outsiders, and were not part of the community.

Regional Centers throughout California were established to provide services and support to individuals with developmental disabilities. As mentioned earlier, there are currently 21 Regional Centers in California (Alta California Regional Center, 2009).

The Lanterman Act clearly illustrates that the control and oversight of the 21 Regional Centers will be by the State Department of Developmental Services (DDS). The important aspect of this information is that the Regional Centers have a legal obligation to provide the supports and services outlined in the Lanterman Act.

The contract which binds the consumer with the Regional Center and the services and supports affiliated with the Regional Center is called the Individual Program Plan (IPP). The Individual Program Plan (IPP) contract is a person centered document. When the consumer is a minor, the family individualized plan is called, the Individual Family Service Plan (IFSP). These documents include services and supports involved with each consumer and their family specific to their needs (Alta California Regional Center, 2009).
The IPP and IFSP include the goals and objectives along with the services and supports that will be used to meet the long-term goals that will assist the individual and/or the family with their quality of life (Alta California Regional Center, 2009).

A consumer can be self-referred or referred by another agency in order to determine eligibility for Regional Center Services. Once a consumer is determined eligible based on the five qualifying factors outlined in the Lanterman Act, the consumer meets the requirement for services throughout their lives (Alta California Regional Center, 2009).

Examples of services and supports funded by a regional center include: life span case management, aid in accessing and locating community resources, preventative and educational programs, parent support services. In addition, services funded by Regional Center must be evidence based and meet Title 17 regulations (Kern Regional Center, 2009).

Grief and Coping

According to Ann Boushey (2001), “there is a third event just as distressing and devastating as divorce and death…the word is disability” (p. 27). Ann Boushey (2001) goes further to say that it is possible that having a child diagnosed with a disability is a parents’ worst nightmare. Although most people would agree that grief is unpleasant in every aspect, it is still considered a part of the natural human process (Boushey, 2001). The grief cycle encompasses: shock, depression, denial, guilt, isolation, panic, anger,
bargaining, and finally, acceptance/hope (Boushey, 2001). The grief cycle occurs regardless of personal choice and/or realization.

Parents may continue to struggle with mourning throughout their child’s stages in life due to the loss of expecting a typically normal development (Berry, 1992). The reason this process continues to occur is because there are constant changes in the needs of individuals with developmental disabilities. According to Berry (1992), “This sorrow is likely to be more pronounced at transition points…” (p. 46). For example, the developmental milestones of a two year old child with a minor developmental disability may not be vastly different form a typical developing two year old. However, a 21-year-old individual who is developmentally disabled will have a larger developmental milestone gap when compared to a 21-year-old individual.

Once the family becomes aware that the child has been diagnosed with a developmental disability, the family goes through a chaotic array of emotions. The first emotion to arise is often shock. Parents are typically not aware that their child is not developing like a typical child. Hence, when the child is diagnosed, they are shocked. After the shock wears off, reality sets in: “parents of children with disabilities tend to report poorer subjective well being and are at risk of physical and mental health problems, such as clinical depression” (Oelofsen & Richardson, 2006, p. 1).

The process in which the grief cycle occurs does not always follow a chronological order; individuals may skip steps, go backwards in the cycle, or may not even experience some of the steps. For example, upon hearing the diagnosis, parent(s)
may go straight to denial; they may not agree or accept the diagnosis (Boushey, 2001). Ann Boushey (2001) groups the following stages: depression, guilt, and isolation together in the grief cycle. Boushey (2001) believes that depression is directly associated with guilt and isolation. For some, due to poor coping strategies, individuals move onto the next stage in grief which is anger. Not only is anger a stage within the grief cycle, it is also a negative coping mechanism (Kramer, 1993).

Bargaining is an extremely normal reaction for a parent to have with regards to attempting to accept a developmental diagnosis (Boushey, 2001). Bargaining is a “primitive defense mechanism designed to let you get your bearings” (Strickland & O’Connell, 2000, p. 24B). According to Strickland and O’Connell (2000), there is an endless battle between hanging onto what is safe and known, versus letting go and taking a risk.

The last stage within the grief cycle is acceptance and hope. This step involves coming to terms with the diagnosis and normalizing one’s thoughts, feelings, and reactions. A recurring theme that arises in regards to acceptance is the family realizing that their reactions and feelings were normal, and this allowed them to move forward with the understanding that “the last step in the cycle does last forever, acceptance and hope” (Bousley, 2001, p. 30).

Child-rearing involves stress and calls for coping strategies to adjusts and become accustomed to that stress. Parents of children with developmental disabilities (DD) face challenges more often than parents with typically developing children (Glidden, Billings,
& Jobe, 2006). Glidden et al. (as cited in Glidden et al., 2006) stated, “[F]or example, coming to terms with the child’s condition and limitations, providing or finding providers for specialized care, procuring community resources, and planning for future caretaking are common demands described by parents of children with DD” (p. 949).

In order for the parents to function as individuals and as part of a system, they must access coping strategies that will further assist them with the process. Human beings rely on coping mechanisms as an antecedent to an event or circumstance. These coping strategies require both behavioral and emotional responses (Glidden et al., 2006). Coping can come in different forms and strategies; one such form involves personal coping and coming to peace with themselves and their surroundings without the involvement of outside support networks (Schilling, Gilchrist, & Schinke, 1984).

Coping could be explained in numerous ways. McCubbin and McCubbin (as cited in Lustig, 2002), defines coping as, “the family’s strategies and behaviors aimed at maintaining or strengthening the stability of the family, maintaining the well-being of the family members, obtaining resources to manage the situation, and initiating efforts to resolve the hardships created by the stressor” (p. 15). According to Lustig’s research study, there were five coping strategies found to be effective: (1) acceptance of the child as/she is; (2) determination to succeed; (3) development of a sense of purpose in the event; (4) development of a sense of personal adequacy and competence; (5) and development of an ability to live successfully with indeterminacy (Lustig, 2002). Caring for a developmentally disabled child can be extremely stressful for many parents. Respite
care is designed in part to alleviate this stress. Studies have confirmed that caring for a child with a developmental disability can be extremely stressful for many parents.

To reduce parental stress, many developmental disability services have pinned their hopes on respite care. In the developmental disability field, respite care typically involves the provision of an organized service that takes over the parental role for as short period of time on some regular basis. The child might, for example, spend one weekend each month at a foster care home or a staff person might come to the parents’ home one day each week to care for the child. For example, Alta California Regional Center is one of the agencies in Sacramento that provides respite for parents who have a child with a developmental disability based on their need (Alta California Regional Center. 2009). There are many variations of respite care available to families (Levy & Levy, 1986), but in each there is the common objective to temporarily relieve parents from the stressful demands of caring for the child. When the level of stress is reduced, parents should enjoy a higher quality of life and be less likely to seek out of home placement for their child (Storey, 1993).

In a study with multiple aims in 1989 examined the changes in maternal stress and coping over an 18-month period. The study involved 32 families who had been using home-based respite care and 25 families who were not using such care. All families had children with comparable levels and types of developmental disabilities. Families who used respite care reported reduced levels of stress and better coping. In comparison, the
25 families who did not use respite care during the 18th month period reported increased stress and reduced coping (Chan & Sigafoos, 2001).
Chapter 3

METHODS

Design

Throughout this exploratory study, the researcher hopes to better understand the educational experiences of clients with developmental disabilities. An exploratory study is implemented when there is limited research on the topic. The researcher’s goal is to try and devise questions that future research can then in turn answer (Neuman & Dickinson, 2001). The researcher will examine the way that special education teachers can better assist students with developmental disabilities. As well, there is little research that has been conducted in the area of educational experiences of clients with developmental disabilities. The researcher will allow the subjects freely to share their stories in order to understand their experiences. The participants are seen as experts of their own lives.

The participants will be families who have a son/daughter that is currently in special education or was in special education and is between the ages of 18 to 25 years old. It will be up to the family’s discretion which parent participates in the interview. In a two-parent household, it will be up to the family if both parents participate in the study.

Subjects

The source of subjects is from the Adult Alternative Living unit caseloads at Alta California Regional Center (ACRC). This researcher has contacted the supervisor at the Alternative Living Unit, Rob Franco and asked for support in recruiting families that would be fitting as interview subjects. Rob Franco from the Alternative Living Unit has

already granted permission to the researcher to conduct the study. Permission from the site was obtained prior to sending a letter to the families, requesting voluntary participation in the research study. Families were informed that whether or not they consented to the study had no bearing on service provision.

Families were contacted by the researcher, and signed the consent form. Once the researcher contacted five families that were willing to commit to the study, the researcher scheduled an interview appointment. Consent forms were submitted by all families to indicate their agreement with participating (see Appendix A). The consent forms included that the interviews will were to be audio taped. Participants were given contact information for the researcher’s advisor, should they have any questions or concerns.

Instrumentation

The researcher developed a list of 11 questions which were used as a guide for the interview. The instrument was designed to gather information about educational experiences of their son/daughter with a developmental disability. The research questions explored the families’ feelings after their son/daughter was diagnosed with a developmental disability, changes in their daily lives, challenges for their child while enrolled in school, supports and services, personal experiences, and recommendations for the specialists within the field. Please refer to Appendices A and B for Consent Form and Research Questions, respectively.
Gathering Procedures

Participants were obtained by accessing the files in the case load from the Adult Alternative Living Unit at Alta California Regional Center. Each family was contacted by the researcher by telephone contact explaining to the family the purpose of the study, researcher scheduled with the family an interview appointment. The location of the interview will be conducted in the environment where the family feels most comfortable.

An audio recorder was used in this study. Subjects’ consent included the use of a recorder in order to accurately documents answers from the participants. The tapes not identified by name and all tapes were destroyed at the conclusion of the study. Participants’ rights to privacy and confidentiality was respected by the researcher assigning the numbers as means of identification for each participant through the project (i.e. “Family 1, Family 2, Family 3” etc.).

Data Analysis

The researcher analyzed the data collected from the interviews by writing down the responses and verbatim quotes. Themes that emerged from the interviews were identified. The researcher listened to the tapes and filtered common themes from the interviews. In order to collect common themes, the researcher color-coded similar findings across each subject’s questionnaire. In order to keep the subject’s experience and narrative as accurate as possible, the researcher reported the process experience with each subject.
Protection of Human Subjects

The request for review by the Committee for the Protection of Human Subjects was submitted and the project was approved by the University as a “minimal risk” study, approval number 08-09-108. Informed voluntary participation was ensured as well as subject confidentiality. The researcher discussed with participants, limits to confidentiality in regards to the researcher being a mandated reporter. No information/comments given by the families’ was shared with the staff at the agency where the clients receive services. Participants were able to cease the interview at any given time with no negative result to their son/daughter’s services.

Limitations and Benefits

Limitations of an exploratory study include the inability to make an accurate assessment of the conducted interviews or to generalize the needs and emotions of a population. This study design does no lend itself to providing predictive results necessarily.

Summary

As Neuman and Dickinson (2006) posit, an exploratory study can provide initial but significant insights into a given situation. Conducting interviews permitted the researcher to gather data from the parents who have raised kids diagnosed with a developmental disability and learn about their experiences from their unique vantage point. The author hopes that this exploratory study will inspire future research on the subject of educational experiences of clients with developmental disabilities. The following chapter (Chapter 4) presents the data collected from this study.
Chapter 4

DATA ANALYSIS

Introduction

This study explored the educational experiences of clients with developmental disabilities. The researcher sought to learn the families’ experiences with raising a child with a developmental disability who was in special education. A qualitative interview was conducted to explore the above mentioned; all the responses were reviewed to find common themes, which will be discussed within this chapter. The population was a convenience sample with all of the clients coming from the Adult Alternative Living Unit at Alta California Regional Center, which is a private non-profit organization funded by the Department of Developmental Services with clients that is currently in special education or was in special education between the ages of 18-25 years old. The five family interviews were all conducted at separate times in a location of preference to them. All of the parents who were contacted to participate in the researcher’s study are heterosexual married couples. The interviews were supposed to only be one parent, but in all the interviews the husband or wife was also present. The families all reported having a positive experience with Alta California Regional Center, and for the most part, having a positive experience related to receiving help.

Support System

Throughout the interviews, all of the parents mentioned having a support system. They mentioned that this played an important role with helping them cope with raising a
developmentally disabled child. When asked about their support system, the interviewees listed family members, friends, school officials, and social workers. However, a supportive husband or wife was found to be the most common answer for identifying primary support. All the participants in the interview discussed in detail about how their significant other would help them. One mother said, “My husband is the best man in the world. He knows how much I had to give up in order to be at home with our child. He acknowledges the things that I do and also empathize with me when I’m starting to break down” One mother revealed within the interview that her husband was her backbone, by stating:

When I’m frustrated or fed up with a situation, my husband is always there to lift me up and make me feel like there is a light at the end of the tunnel. He knows that I am pessimistic in some ways and that I worry a lot. He knows what I’m feeling even when I don’t tell him. He looks at me and hugs me. Almost as if he could read in my eyes. I remember him coming home one day and I was in the kitchen crying, he looked at me and said, “everything is going to be fine.” He told me that he understands what I’m going through. He even expressed how he wanted to cry sometimes in the middle of night, but because he knew if I saw him cry I would break down as well. He is my backbone. He keeps me going. He is my biggest support system. Not only is he the breadwinner for the family, a father for our child, but also a husband. I know he tries so hard to make things work. I
give him a lot of credit. Without his patience and perseverance, we would not be
where we are today. I love him.

Being a parent and raising a child is already difficult, but raising a child that is
developmentally disabled requires more time, patience, and energy. The families that
were interviewed all had support from their husband, wife, and family members as
mentioned. Many of the family members were willing to go out of the way to help one
another. One family for quite some time had a long commute in order to ease transition
for their daughter who had been dealing with the loss of her biological mother. A parent
shared the sacrifice he made commuting from Rocklin to Rancho Cordova and back to
downtown. The following are his word regarding his struggle and sacrifice:

Despite the fact that my wife and I lived in Rocklin, our child was still going to
school in Rancho Cordova after her mother died. We made every possible
sacrifice as best we could to slowly transition her into living with us in Rocklin,
but it was about a month or so where we would wake up early in the morning and
drive from Rocklin to pick her up at her grandmother’s house in Rancho Cordova
and drop her off to school. I would then go to work downtown. There were times
that I was late several times to work. It was very exhausting. It wasn’t so much
the driving. I think it was more of the traffic that contributed to my stress. In the
afternoon, when my fiancé at the time would pick her up and take her to
grandma’s house to get her stuff and take her all the way back to Rocklin where
she would want to stay. This was a routine that my fiancé was willing to endure,
all for the sake of my child. We both agreed that it was hard for her to lose her
birth mother, let alone take her out of her routine and natural environment that she
was already familiar with. It was not fair to her. So my fiancé and I did our best.
Another family who was interviewed shared about some of the support they
received from family members. The mother indicated that finding a babysitter was not the
problem.

Our child had family all around her for support. Finding someone to look after her
was never an issue. A family member was always willing to help us out when we
needed someone to look after our daughter. She had her cousins, aunts, uncles,
grandparents, and so forth. When we would have family gatherings on the
weekends she would be at every family gathering. There was not a moment where
she was left by herself. We tried to get her to interact with her peers despite her
disability. We wanted her to still able to do a lot of the things that normal people
get to do. She grew and learned from each experience which I think makes her a
better person and also more sociable. At every family function she would be the
center of attention. She loved the attention she received from her family. Her
grandmother had a big impact. Her grandma would spoil her.

Difficult and Resilience Building Experiences

The information from the parent interviews suggests that certain practices within
a particular school and classroom helped students construct a sense of themselves that
was significantly different (and more positive) in comparison to being segregated in the
class room. One parent was happy that their child was able to become a part of special education and what was offered at her school. He believed that his daughter’s future seemed bleak in the beginning, but as the years progressed, change started to happen for the better.

Twenty-three years later she walks with society. She’s like the rest of us. She’s sociable, outgoing, and polite. She knows how to wash the dishes, take out the trash, and fold her laundry. She may not do her own laundry but given her disability and her being able to fold her clothes and put them away and do some cleaning around the house is a tremendous help for us. The people skills that she has acquired through special education allows has certainly opened more doors for our daughter than we had originally expected. I remember she would talk about moving out of the house one day. The thought just terrified us as parents. But it wasn’t until recently that she moved out. She may not be living on her own, but the fact that she’s able to have a life of her own living in a group home gives her the independency she would always talk about. Now she is talking about having a family one day. As parents we are forever grateful for the people that supported us. We’re glad that she was able to be a part of special education instead of putting her into a regular program where she would not have succeeded. If they didn’t have that they would not have a chance to grow. It’s important for their self esteem and self growth. They would not be smart as they
are. She didn’t have those opportunities she would be a different person today. It would be a different world for her.

Another family’s experience with special education and going on a field trip helped their daughter become more responsible as an adult. They emphasized the power of one single event.

I remember there was this one incident where our daughter took a field trip to ARCO Arena to see the Sacramento Kings with her school. Chris Webber had signed basketballs and gave them to a few of the kids. Our daughter was fortunate enough to get one. On the way home when she was on the bus playing around with her peers someone had stolen the autographed basketball from her. My wife tried calling ARCO but they never got back to us. The next day, she didn’t want to get back on the bus. She must not have been paying attention to let a basketball either stolen or perhaps even left on the bus. One of the worst things that she did not understand was the fact that if she’s not paying attention to her belongings, more than likely someone will steal it. It was maybe the only most traumatic things she has experienced growing up, but she soon learned to take more responsibility. Now she is very cautious of her belongings.

Being in special education sometimes meant being in a classroom that was located in the corner of the school that was separate from the rest of the kids at school. It also meant the other kids knew that someone was in special education if they were in either the portables or a different section of the school. One particular parent shared her story of
her daughter who would come home crying. The sad part about it is that she was also teased by her peers who were in the same classroom, but higher functioning. The mother described her daughter’s experience as being traumatic by stating:

I remember when she would come home from school and she would go straight to her room and cry. When I asked her what was bothering her, she would tell me the kids would tease her by making fun of the way she talked and dressed. Sometimes her own classmates would pick on her and make fun of the way she looked. My daughter could not wait to leave high school. She said she didn’t want to go to school anymore and face the mean kids. She simply wanted to make friends but it was hard. It came to a point where we had to move her to a different school. We didn’t want her to hate school. Schools should be a place where kids don’t have to worry about being teased. It came to a point where my husband and I decided to move her to a new school so that she can start fresh and make new friends.

Acceptance

Accepting the fact that your son or daughter has a developmental disability is never easy. For some parents it can take months and for some years. One parent was reminded of the early years when she would volunteer in her son’s classroom to help. This is what she said:

I remember having a normal pregnancy and birth of my son but recognized developmental milestones. It was hard when he was six and we requested an
assessment to determine where he should be placed appropriately. It was very
disheartening when we found out that his intellectual functioning was within
range of mild retardation. But I knew my husband and I were not going to give up
so soon. I gave up a few days out of my work schedule and volunteered in my
son’s classroom because I knew as a mother he was more successful in a smaller
class setting where he can receive more individual attention.

Another family was not prepared to have a daughter that was going to be in
special education due to her developmental disability, but the parents were strong willed
and quickly accepted the fact and moved forward. The father stated:

As a parent, we feel that there’s your baby. No one wants anything like this to
happen to their kids, but they are unpredictable things that happen. She was pre-
mature at birth about six weeks early so that could’ve been part of it. But until
you hear from the doctor you feel sad and sorrowed and it could have been
something different and something that could have been better. You know, a little
disappointment, you can’t change that, you have to learn to live with it and you
deal with it.

Other parents find it more difficult to accept and cope with having a child with a
developmental disability. I found one parent’s story that was different from all the other
interviewees. This is what the father had to say:

When my wife and I referred our son to Alta California Regional Center, who we
have been told by a doctor, school staff, and a family friend, we were interested in
having additional testing completed to determine the source of his developmental
delays. I have to admit, we were quite frustrated and concerned about our son’s
delay. We have an older child and have reported that our son was developing
much differently from his older sibling. Our son was served through Sacramento
City Unified School District in special education two days a week. He was
attending speech classes at Martin Luther King Elementary school. My wife and I
were concerned with our son’s schedule. We believe that he will not adapt well to
an afternoon schedule as he typically requires a nap in the afternoon. We’ve
always thought of our son as the baby in the family so we have never been led to
believe that he had developmental delays at the time. Our son would be defiant at
times, but what kid is not defiant at times. My relationship with my son is
somewhat different as opposed to his relationship with his mother. I expect more
from my son and my wife is more of the helping type for our son. What I don’t
understand is how he could have autism in the beginning. There were no problems
or difficulties with the pregnancy or labor. Growing up for our son he had a slight
delay with potty training. It was not until our son was two that he used single and
up to two words together to communicate. We had to dress our son or at least help
him out. Our son had difficulty with fasteners and understanding the order of
clothing when it comes to putting them on. For example, he may put his pants on
and then attempt to put his underwear on. He would also use one or two words to
communicate with others. He had difficulty with his fine and gross motor
activities, and engaged in parallel play versus interactive play. He played with toys growing up but used his imagination in making up games with toy cars, trucks, etc. Even with speech therapy our son had a difficult time carrying on a conversation. It has taken us a long time to accept that he has a developmental disability, but we’re still counting on that he will be able to do more than what he is already capable of doing now.

Although the family mentioned now they accepted their son’s disability, I found out that the goals that they wanted for his son did not seem realistic. Their son had just turned 20, but the parental goals did not seem to match his current functioning level. This is what the father had to say: “I want my son to be employed part time in the community…” “Within two years of exiting school he will be employed full time in a community office occupations environment with or without supports.” “My son will be able to utilize public transportation to go to and from work.” “He will also be able to attend one to two community based activities per week.” “In two years my son will be ready to live independently.”

Based on my observations during the interview, their son did not say a word. It seemed as though the son was in his own little world oblivious to what his father was talking about. The things that the father mentioned seemed like aspirations that did not have a high likelihood of being realized.
Views of Professionals

Overall, the sample expressed positive sentiments about helping professionals. “Having the Alta worker right by our side felt like we were not alone in facing some of the issues that we’ve had. Even fears…” “I think that summer camp is great for those who are very shy and who have never really been away from home. It gives the kids a chance to be individuals and venture out into the world that there’s more to just being developmentally disabled. The possibilities are endless.” “I don’t know what I would do with Alta.” “My experience with the agency has been positive. In the planning team meetings and including educational planning team meetings. The service coordinator’s input is just as valuable as my wife’s.” “When we’re gone, I hope that my son will be taken care of just like they have been throughout his life.”

The parents included their awareness of multiple professionals that were involved with their child’s life. Most of the families spoke about at least one of the following professionals: pediatricians, psychiatrists/psychologists, teachers and social workers. One family shared how the school district officials, including the teachers, helped guide them each step of the way up until their daughter graduated from high school with a certificate of completion.

Everyone that we dealt with has really been good. Speech therapy and physical therapy were available to us because her motor skills and flexibility were limited. Her balance was off. Her arms could not reach behind her head. She challenged herself to be more physical in different things and holding things. So getting into
those classes, she challenged herself. With therapy we were able to find more things of what she was able to do and not do which helped us a lot. School officials helped guide us each step of the way. We also did our part in doing our own research to best help our daughter. We didn’t know her capabilities until she interacted with other kids as well. We didn’t know what her limitations were but we tried our best to push her to help her succeed in school. We felt good that there were people out there that were willing give their time to guide special kids. With people helping her, she was not restricted with the things she can do with her life. The family even expressed feelings the sense that teachers were very concerned with obtaining every possible resource for their child.

The school district had a good ratio of teacher to student. They always tried to teach the kids their personal responsibilities. They showed them that there were more than just the people in the classroom. They try to interact with them with society. They all did well.

Two families reported their feelings regarding the experience they had with the Service Coordinators at Alta California Regional Center for their son or daughter. The following mother disclosed her experience when her child was first diagnosed with a developmental disability.

It was not easy for me and my husband when we found out that our baby was developmentally disabled. I have never dealt with this kind of situation before. I did not know where to start or where to go. I have always heard of kids that had
Down Syndrome or were developmentally disabled. When I first met with my son’s Service Coordinator, she helped me get him speech therapy right away. The time it took for services to begin was faster than I had expected. She explained a little more information about my son’s disability. At the time, I didn’t know such services even existed. She explained the services that my son could qualify for as he got older. Her demeanor towards me made me and my husband felt like I was talking to a family member instead of a professional or just another doctor who lacked empathy.

The following is another family who has had services for quite some time that are happy with the services that were provided for their daughter.

Alta Regional was a very big influence on our child’s life. My wife at the time didn’t know if she was ever going to talk, be able to walk, and socialize with people. They helped guide and show us the differences in the courses and directions that we wished to pursue and to the best interest of our child. Things like camping, work programs, school, after school program, and overall guidance each step in her life. The summer camp is invaluable. It got her to be more independent when she would go to summer camp. It was her time away from family and she made new friends and looked forward to each year. It really helped her grow as an individual. Having a job for my daughter gives her a sense of importance which is good for her self-esteem. The school had a big role in her development as well. They always encouraged my daughter to try new things
when we had the IEPs and to push her even more academically. She may never learn how to multiply or divide, but she can do simple addition and subtraction. To us that is a big deal and a big improvement.

Three out of the five families interviewed depicted the communication between the parents and the school district as being wonderful. One mother stated:

Whenever we had an IEP meeting the school district will always ask me who are all part of the planning team and that usually included the social worker from Alta Regional. At the age of four, we started to work with the school district and it’s been wonderful. The school district coordinator has gone above and beyond what we have expected. The teachers push our child to their potential which we think is great. There is nothing bad that I can say about the district.

The consensus, as has been depicted in the previous statements, is that the parents were happy with the services being provided by professionals within in the school district as well as Alta California Regional Center. However, the parents also played a part in the success they believed their children have attained. This success was accomplished by the parents becoming actively involved in the everyday life of their child. According to the mother, she and her husband have found services such as behavioral interventions to be extremely helpful and facilitating significant growth in their son. The experience was stated by one of the parents:

I was glad that we were able to contribute our input to the planning on our son’s behalf. There has been a tremendous gain in his growth. The speech therapist has
helped our son communicate his wants and needs. It may not be where we want him to be, but it is so much better than how he was before. When my son is not motivated he will just sit there. The teachers have motivated him in a way he could use his skills more than he would otherwise. The aide in the classroom that sat with our son has also been helpful. I remember way back when the teacher mentioned that our son has shown gains in his level of compliance and his communication skills. The teacher says it was because of us and our understanding how to functionally analyze his behavior and to intervene appropriately. The behaviorist had concerns for our son’s future, in that he will likely continue to engage in non-compliant escape and avoidance behaviors, but if we have the tools as parents to help us guide him, we can be successful.

Changes in Life

In the qualitative interviews conducted by this researcher, all of the families that were interviewed had mentioned that they had to give up a career, a goal, or something that they were pursuing in life in order to be with their child and take the extra time to raise him or her. In addition, parents started doing research to find out more about their child’s diagnosis and how they could better help their child.

When my child was diagnosed with autism, I knew it was not going to be easy. I knew that it will be difficult for my husband and I. So I decided that one of us will have to stay home and care for our child. We were fortunate enough that even if one of us stayed at home, we were still able to live comfortably. I did not feel
comfortable having our son not having the support he needed. It was hard because I was giving up my career working for the state for thirteen years, but my son came first. When I stayed home, I was focused on researching about available resources for my son. I wanted to know the services available for him and what each can do for him. The research that I did was a part of me. I had to know that my husband and I were doing everything we can for our son.

Every family reported that they needed to learn more about what accompanied the diagnosis in order to better assist their children and assure that they were receiving the services they needed. All the families that did research on their child’s diagnosis were from more affluent neighborhoods.

Three out of the five families had aspirations of having their son or daughter go to a college or university and pursue higher education. When their son or daughter was diagnosed with a developmental disability they were sad. They could not see past high school for their children, but after their child was in special education, they saw that there were more opportunities beyond high school for their child. The parent stated:

After she graduated from high school and she received her certificate of completion we met with our Alta worker to find out what services were available for our daughter. The Alta worker was very patient with us in showing us the different programs that were available. He discussed the different vocational programs, adult day programs, work programs, etc. Our worker gave us a better
understanding of what kind of future lied ahead for our daughter. We actually had more options that we have ever anticipated.

Another family who had two kids found it difficult raising two kids especially when the older one did not have a disability and the younger one did. It made it difficult for the parents to explain to their inquisitive developmentally disabled child why he was different from his older brother.
Chapter 5
CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

Conclusions

The purpose of this study was to explore educational experiences of clients with developmental disabilities. There is limited literature regarding what parents and students go through on a daily basis when they are involved with the educational system as well as special education. This researcher sought to hear and analyze parent stories regarding the experience of parenting for a child with a developmental disability as well as guiding that child through special educations.

The common theme in the literature on educational experiences of clients with developmental disabilities suggests that there are many parents that find it hard to accept that their child has a diagnosis of being developmentally disabled. There are stressors that come along with it. New responsibilities arise for parents and they must plan for a different future for their children. Furthermore, parents often know what is best for their children. Despite the stressors and obstacles that they may incur along the way, parents of clients with developmental disabilities have a support system which helps with coping.

There were five families that participated in this study. The population was a convenience sample with all off the clients coming from the Adult Alternative Living Unit at Alta California Regional Center ages 18-25 years. The parents interviewed had children at one time or another in special education. The parents that were contacted to participate in the researcher’s study were married male-female couples; three of the
interviews conducted included both the parents; the other two were solely the mother. The interviews were constructed in such a way that the families were able to share with the researcher their stories and experiences as a parent of a client who has a developmentally disabled.

Ann Boushey (2001) states, “there is a third event just as distressing and devastating as divorce and death…the word is “disability” (p. 27), and disability may be described as a parent’s worst nightmare. Once the family becomes aware that the child has been diagnosed with a developmental disability, the family goes through a tumultuous array of emotions and stressors.

I have found that parents’ involvement in their child’s life has led to their success. I find it compelling the resiliency of the children’s success despite the obstacles that they and their families’ undergo. For the parents, instead of seeing their child with a developmental diagnosis as a death sentence, they saw that their children had a future past high school and became more optimistic with their child’s future.

Family support is a key factor in raising a child with a developmental disability. The stories that the families have shared could perhaps be a model for other parents out there who are struggling with their developmentally disabled child.

Implications

It is important that professionals and parents to identify the socio-emotional needs of parents who have children that are developmentally disabled and in special education. Awareness and education training on this topic should be available for both families and
professionals to help increase the awareness and promote change for a better overall well-being of clients that are developmentally disabled. A collaborative relationship needs to be established between the professionals in education and the families who are affected by a family member who has a developmental disability. Professionals need to recognize the needs of parents and the stressors that they carry with them on a daily basis. The schools should be responsible for taking the initiative to learn from the parents; their experiences of having a child with a developmental disability that’s in special education.

Recommendations

It would be beneficial for future research to struggle with schools and service delivery who work with children with diverse developmental levels and diagnosis. Perhaps if more money was offered as an incentive for the interviews, the researcher would have received more responses from a more diverse ethnic and socio-economic background. In addition, interview parents who have struggled with the special education system who are not happy with the services that are being provided for their children. In doing so, professionals will be able to recognize specific educational needs of individual students to better their educational experiences and further their education. This recognition will hopefully have a greater sense of insight and understanding that accompany of having a child with a developmental disability who is enrolled in special education.
APPENDIX A

Consent Form

Parent(s) Phone#_______________________

Consent and Agreement Form

I am being given the opportunity to volunteer to participate in a project conducted through California State University Sacramento. The purpose of this study is to understand the educational experiences of clients with developmental disabilities. This study will give a greater sense of insight to the experiences parents of students with developmental disabilities and their experiences. This will be done by completing an interview with a Master’s level student at your convenience.

By choosing to participate, I will provide the researchers with demographic information and life experiences. My name will not be connected with the information I provide, but will be replaced with a number and letter to maintain my anonymity. If such an experience may arise, I have the option to process it with the researcher. You may consult the list to receive services should you be distressed after this process.

I understand that the risk associated with participating in this study will be no greater than those encountered in my daily life. As previously stated, the researchers will not use my name in any of the material collected and the audio tapes will be destroyed once all research is complete. All of my pertinent information, including my responses in the interview, will be kept absolutely confidential unless meeting the criteria outlined in the “Information and Consent Policy” that has been reviewed with me by the researchers.

Refusal to participation in this study will have NO EFFECT ON ANY SERVICES that I may be entitled to from Alta California Regional Center. I am FREE TO WITHDRAW FROM THE STUDY AT ANY TIME WITHOUT PENALTY. I will be given a copy of this form to keep. If I have any questions at any time during the study, I may contact Andrew Bein at the CSUS Department of Social Work (916) 278-6170.

Respectfully,

Ronald Quilacio, B.A.
I have been given information about this voluntary research study and its risks and benefits. I have had the opportunity to ask questions and to have my questions answered to my satisfaction. I freely give my consent to participate in this research project.

______________________________  _________________________
Signature                                      Date

______________________________  _________________________
Signature                                      Date
APPENDIX B

Research Questions for Parents

1. What feelings arose in you after your child received his or her diagnosis? Before your child’s enrollment, had you heard of Special Education?
2. What changes occurred in your family when your child was enrolled in special education and when your child started special education?
3. What do you feel has contributed to your child being in special education?
4. What have been challenges for your child while being enrolled in Special education?
5. How have you and your family coped with your child being in special education?
6. To what degree did you have a support system? If there is or was not a significant support system in place, why not?
7. Please describe your relationship and communication with your child?
8. What services has your family received in this community and what has been your experience with those agencies?
9. What has been the families’ experience with your child’s school/therapy?
10. In what ways have you had to advocate for your child?
11. How do you feel the school officials within the field could better assist your needs?

Demographics Questions
- How old was your child when they first enrolled in Special Education?
- What is your child’s gender and your family size?
- What is your family’s ethnicity/culture?
- Has your family had to relocate in order to access services?
- If your comfortable, would mind telling me your child’s diagnosis?
REFERENCES


