FACTORS AFFECTING PLACEMENT OF INDIVIDUALS WITH
DEVELOPMENTAL DISABILITIES

A Project

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MASTER OF SOCIAL WORK

by

Rachael Anne Bernath

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Rachael Anne Bernath

Approved by:

__________________________________, Committee Chair
Francis K.O. Yuen, DSW, ACSW

____________________________
Date
Student: Rachael Anne Bernath

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__________________________, Graduate Coordinator

Dale Russell, Ed.D., LCSW

Date

Division of Social Work
Abstract

of

FACTORS AFFECTING PLACEMENT OF INDIVIDUALS WITH
DEVELOPMENTAL DISABILITIES

by

Rachael Anne Bernath

The population of individuals with developmental disabilities has steadily risen as longevity has increased and definitions of developmental disability have expanded. With this increase, the need for services and supports that meet the unique needs of this population has grown. Once housed in large institutions that provided bleak custodial care, the normalization movement begun in the 1960s, has resulted in efforts to integrate this group of individuals into society. This has necessitated a variety of services and supports to meet the needs of these individuals and their families in settings that range from in-home care with family, to living out-of-home, independently, or in community-based facilities. The primary purpose of this study was to examine factors that impact the decision to care for individuals in-home or to seek out-of-home placement; data was collected via a survey of parents and primary caregivers of individuals with developmental disabilities from a small sample in Yolo County and the greater Sacramento region. Findings from this study suggest a combination and accumulation of factors determine placement of individuals with developmental disabilities, rather than a single deciding factor. This study also found Hispanic/Latino parents or primary
caregivers to be more likely to care for their loved one in-home, while White respondents placed their loved ones with developmental disabilities out-of-home more frequently. With increased knowledge and a better understanding of the various factors and cultural dynamics associated with caring for individuals with developmental disabilities, service providers may better address their unique needs.

__________________________, Committee Chair
Francis K.O. Yuen, DSW, ACSW

__________________________
Date
DEDICATION

I dedicate this project to every individual with developmental disabilities I have been blessed to know or work with, and to all those I will have the joy of knowing in the future. I am better for this.
ACKNOWLEDGEMENTS

I am forever grateful to my family, friends, professors, and field instructors, who have encouraged, supported, loved and stood by me through this process. I am most thankful for my parents, James and Holly, who instilled the desire and drive to push myself and pursue my dreams. To my sisters, Janelle and Emily, who listen and talk just the right amount – you rock! To the loveliest nieces in the world, Kali, Maelina and Eden, and the spunkiest nephews around, Isaiah, Milo and Alexi – you all light up my life! To Paula Bosler, LCSW, the finest social worker I know – thank you for your guidance and wisdom as I found and navigated the path to professional social work. To Dr. Francis Yuen, whose excellence and wit made this program stellar, and who helped guide this project – done is good! Lastly, I give great thanks to my Woodland Residential Services and Summer House families – with you, my life has been enriched and my heart has been filled. ♥
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Chapter 1

INTRODUCTION

In addition to the duties and challenges that come with raising children, parents of children with developmental disabilities face a variety of issues unique to their role. They must address day-to-day educational-, health-, social-, and financial-related responsibilities involved in rearing a child, as well as additional tasks in each of these areas to ensure the child’s disability-related needs are being met. At some point, the question of whether to care for the individual in-home or to seek out-of-home placement, will inevitably arise. Several factors such as family dynamics, health of the child and/or parent, cultural, or financial reasons, determine if and when the question surfaces, though additional factors related to demographics and coping skills also influence the decision families ultimately make.

Background

As a result of the shift toward promoting autonomy and normalization for individuals with developmental disabilities, there has been a significant increase in placement options available, with the plan of a minimally restrictive living environment being the primary goal. While this is clearly a positive change that bodes well for life satisfaction of the individual with developmental disabilities, it has resulted in a more complex decision-making process for the parents and family members of the individual with respect to the best possible placement in the least restrictive environment. This decision-making process can be stressful for parents, family members and the individual with disabilities alike, as the family works to sort through and understand resources
available to them. The added pressure of doing what is best for the individual in the long-term, has the potential to increase this stress to an even greater extent.

The period of transition when a child moves away from their parents’ home can be a trying time for all involved regardless of reason. For the parents of a developmentally disabled child, the transition process can be fraught with an abundance of emotions including guilt, apprehension, relief, joy or sadness. Depending on the age of the child, whether it is during the infant years, elementary age, the normal transition years, or even into older adulthood, there are a significant number of factors that influence the decision to care for a loved one in-home or to place them in an out-of-home setting.

The complexity of this decision-making process makes it such that it should not be done without knowledge of options and emotional support throughout. Unawareness of resources and options such as respite or in-home support services, day programs, and supported living services, can result in a decision that may be regretted later, or which does not serve the best interest of the individual with developmental disabilities. In order to make an informed decision, parents and/or family members require support from additional family members, professionals and social service agencies.

Identifying key factors that influence the decision-making process, and examining how they impact the lives of parents, opens the door for further studies to examine the quality and effectiveness of services that assist with placement decisions. This type of research can guide education of both service providers and parents or primary caregivers who will be utilizing the services, decreasing the level of stress for all involved.
Statement of the Problem

As a vulnerable population, individuals with developmental disabilities are a group often served by social workers. Recent shifts toward normalization and integration into the community have resulted in an increase in types of services offered and placement options available for individuals with developmental disabilities. While this is clearly a progressive step in the right direction to benefit those being served, it potentially opens the door for a more complex and time-consuming decision for parents and primary caregivers with regard to the best option for their loved one. This has resulted in a critical need to recognize key factors which influence the parent or primary caregiver in their decision to care for the individual in-home or to seek out-of-home placement, so as to design and implement services that will better address their complex and unique situations.

Purpose of the Study

The primary purpose of this study is to identify those key factors that influence a parent or primary caregiver’s decision to care for an individual with developmental disabilities in-home or to seek out-of-home placement. By identifying these factors, professionals and parents alike will have a better understanding of considerations during the process and a greater awareness of what options are available, leading to more informed decisions. Likewise, agencies serving individuals with developmental disabilities and their families will be better prepared to offer services and supports to them. This will ultimately result in a reduction of stress experienced by those faced with
the decision and will increase the likelihood of the individual living in a setting that fosters an optimum level of well-being.

**Theoretical Framework**

This study utilizes concepts from the Ecological Systems Theory, the ABCX Model of Family Stress, and the Double ABCX Model of Family Behavior. Ecological Systems Theory lays the framework for the notion that parents and members of families with developmentally disabled children are part of systems on the individual, family and societal levels, all of which are interrelated and influence the other. The ABCX and Double ABCX models of family stress and behavior explain the family experience in terms of stress, family coping styles and resilience during stressful periods such as that which can arise with the presence of a developmentally disabled child in the family.

Ecological Systems theory calls for the examination of individuals as a unique product of the interrelated systems in their environment on a micro, meso and macro level. Germain and Gittermain (2008) explain ecological theory as a holistic view in which:

People (and their biological, cognitive, emotion, and social processes) and physical and social environments (and the characteristics of those environments) can be fully understood only in the context of the relationship between and among them, in which individuals, families, groups, and physical-social environments continually influence the operations of the other (p. 52).

Psychologist, Urie Bronfenbrenner, in his 1979 book *The Ecology of Human Development* proposed that in order to better understand human development, the
interaction between a child and his or her environment must be examined.

Bronfenbrenner suggests children have a variety of personal characteristics that are “developmentally generative- capable of influencing other people in ways that are important to the child” as well as “developmentally disruptive- capable of causing problems in the environment with corresponding negative effects on the child” (as cited in Vasta, Haith & Miller, 1999, p. 50). This suggests that to best understand the function or dysfunction of an individual or a system, all parts of the sum must be examined to determine their role. Viewing the individual in the context of his or her whole surroundings, including domains such as the family system, school environment, and culture, allows the impact of each factor to be more clearly understood with regard to function or dysfunction.

The importance of viewing clients from a person-in-environment perspective and recognizing the multiple systems that affect an individual’s life, are both stressed in the field of social work in order to promote optimal social functioning (Gittermain & Germain, 2008). The interrelatedness of systems and factors of resilience are both key themes in the field, and as such, have important implications with regard to practice with the developmentally disabled population to promote optimal functioning. This is especially relevant in relation to the family experience and how it relates to the decision to care for the individual in-home or to seek out-of-home placement. Naturally, harmony within a system will promote the sought-after optimum level of functioning, while imbalance within or among any of the systems will have a ripple effect and thus
consequences, either positive or negative, for each member including the individual with disabilities.

Reuben Hill’s 1958 ABCX Model of Family Stress, is widely used as the guiding framework for research involving families and mental retardation or developmental disabilities. Hill developed the model to describe the stress experienced by families of soldiers during wartime (Blacher, 2001) but the model has been found useful when generalized to various other aspects of the family experience, including how parents of developmentally disabled children cope with the stressors that come with raising such a child. This model suggests three main factors – a stressor or stressful event (A), the family’s existing resources and supports (B), and the family’s perception of the stressor or event (C) – are what contributes to crisis within the family (Webber, 2011).

McCubbin and Patterson’s (1983) Double ABCX Model of Family Behavior expands on Hill’s ABCX Model by looking at the family’s ability to cope and essentially regroup after a crisis (see Figure 1). In this model, post crisis pile-up (a), existing and new resources (b), and the perception of these factors (c), in response to the original crisis, all interact with parental coping strategies. How they interact results in either balance or imbalance in family functioning (McCubbin and Patterson, 1983; Webber, 2011). McCubbin and Patterson (1983) described pile-up as stemming from five sources: 1. The initial stressor; 2. Chronic strains that result when the original stressor is persistent or unable to be resolved (such as a disability in the family); 3. Normative transitions or changes such as parenthood or midlife changes; 4. The coping behaviors used in response to the crisis; and 5. Ambiguity within the family and society (McCubbin and Patterson,
1983, p.94-95; Webber, 2011, p. 87). McCubbin and Patterson (1983) purport that balance in family functioning results from the ability to cope with and manage family life changes related to the pile-up of stressors, and overt efforts to continue on as a family unit.

(Gaudet, L. and Powers, G.,1989)

**Figure 1** Double ABCX model of family behavior.

The manner in which a parent perceives a child’s disability, their propensity to utilize available resources, and their aptness to seek outside support, are all critical factors in the function or dysfunction of families of developmentally disabled individuals. Both Hill’s ABCX model, and McCubbin and Patterson’s Double ABCX model, are ideal for studying families with developmentally disabled children, as the initial diagnosis and subsequent stressors related to raising an individual with such disabilities have the potential to create crises. Responding to such crises calls for a certain amount of
resilience and ability to adapt on the family’s part, but also highlights the importance of the need for external supports and resources provided by knowledgeable service providers.

**Definition of Terms**

**Normalization**

“The utilization of means which are as culturally normative as possible, in order to establish and/or maintain personal behavior and characteristics which are as culturally normative as possible” (Wolfensberger, 1972, p. 28).

**Developmental disability or developmentally disabled**

This term will be used in accordance with the federal definition but may also be used interchangeably with the terms: intellectual disability or intellectually disabled, mental retardation or mentally retarded.

**Child**

This term will be used to refer to a relationship - any individual, living or deceased, who was born to a mother and/or father, or for whom one acts as a primary caregiver, regardless of age or legal status.

**In-Home Care**

This term will be used to refer to a primary living arrangement in which the individual with developmental disabilities resides with and is cared for by a parent, family member or other person in the primary caregiver role. The use of in-home supports such as respite services does not exclude the individual from falling into the in-home definition.
Out-of Home Placement

This term will be used to refer to any of the following types of living arrangements, in the Yolo and Sacramento counties for individuals with developmental disabilities from October 2000 until the present:

- Adult Residential Facility (ARF)
- Independent Living Services (ILS)
- Supported Living Services (SLS)
- Skilled Nursing Facility (SNF)
- Intermediate Care Facility (ICF)
- Developmental Center (DC)
- Foster Care (FC)

Assumptions

This study is based on the assumption that there has been a general acceptance of the movement toward normalization in the United States, in which individuals with developmental disabilities have been steered toward living environments that are considered to be least restrictive in nature and promote an optimum level of functioning. Additionally it is assumed that parents or primary caregivers raising individuals with developmental disabilities face additional tasks and stressors not experienced by those of their non-disabled peers. It is assumed that professionals in the education and social service sectors of society, along with the parents or primary caregivers of individuals with developmental disabilities, are key players in determining whether in-home care or out-of-home placement is warranted and in the best interest of the individual.
Additionally, support in the decision-making process can potentially decrease the amount of stress experienced by both the parent and the individual alike.

**Justification**

Social workers play an important role in the lives of individuals with developmental disabilities through advocacy, case management, service coordination and in direct clinical practice. In addition to working directly with individuals with developmental disabilities, they have the additional responsibility of working with parents and primary caregivers of these individuals, to ensure their overall wellbeing and functioning is at an optimum level. Increased awareness of the factors that play a role in placement decisions will lead to efficient and effective service delivery to all involved parties. This in turn will result in smoother transitions and long-term security for individuals with developmental disabilities.

**Limitations**

This study focused on the experiences of a small number of parents and primary caregivers of individuals with developmental disabilities in Yolo County and the greater Sacramento region. While findings may be consistent with those of other larger studies, they cannot be generalized to the greater population.
Chapter 2

LITERATURE REVIEW

This literature review analyzes the multifaceted decision-making process faced by parents or primary caregivers of individuals with developmental disabilities, when considering in-home care or out-of-home placement. The review will examine common experiences reported by persons who are raising or have raised an individual with developmental disabilities, as well as factors identified through various studies as being significant in the caregiver’s choice of whether or not to place the individual outside of the home.

Additionally, a historical perspective of the experiences of developmentally disabled individuals, and key pieces of legislation in the United States are considered to demonstrate how changing perceptions of this population have directly influenced the decision-making process.

An out-of-home setting can vary from an independent or supported living arrangement, an intermediate care facility, skilled nursing facility, developmental center or foster care home. Determination of the type of setting best suited for an individual is based on their abilities, disabilities, both cognitively and physically, as well as the level of care needed, whether it is medical, physical, or behavioral in nature.

Research has shown the decision to place or not to place an individual out-of-home is influenced by a multiplicity of factors including emotional ones such as fear, guilt, and relief when a decision is made; but also practical issues that might include the ability to support the child financially or even physically. Decisions are certainly made
with the ultimate intent of maintaining or improving the well-being and comfort of the individual, as well as for the parents and family as a whole. While the complex decision-making process cannot necessarily be made simpler, with the help of education, community resources, and support, it portends to be a less strenuous process for parents and the individual with disabilities alike.

**Defining Developmental Disability**

The term, *developmental disability*, is a blanket term whose meaning varies depending on the author defining, but generally encompasses a range of mental and physical conditions, some of which are more commonly known, such as Cerebral Palsy, Down syndrome, Autism, and mental retardation, as well as other less common conditions such as Phenylketonuria (PKU) or Williams syndrome (National Organization for Rare Disorders, 2011). *Developmental disability* became a widely used term for individuals previously labeled as mentally retarded, after the enactment of Public Law 91-517, The Developmental Disabilities Services and Facilities Construction Act of 1970 (United States Department of Health and Human Services, 2002). This federal piece of legislation sought to improve the well-being of individuals with developmental disabilities who had long been housed in large institutions, separate from the larger population. The term is often used interchangeably with the terms *mental retardation, developmental delay, and intellectual disability*. These have replaced terms now considered insulting to such individuals such as: *idiot; feeble minded; mentally deficient; mentally handicapped; and mentally subnormal* (Schalock et. al, 2007). As attitudes toward this population shifted and a movement toward normalization gained momentum,
efforts were made to use common, person-centered terminology that promoted dignity and worth of the individual rather than focusing on the disability.

According to the United States federal government, as defined in Public Law 106-402, The Developmental Disabilities Assistance and Bill of Rights Act of 2000, the term developmental disability, refers to:

- a severe, chronic disability of an individual that-
  - (i) is attributable to a mental or physical impairment or combination of mental and physical impairments;
  - (ii) is manifested before the individual attains age 22;
  - (iii) is likely to continue indefinitely;
  - (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:
    - (I) Self-care.
    - (II) Receptive and expressive language.
    - (III) Learning.
    - (IV) Mobility.
    - (V) Self-direction.
    - (VI) Capacity for independent living.
    - (VII) Economic self-sufficiency; and
  - (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of
assistance that are of lifelong or extended duration and are individually planned and coordinated.

(United States Department of Health and Human Services, 2011)

Individuals seeking services provided by the federal government must meet these criteria, though the federal government allows individual states to establish their own definitions to best meet the needs of their population. According to section 4512 of the California Welfare and Institutions Code, also known as the Lanterman Developmental Disabilities Services Act of 1969 (Lanterman Act), a developmental disability is considered to be:

A disability that originates before an individual attains age 18 years, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual. As defined by the Director of Developmental Services, in consultation with the Superintendent of Public Instruction, this term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, but shall not include other handicapping conditions that are solely physical in nature (California Department of Developmental Services, 2008).

Alta California Regional Center (ACRC), a product of the Lanterman Act, which serves Sacramento and surrounding counties, determines eligibility based on criteria defined in the Lanterman Act, but also offers services to those at risk for developmental disability. Alta California Regional Center’s eligibility criteria states “An infant or
young child under age three may be accepted by the regional center as ‘high risk’ because of a significant delay in one or more developmental areas, because of medical problems and complications, or because one or both parents has a developmental disability” (Alta California Regional Center, 2011b).

**Prevalence of Developmental Disabilities**

As longevity of the population as a whole increases, so too does the prevalence of individuals with developmental disabilities. In 1931, the average life span for individuals with disabilities was 15 years for males and 22 years for females (Carter & Jancar, 1983 as cited in Heller, Caldwell, & Factor, 2007). In the 1970s, the mean age at death for individuals with developmental disabilities was 59 years. This increased to 66 years by the early 1990s (Braddock et al., 2005). Also potentially affecting prevalence is the variation in definition of what qualifies for a diagnosis of developmental disability. The federal definition requires the diagnosis be made prior to age 22, while the state of California only recognizes individuals as developmentally disabled if the disability is diagnosed by the age of 18. Differing criteria such as this, results in a varied representation of the prevalence of developmental disabilities in the population.

The California State Council on Developmental Disabilities reports, using the Gollay and Associate national prevalence estimate that 1.8 percent of the nation’s population meets the federal definition of having a developmental disability. Using this standard estimate, of the 308,745,538 individuals reported to live in the United States during the 2010 census, more than 5.5 million of the United States population have a developmental disability of some type. California’s population reported by the 2010
census was 37,253,956, and using the same estimate from Gollay and Associate, approximately 670,571 California residents meet the criteria for having a developmental disability (State Council on Developmental Disabilities, 2011).

As of July 2011, there were 17,303 clients with developmental disabilities being served by Alta California Regional Center, which covers the greater Sacramento region and several surrounding counties. Of the 17,303 clients receiving ACRC services, 11,180 of these clients lived in Sacramento County and 1,123 lived in Yolo County (ACRC, 2011a).

**Institutionalization, Deinstitutionalization, and Normalization**

Placement trends for the developmentally disabled population in the United States have shifted over time. Once housed in large, overcrowded institutions away from their communities, many individuals with an array of developmental disabilities now live amongst their non-disabled peers in a variety of settings within the community. This includes with immediate or extended family members, alone in the community with supportive services, in smaller community-based group homes, or in skilled nursing facilities where their roommates and neighbors may or may not have developmental disabilities. This is congruent with the normalization ideology that suggests that normative environments—those that are home-like and age-appropriate—will result in more normal behaviors (Landesman, 1987).

Dating back to the mid-1800s, a movement began to house the country’s developmentally disabled population in settings similar to boarding schools or small-scale institutions. These facilities were intended to not just house the individuals, but to
educate and rehabilitate them (Bruininks, Meyers, Sigford, & Lakin, 1981). Eventually this concept was set aside as efficiency and efforts to cut costs led to larger institutions that could house greater numbers of individuals. By the 1920s, these institutions became long-term placements that provided custodial care, often with the goal of preventing mental retardation from being passed to future generations. The developmentally disabled population became isolated in the soon overcrowded institutions that were steadily declining in quality (Vitello & Soskin, 1985).

During the 1950s, the United States saw organized movements by parents and families of individuals with developmental disabilities who sought to improve the condition of these institutions. These movements eventually led to the formation of schools and sheltered workshops specifically designed to meet the needs of this population. It was during this decade that National Association for Retarded Children, now the Association for Retarded Citizens (ARC), was created (Braddock, 2002).

At the height of the Civil Rights movement of the 1960s, efforts to improve living conditions for individuals with developmental disabilities gained further momentum (Leitzell & Somppi, 1989). In 1961, President John F. Kennedy created the President’s Panel on Mental Retardation, which aimed, among other things to move institutionalized individuals back to their communities (Croser, 2002). Four years later, in 1965, a televised tour of a New York institution for individuals with mental retardation by Senator Robert Kennedy stirred the nation. Senator Kennedy and others joined to expose deplorable conditions such as poorly fed and clothed residents, individuals contained by cells and ropes, and others wandering the grounds aimlessly (Vitello & Soskin, 1985).
This prompted widespread outrage and resulted in organized efforts to not only denounce such inhumane treatment, but to do something about it. It sparked a nationwide effort toward normalization in the lives of those with developmental disabilities.

**Key Legislation Supporting Normalization**

The normalization trend and fight for equal rights of all groups that started in the 1960s, led to pressure to deinstitutionalize the developmentally disabled population and to an increase in services offered to and types of residential settings being established for this group (Landesman & Vietze, 1987). Several progressive pieces of legislation were passed in the years to follow and continue to be enacted to the present day. This has resulted in the formation of a variety of residential facilities, inclusion in the education realm, increased community access and integration, and financial supports.

Public Law 91-517, The Developmental Disabilities Services and Facilities Construction Act of 1970, required individual states to establish developmental disability councils. These councils were to be responsible for developing state plans coordinating comprehensive services for the developmentally disabled population, including grants that supported higher education programs to train persons serving this population (Paul, Stedman, & Neufeld, 1977). Amendments have since been consistently made to improve the lives of this population. Five years after Public Law 91-517, Public Law 94-103, The Developmental Disabilities Assistance and Bill of Rights Act (Developmental Disabilities Act), began supporting programs such as community housing and habilitation services that reduced the need for institutional care, and ordered states to develop plans for deinstitutionalization in their communities (Vitello & Soskin, 1985). Furthermore,
the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Public Law 106-402, calls for

The acceptance and encouragement of the presence and participation of individuals with developmental disabilities, by individuals without disabilities, in social, educational, work, and community activities, that enables individuals with developmental disabilities to: (A) have friendships and relationships with individuals and families of their own choice;
(B) live in homes close to community resources, with regular contact with individuals without disabilities in their communities;
(C) enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and
(D) take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working, and enjoying life in regular contact with individuals without disabilities.

(DHHS, 2011)

Another significant piece of legislation enacted in 1975 was Public Law 94-142, the Education of All Handicapped Children Act. Like other pieces of legislation regarding the developmentally disabled population, this law has been amended several times to improve and increase services for children with special needs in the public school system. It required all states to provide “a free, appropriate public education for all children with disabilities, regardless of the nature or severity of the disability” (Schalock, Baker, & Croser, 2002, p. 5). Amended to Public Law 101-476 and renamed
The Individual with Disabilities Education Act (IDEA) in 1990, this legislation has resulted in early intervention and school-to-work transition programs, advocacy for individual rights, and supports including transportation and assistive technology. It requires that services be offered in the least restrictive environment and guarantees this by requiring an individualized education program (IEP) for each child based on their specific needs and including the input of the parents (Schalock et al., 2002; Vitello & Soskin, 1985).

Provisions under the Social Security Act include Social Security Disability Income (SSDI), Supplemental Security Income (SSI), and Medicare and Medicaid. The provisions have provided financial support to individuals with developmental disabilities and helped stimulate growth in community-based, rather than institutionally based, supports and services (Schalock, et al., 2002). In 1971, Title XIX of the Social Security Act was amended to allow states to use Medicaid funds as a means of prompting institutions to transition individuals with developmental disabilities back into their communities by providing funding for intermediate care facilities for the mentally retarded (ICF/MRs) (Vitello & Soskin, 1985). Title XVI of the of the Social Security Act, the Supplementary Security Income for the Aged, Blind, and Disabled or Supplemental Security Income (SSI), gives monthly income support to individuals with developmental disabilities or low-income families who provide care for such individuals, again promoting community-based living as an alternative to institutionalization (Vitello & Soskin, 1985).
The Lanterman Developmental Disabilities Service Act (Lanterman Act) was enacted into California law in 1969. This law is responsible for the creation of, and now governs, the 21 regional centers in the state. These centers offer services and supports to individuals with developmental disabilities and their families, to promote community-based living as an alternative to institutionalization (ACRC, 2011). The Lanterman Act called for services and supports “available to enable persons with developmental disabilities to approximate the pattern of everyday living available to people without disabilities of the same age,” and required the individual or a legal guardian to be included in decisions made about their life (California Department of Developmental Services, 2008).

**Raising a Child with Developmental Disabilities**

Parents play a significant role in helping their child successfully move from one stage of development to another. They are the first source of nurturing and socialization for children. Raising a child with developmental disabilities brings with it added responsibilities, which include but are not limited to extra medical appointments, more intense involvement with the education system, and navigating relations with social service agencies such as regional centers and federal programs like those administered by the Social Security Administration. According to Boyle, Decouflé, and Yeargin-Allsopp (1994), children with developmental disabilities have 1.5 times more doctor visits, 3.5 times more hospital stays, twice the number of days absent from school and are 2.5 times more likely to repeat a grade in school than are their non-disabled peers (p. 399). Parents are the primary persons who respond to their needs and coordinate services for their
children. Depending on the nature and extent of these needs, this can become an enormous source of stress, or to the contrary for some, may be accepted and embraced as routine.

Adolescence is a time that involves a fading influence of parents as individuals begin establishing their own identity (Berger and Thompson, 1995). For parents of an adolescent with developmental disabilities, this normal waning in care may not occur and the role of the primary caregiver might continue into adulthood. However, the trend toward normalization has resulted in an increase in younger children with developmental disabilities remaining in-home, while the adolescent and young adult population moving into more independent, community-based settings has increased (Lakin et al, 1998; Blacher, 2001; Lakin et al., 2000 as cited in McIntyre, Blacher & Baker, 2002).

While it clearly includes stressors not likely present when raising a non-disabled child, the positive aspects of being a parent or primary caregiver of children with developmental disabilities should not be overlooked. In fact, positive experiences can also be influential when considering in-home or out-of-home placement options. Successful experience with services that support parents or primary caregivers of children with developmental disabilities in-home, may lead to a parent continuing this care. Likewise, a positive interaction with an out-of-home service supporting the individual with developmental disabilities and providing integration into the community, such as a day program, may influence a parent’s level of comfort with the idea of an out-of-home placement.
Factors Associated with Placement of Individuals with Developmental Disabilities

Current literature postulates that there are a variety of factors which influence the decision to care for a developmentally disabled loved one in-home, or to place the individual in an out-of-home setting such as a group home, skilled nursing facility, or supported living arrangement, amongst the many options available. These factors fall into different realms of normal day-to-day life including family dynamics, social, financial and medical. Coping styles, support systems of the parent(s) and/or family as a whole are also central in determining whether out-of-home placement is sought. Caregiver stress is one of the most significant factors in determining if and when a parent or loved one seeks out-of-home placement for the individual with developmental disabilities. Finally, consideration for the future of the individual can influence the decision: whether a parent foresees no longer being able to care for the individual, or because they want the child to experience the natural transitions and milestones in life.

While these areas are fundamental when raising any child, the added component of a disability all but guarantees additional tasks to maintain an equal level of well-being to that of their non-disabled peers. Some of these include: the cost of caregiving outside of what may be supplemented by programs such as Social Security or respite programs, frequent medical appointments due to compromised immune systems or degenerative conditions, and lost income when a parent is forced to take time off work to tend to their child’s needs.
Family Dynamic-Related Factors

The presence of siblings in families where one or more children have developmental disabilities affects the decision to care for the individual in-home or to seek out-of-home placement. Many parents express concern for the siblings of their developmentally disabled child having to endure the burden of helping to care for the individual, and also the effect it has on their social lives growing up (Heiman, 2002). McCullough and Simon (2011) determined four areas of difficulty for siblings of children with developmental disabilities: lack of attention, limited opportunities for affective expression, isolation from peers who also have a developmentally disabled sibling, and not enough education about their sibling’s disability (McCullough & Simon, 2011). Likewise, the ability to develop a sense of self has also been identified as being influenced by the presence of a sibling with disabilities, as the non-disabled brother or sister may receive less attention and nurturing as a result of the increased needs of their sibling with disabilities (Dyke, Mulroy, & Leonard, 2009). In families where these difficulties are experienced, it is likely parents or primary caregivers will recognize the effects and attempt to address them with internal or external supports, but in the absence of improvement will consider whether out-of-home placement may benefit the family as a whole.

The positive impact of having a sibling with developmental disabilities should not be overshadowed by potential troubles. Individuals can benefit from the presence of their developmentally disabled sibling in several ways, such as tolerance of differences in others, development of a compassionate nature, and greater level of maturity and
prosocial behavior (Dyke, Mulroy, & Leonard, 2008; Rossiter & Sharpe, 2001). For parents strongly opposed to out-of-home placement, adult siblings, usually adult sisters, are among the first family members to take over care when an elderly parent is no longer able to function in this role. This is often the hope or expectation of the elderly parent (Freedman, Krauss, & Seltzer, 1997) and can be more easily fulfilled if the aforementioned positive aspects outweigh the existence of negative ones. As such, the importance of a positive experience and relationship with the sibling with disabilities while growing up cannot be underestimated. A positive relationship growing up would be more likely to result in a strong relationship later in life, whereas resentment or perceived lack of attention or affection from the parent as a child may lead to a strained or non-existent relationship in adulthood.

Role strain can be a source of stress and dysfunction in families in which mothers, who often have the dual role of caregiver and working parent, become overwhelmed by demands and lack of caregiving tasks performed by the father (Heller et al., 1997 as cited in Heller et al., 2007). As Brandon (2011) notes, mothers of children with developmental disabilities experience a more stressful “second shift” that calls for flexibility either from employers or support from kin, both of which are not always feasible. Families in which responsibilities and workload are shared between parents are less likely to seek out-of-home placement (Llewellyn, McConnell, Thompson, & Whybrow, 2005).

Raising a child with developmental disabilities can be a challenging feat that has been shown to be positively correlated with an increased level of marital strain. Additionally, the divorce rate among parents with developmentally disabled children is
greater than for the general population (Weisz, 1996; Risdal & Singer, 2004); however, some parents report the presence of disability in the family actually improve their relationship with one another and report better communication between parents (Heiman, 2002). This is likely the case in situations in which the burden of care is shared by both parents and possibly other children. It should be noted that much of the past literature regarding experiences of families raising children with developmental disabilities assumes a two-parent family in which the mother and father are both actively involved in the child rearing process. As Levine (2009) argues, this is not representative of current trends in which many single parents, namely mothers, are raising their children without the support of fathers. While Levine (2009) notes resilience in this demographic, single mothers are reportedly more likely to seeking out-of-home placement for the simple fact of not having the physical time or finances to adequately support their child (Freedman, Kraus, & Seltzer, 1997).

Examining the experience of families with a developmentally disabled child through the ABCX Model draws attention to the capacity of families to organize into a more functional unit based on the needs of both the child with developmental disabilities and the family as a whole. As disability-related stressors such as role strain or sibling problems, arise in the family system, however, there is potential for crisis depending on how the family uses existing resources and how they perceive the severity of the stressors. As long as the child with disabilities remains in-home, disability-related stressors may arise and may eventually become what McCubbin and Patterson (1983) referred to as pile-up. The family’s subsequent ability to cope with these stressors
through acceptance as well as utilizing existing or new resources, will determine whether they can continue as a functional unit or if alternatives such as out-of-home placement for the individual with disabilities are necessary to make it functional once again.

**Child-Related Factors**

Child-related factors such as disability type and severity, emotional well-being of the child, level of function and the presence of self-injurious behavior or aggression toward others, all have the potential to impact the experience of the caregiver of a developmentally disabled loved one. While non-disabled children have routine medical check-ups, immunization schedules and medical attention as needed for general childhood illnesses such as common colds, ear infections or injuries, children with developmental disabilities often have greater medical needs due to compromised immune systems, genetic disorders, orthopedic needs and seizure disorders, among others. The way in which the parent or primary caregiver is able to manage or not manage stressors related to their child’s disability, affects the decision to care for the individual in-home or to seek out-of-home placement.

As discussed by Haveman, van Berkum, Reijnders, and Heller (1997), a child’s level of intellectual functioning, physical health problems, adaptive skills and behavior problems, have been shown to be directly correlated to the individual’s level of mental retardation, and have a significant impact on the burden parents and primary caregivers experience. Greater dependence on parents due to fewer adaptive skills, as well as the presence of behavior problems associated with the disability, increase the time demands for parents and the overall burden experienced (Haveman et al, 1997). Conflicting
evidence shows some parents and primary caregivers of individuals with mild to moderate levels of disability planned to place their loved one in an out-of-home setting at a higher rate than caregivers of individuals with severe to profound disabilities (Freedman, Krauss, & Seltzer, 1997). These conflicting findings highlight the diversity in the ability of families to adapt to and cope with their child’s disability. Some parents may feel their child will fare well in an out-of-home placement that promotes the independence of their child with mild to moderate disabilities, while parents of children with more severe to profound disabilities may feel safer and more in-control keeping the child in-home.

A number of parents and primary caregivers feel that as a child grows older, caring for them in-home as opposed to placing him or her in an out-of-home setting, will have adverse effects on the individual’s life. They may perceive the individual as having fewer opportunities for a social life as well as limited leisure or outing time, since children with developmental disabilities living in-home tend to spend time primarily with family members and friends of their parents or siblings rather than their own peers (Tabatabainia, 2003). Challenging behaviors and the difficulties that are associated with them, such as physical harm and social isolation, are reportedly one of the most common reasons for parents seeking out-of-home placement for their child with developmental disabilities (McIntyre, Blacher, & Baker, 2002).

The physical size of the child with developmental disabilities was a factor identified by Bromely and Blacher (1991) in parental decision to seek out-of-home placement. Their study found that the larger and more physically dependent the child is,
the greater probability he or she would be placed outside of the home. Physical size as a factor, in combination with Tabatabainia’s (2003) contention that parents of developmentally disabled individuals living at home tend to do more for the child than is necessitated by their abilities, suggests physical stress experienced by the caregiver may be common when raising a child with disabilities. This tendency to do more for the child than is necessary also leads to decreased independence (Tabatabainia, 2003), which goes against current the current trend toward normalization. This suggests out-of-home placement may promote increased skills acquisition and a greater opportunity for independence for the individual than may be provided in-home the individual’s parents or family members.

Blacher, Kraemer, and Howell (2010) reported disability type, specifically autism, Down syndrome, cerebral palsy, and undifferentiated learning disabilities, as a noteworthy factor in family expectations and the transition process for young adults with developmental disabilities. They discovered that parents of young adults with autism had an expectation that their child would move out of their home, while parents of young adults with Down syndrome did not have plans for their child to live outside the home or tended to care for them in-home longer. Nevertheless, Dykens et al. (2000) noted success rates in group home settings being poor for individuals with autism, but high for those with Down syndrome (as cited in Blacher et al., 2010). This study also related the possibility that the tendency for parents of children with Down syndrome to care for the children in-home, may be the result of the fact that many mothers of individuals born with the syndrome are aged 35 or older, and as a result may have more child-rearing
experience, and are likely more financially established (Dykens et al. 2000, as cited in Blacher et al., 2010). This incongruity between the desire for out-of-home placement for individuals with autism, versus actual success in such placements, supports the notion that disability type does matter. The reasons for lack of success in the group home setting may be the same reasons the parent opted for out-of-home placement.

The presence of a child with developmental disabilities is not only a source of stress, but a source of pleasure and companionship for other family members. Townsend et al. (1989) suggests that over time families establish routines and become more stable, leading to greater acceptance and harmony within the family, despite the added stressors that may remain (as cited in Heller et al., 2007). As Bronfenbrenner (1979) explains in his ecological approach, children hold an assortment of characteristics that affect their environment in positive ways in addition to potentially disruptive ways (as cited in Vasta, Haith, & Miller, 1999) and there is no reason to suggest this is not true for children with developmental disabilities as well.

**Caregiver Health-Related Factors**

Murphy, Christian, Caplin, and Young (2006) found five themes in the caregiver experience, specifically with regard to their own health and well-being. These themes were: stress of caregiving; negative impact on caregiver health; sharing the burden; worry about the future; and caregiver coping strategies (Murphy et al., 2006, p. 182). The impact of parent or primary caregiver health, both mental and physical, are central factors that determine whether an individual is cared for in-home or placed in an out-of-home facility. Compromised mental or physical health would seemingly increase the need for
out-of-home placement, though good mental or physical health does not necessarily suggest the child will remain in-home long term, as the focal point continues to shift toward independence and community integration of the individual with disabilities.

Parents caring for a child with developmental disabilities have been reported to have higher rates of heart disease, high blood pressure, poorer immune function and a negative perception of their own health (reviewed in Feinberg et al., 2006 as cited in Heller et al., 2007). Physical conditions such as back and shoulder pain, arthritis, as well as chronic fatigue and sleep deprivation, are commonly reported by parents whose children require lifting or physical assistance for activities of daily living such as bathing and dressing (Murphy et al., 2006). Likely interrelated and arguably cyclical in nature, these physical health complications, when experienced over a length of time and in the absence of substantial support or relief, can become so wearing on the caregiver they may be compelled to seek out-of-home placement.

The age of the parent or primary caregiver has also been established as having weight in determining both placement and use of services. Hayden and Heller (1997) found older parent caregivers of developmentally disabled children used fewer supportive services than did their younger counterparts though reports of burden were less prevalent in the older parent caregivers. This may be the result of younger, possibly first-time parents, having limited child-rearing skills, while older parents have more life experience and resources to help them through the process; however, as longevity and the prevalence of developmental disabilities increase, the age of parent caregivers and length of time a parent provides care for the child increases as well. With this extension, natural age-
related health issues for caregivers may arise and affect their ability to physically care for their child (Heller et al., 2007). When the burden of caring for the individuals with disabilities is combined with the parent or primary caregiver’s own age-related health issues, the likelihood of seeking alternate placement for the individual may increase.

In addition to the physical health of the parent or primary caregiver, mental health has also been found to be directly related to the placement of individuals with developmental disabilities. Anxiety, depression and guilt are all documented mental health concerns reported by parents raising children with developmental disabilities (Murphy et al., 2006). Conversely, parents or primary caregivers who report satisfaction in their role as caregiver are far less likely to experience stressors to the point of seeking out-of-home placement (Murphy et al., 2006).

Parent and primary caregiver coping styles have been found to have a direct effect on the experience of raising a child with developmental disabilities. In a study focusing on coping, expectations for the future and resilience, Heiman (2002) found that parents raising children with developmental disabilities felt a sense of fatigue, both emotionally and physically, and also reported feeling socially isolated as a result of the needs of the child as well as the uncertainties regarding their future. In a study of families raising children with severe or profound developmental disabilities, Roper and Jackson (2007) focused on the uncertainties of out-of-home care for their children. They suggest that for parents who experience confusion in caring for a child whose mental absence or presence is unclear, the level of stress is greater than for parents who are certain of their child’s wants and needs. Roper and Jackson (2007) propose that during the process of
determining placement, this stress is significantly increased, prompting feelings of sadness and guilt, and relief when a decision is finally made.

Social- and Cultural-Related Factors

Several social and cultural factors have been identified as playing a role in a parent or primary caregiver’s decision to care for an individual with developmental disabilities in-home or to seek out-of-home placement. This includes gender roles, cultural norms related to the transition from adolescence to adulthood, and stigma experienced as a result of the disability. Social and cultural factors can be negative or positive as they may be related to either aspects that negatively impact the individual or family, or conversely may help promote independence and well-being of the individual with developmental disabilities.

As a result of the increased involvement in their life, parents or primary caregivers of individuals with developmental disabilities may have decreased opportunities to participate in social activities and relationships in order to fulfill their caregiver duties (Kelly & Kropf, 1995). As such, they are at risk of becoming isolated and having a smaller support network that would ultimately benefit their situation.

Mothers have traditionally been expected to take on the role of caregiver in families and this has been shown to be consistently true in families of children with developmental disabilities as well. Fathers of children with developmental disabilities are less often primary caregivers and thus report a lower sense of burden than do mothers (Heller et al., 1997 as cited in Heller et al., 2007). This imbalance can eventually overwhelm the mother. As McCubbin and Patterson’s (1983) Double ABCX model...
implies, this can be experienced as a crisis that the family may or may not be able to recover from with existing or sought-after services. Inability to balance the burden may result in the need for out-of-home placement.

Haveman et al. (1997) examined caregiver burden experienced by parents of children with developmental disabilities and found that as their children reached the age normally felt to be appropriate for living outside of the home, these parents perceived their role as caregiver to be less normal, and more arduous. Of equal importance is the number of parents who have expectations that their child be included in society to the greatest extent possible (Heiman, 2002). This is in line with the normalization principle in which the goal is for individuals with developmental disabilities to be offered the opportunity to experience life as similarly to their non-disabled peers as is feasible.

Heller et al. (2007) discussed the fact that families of minority groups are less likely to apply for or receive formal services for developmentally disabled family members. They suggested this could be the result of distrust of formal service providers, as well as a tendency to rely more on other family members possibly due to cultural beliefs regarding a family’s responsibility to take care of other members. Should these families be unable to manage stressors related to the individual’s disabilities, they will likely turn to extended family members leading to the individual benefitting less from services available to him or her. This highlights the importance of culturally competent services offered to individuals with disabilities, and the persons caring for them.

Erving Goffman (1963) explains stigma as a negative label that affects an individual’s identity and leads to disapproval from others, eventually resulting in social
isolation (as cited in Maciones, 1998). This label is based on personal characteristics and is arguably felt by the developmentally disabled population to a great extent, but also by their families as well. Increased community integration through job support programs and workshops, inclusion in the school system, and general presence through day program and residential facility community outings, have resulted from normalization efforts and serve to lessen stigma experienced by family members, staff members and by the individual with developmental disabilities. In a study of the willingness of mothers of children with developmental disabilities to consider out-of-home placement for their child, Green (2004) examined perceived stigma, such as when others expressed sadness or appeared awkward when coming across the individual with disabilities, as a possible factor influencing their decision-making process. It was concluded that in addition to factors that may be expected to influence the decision to pursue out-of-home placement such as age, or level of disability or assistance required, perceived stigma led to a greater degree of burden felt by mothers with regard to caring for their developmentally disabled child, and was influential in the consideration of out-of-home placement (Green, 2004).

Financial- and Legal-Related Factors

Families of individuals with developmental disabilities have been found to face greater rates of poverty and spend far more out of pocket money in order to care for the individual than do families without (Fujiura, 1998 as cited in Heller et al., 2007). Parents in such families are less likely to be working, work fewer hours and have more missed days of work, all of which can be attributed to the additional demands that come with raising a child with special needs (Anderson et al., 2002 as cited in Heller et al., 2007).
Additionally, parents of children with developmental disabilities who do work, tend to make less money (Hodapp & Krassner, 1995 as cited in Weisz, 1996). Given that private care specialized for a developmentally disabled child can often be difficult and costly to acquire due to the disability-related needs of the child (Kagan et al., 1999 as cited in Porterfield, 2002), it may be more practical for one parent to care for the child rather than work. The increased rate of poverty resulting from decreased rates of employment and earnings can likely be attributed to the additional tasks faced by these parents, making consistent employment outside of the home for both parents – a difficult feat.

In addition to the aforementioned need for specialized daycare services, families of individuals with developmental disabilities also face the added costs of things such as therapy services and home modifications to accommodate the individual. Likewise, some estimates suggest out-of-pocket medical expenses for children with developmental disabilities are up to twice that of non-disabled children (Parish, Rose, Grinstein-Weiss, Richman, & Andrews, 2008). While there are a variety of social service programs that offer assistance to these individuals, parents of children with disabilities clearly face added expenses not faced by others.

Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues to provide financial assistance to individuals who have limited resources due to disability, including developmental disabilities. Social Security Disability Insurance (SSDI) is a benefit available to adult children based on parent earnings and contribution of Social Security taxes from employment for a sufficient period of time (Social Security Administration, 2012). These benefits can serve as a
safety net for parents or family members who care for their developmentally disabled loved one in-home and who have limited resources; however, some individuals with disabilities whose parents or family members have higher incomes may not qualify for these benefits. While some families with incomes too high to qualify for supplemental assistance may be able to continue providing care for the individual, the additional expenses associated with having a developmental disability (Fujiura, 1998 as cited in Heller et al., 2007) may prove to be too challenging on the family’s financial stability. This, in turn, may lead to out-of-home placement where all basic expenses are guaranteed to the individual.

Another expense and legal process parents and family members of adults with developmental disabilities may face results from the conservatorship process. Parents or family members can choose to become conservator of their child to ensure control over important financial, legal, and medical decisions. Conservatorship requires a court case in which a judge appoints a person to care for and make decisions for another adult that is unable to care for him or herself or be responsible for his or her own finances (Judicial Council of California, 2012). This is an expense not faced by parents of non-disabled children, and may or may not be practical, leading the state, public guardian or regional center to assume conservatorship. Those wishing to maintain control of decisions made for and about their loved one with developmental disabilities may feel obligated to pursue conservatorship and, as such, will have to endure the financial and legal costs which could potentially present a hardship.
Additional legal factors include divorce and its implications such as custody arrangements and child support related to this process. As Risdal and Singer (2004) found, the divorce rate for parents of children with developmental disabilities is consistently higher than for that of families without individuals with disabilities. The reported additional stressors that come with the raising of such children likely contribute to this increased rate of divorce.

**Service- and Support-Related Factors**

Literature suggests that with the trend toward normalization that began in the 1960s, there has been an increase in services and supports available to the developmentally disabled population in the United States. As McCubbin and Patterson’s (1983) Double ABCX model suggests, a family’s ability to cope with stressors is greatly affected by the supports and resources it has available, as well as their perception of and ability to utilize such supports. The model highlights the importance of service utilization as a means of coping in order to promote a functioning unit. Parents and family members of these individuals should be familiar with the services and supports available to all involved parties in order to prevent crises, such as emergency or unplanned placement of a loved one with developmental disabilities. If a crisis does occur, the supports can be utilized to regain equilibrium. Use of formal services available to individuals with developmental disabilities and their families has been found to decrease time constraints and perceived burden experienced by caregivers (Haveman et al., 1997). Social workers play a key role in educating about and linking to such services and supports.
One of these supports, respite care, entails the care of an individual, including one with developmental disabilities, in an effort to give the full-time caregiver a break from his or her duties. Respite care can decrease the level of stress experienced by parents or other full-time caregivers of these individuals. Chan and Sigafoos (2001) propose, however, that the reduction may be short-lived. This was also shown in a 1989 study by Rimmerman (as cited in Chan & Sigafoos, 2001), which showed a marked decrease in stress with the use of respite, but noted a rise 12-16 months after using a respite service. These findings hint at the possibility that families seek out services during times of stress, experience relief in the short-term, but do not address the actual sources of stress. Thus, the underlying problems persist.

The Individuals with Disabilities Educational Act requires services and supports, such as preschool, be offered to individuals with developmental disabilities over the age of three, though they are frequently offered on a non-fulltime basis (Porterfield, 2002). For adult individuals with developmental disabilities, participation in day programs, vocational training services, and supported employment can benefit the individual, as well as their parent(s) or primary caregiver(s). These programs are specifically designed to meet the needs of individuals with developmental disabilities by providing enriching activities as well as skills training (Allen & Mor, 1998; Landesman & Vietze, 1987). Caregiver burden can be considerably lower for parents or primary caregivers of individuals who attend these programs as it gives them a natural respite (McDermott, Valentine, Anderson, Gallup, & Thompson, 1997). Such programs provide an added benefit of permitting individuals with developmental disabilities to participate in daily
activities in ways similar to that of their non-disabled peers (Landesman & Vietze, 1987).
However, children attending school on a part-time basis rather than full-time like their non-disabled peers, and adult children with disabilities who attend day programs but require care in the evening, can be problematic for families in which both parents, or in some cases a single parent, must work to financially provide for the family.

In California, Regional Centers provide and promote services, both in-home and out-of-home, to individuals with developmental disabilities, with the intent of facilitating the least restrictive environment or greatest level of community inclusion. Regional Centers also seek to ensure the adherence of service providers to the Lanterman Developmental Disabilities Service Act (Association of Regional Center Agencies, 2011). Service coordinators or caseworkers from such agencies are identified by many parents as being the most helpful during the placement process (Blacher & Baker, 1994).

Freedman et al. (1997) proposed that decreased funding and long waiting lists for services have led families who desire out-of-home placement to continue in-home care longer than they had planned. This can produce additional feelings of stress that are compounded with pre-existing stressors that led to seeking out-of-home placement in the first place. Similarly, the amount of additional services available to and often necessary for maintaining the well-being of a child with developmental disabilities can alone serve as a source of stress. Chan and Sigafoos (2002) noted that the very respite services which aim to give parents a break from their role as caregiver, are also capable of causing stress as the parents worry about the quality of care the child is receiving in their absence. Similarly, Murphy et al. (2006) pointed out the fact that these parents must develop a
significant number of relationships with teachers, medical professionals, and agency staff that parents of non-disabled children likely do not experience.

One of the key tenets in the ecological systems theory is the presence of constant interplay between systems and the players of each on the micro, mezzo and macro levels. Parents of individuals with developmental disabilities must learn to navigate systems on all three levels to a different extent than those raising non-disabled children. In order to satisfy the family system, respite services may be used to allow parents time to regroup or participate in outside activities. The education system and supports it offers not only benefits the individual with disabilities, but also promotes acceptance of difference in society as a whole.

Accumulation of Factors as Stressors

A common theme experienced by parents raising individuals with developmental disabilities is stress. As the literature demonstrates, there are a variety of factors experienced as stressors by parents and family members, such as family size, socioeconomic status, age and health of parents, needs of siblings being neglected, and lack of community services and social supports which have influence over the decision to continue in-home care or seek out-of-home placement. Likewise, factors which are experienced as stressful by one parent, may not be considered a stressor to another, and a single factor may prompt the seeking of out-of-home placement for one family while it may take a combination of factors to prompt this consideration by another.

In their study of decision-making factors of parents who had placed their children with developmental disabilities in out-of-home facilities, Blacher and Baker (1994)
concluded that there was no specific factor that led to the decision, but rather was the result of an accumulation of stressors over time. Referred to as pile-up in McCubbin and Patterson’s (1983) Double ABCX Model, chronic stressors that can arise when raising a child with developmental disabilities must be addressed in order for families to continue as a functional unit. There is a critical need for service providers or counselors that offer programs and services that attempt to ease the accumulation of child-related stress (Blacher & Baker, 1994), and utilization of these services is one of the ways families cope with the stress (McCubbin & Patterson, 1983). The other component is the parent or family’s perception of the stressors and whether they feel capable of managing or changing the situation (McCubbin & Patterson, 1983). The manner in which the parent and/or entire family copes with disability-related stressors determines whether in-home care continues, or out-of-home placement is sought for the individual with developmental disabilities.

**Placement**

**Pre-Placement**

Worrying about the future is an almost universal experience for parents of children with developmental disabilities. This entails the parent feeling uneasy about what will happen to their developmentally disabled child once the parent is deceased, as well as what types of services, specifically with regard to housing and employment, the individual will receive once he or she has aged out of the public school system (Murphy et al., 2006). Support from others is essential when a parent or primary caregiver is considering out-of-home placement for their child with developmental disabilities and if
so, what type of setting would best suit their child. This support can come from a variety of sources including family members, friends, medical professionals, teachers or even clergy; but the approval of at least one person they respect, is vital to prompt pursuit of placement (Bruns, 2000). Heiman (2002) studied the resilience and coping factors, as well as future expectations in parents of developmentally disabled children, and found several services which they were consistently referred to. These included psychological services for the child, themselves or other family members, which points to the importance of acknowledging the magnitude of the decision and the implications it will likely have on all involved.

**Planning for Placement**

Planning for future placement of an individual with developmental disabilities can take many forms and may involve both short-term and long-term goals. This may involve exploring and visiting different types of care facilities such as community-based group homes, or more restrictive and skilled facilities for those individuals with more intensive needs. Other parents or primary caregivers may wish for their loved one to remain with family members in an in-home setting, and the planning process may involve a family discussion about which siblings or other relatives will continue this care when their parent or primary caregiver is no longer able to continue in that role. In situations where the parent or primary caregiver is at an advanced age, planning often includes the input of the individual’s siblings when present. These siblings often take on the caregiver role for individuals not placed in out-of-home facilities (Griffiths & Unger, 1994).
In the event a plan is not in place, an emergency placement may be necessary, requiring the individual to suddenly adapt to a new environment and system (Kelly & Kropf, 1995). This is when the pile-up factor described in the Double ABCX model begins to take shape and calls for family resilience and external supports to successfully make it through the crisis. To avoid crisis and disruption in the life of the individual with disabilities, it is vital that families have a plan for care in the event the primary caregiver is no longer able to function in this role for whatever reason.

Blacher and Baker (1994) concluded the expected feelings of guilt and loss after placing a developmentally disabled child in an out-of-home setting, could be addressed through assisting the family in adjusting to life post-placement. They suggested promoting family involvement that has meaning and that will contribute to feelings of relief as opposed to guilt and will likely help with the individual’s transition (Blacher & Baker, 1994).

**Post-Placement**

Out-of-home placement of an individual with developmental disabilities can have both negative and positive impacts on parents, primary caregivers, and the family as a whole. Prior to placement, emotional and physical exhaustion are common feelings experienced by parents; these feelings decrease dramatically when the child with developmental disabilities is placed out-of-home (Werner, Edwards, & Baum, 2009). Parents also experience worry and guilt when considering out-of-home placement of their child, and these emotions are amplified for some parents during and after the placement process (Werner et al., 2009). Werner et al. (2009) suggest this is the result of the
caregiver experience being a lifelong commitment, regardless of where the child resides, and is largely connected to issues of health and safety of the child in their new living environment.

Out-of-home placement can also result in feelings of relief or hope for the future, when there is the feeling the individual is being well taken care of (Werner et al., 2009). Parents raising a child with developmental disabilities along with non-disabled children find that after placing the child with disabilities outside of the home, they are able to spend more time with their other children and experience an overall improved family relationship (Werner et al., 2009). Additional positive outcomes post-placement include the ability to pursue personal interests, improved physical health, as well as an overall reduction in stress and worry (Blacher & Baker, 1994). Finally, placement in a larger residential facility may shift care focus from custodial-based in the family home due to the small, family nature, to a setting in which the formal goal is to teach skills and community participation (Thorn, Pittman, Myers, & Slaughter, 2009). All told, the intense emotions involved in both the decision-making process and life, post-placement, emphasize the importance of support for all persons faced with this decision to assist in ensuring the well-being of the individual in-home, during periods of transition, and post-placement, when applicable.

Summary

This review of literature highlights the common experiences had by parents and primary caregivers of individuals with developmental disabilities and the essential role social workers may play in the placement process for these individuals. With a push for
normalization, it is critical social workers and other professionals working with this population be aware of the implications of different placement settings and promote services in line with this principle. The lower rate of services used by families of developmentally disabled children from minority groups (Heller et al., 2007) reveals the need for agencies serving this population to offer culturally competent services. Doing so will increase the likelihood these groups will take advantage of services available to them, and in turn may improve the experience of the family as a whole, as well as the well-being of the individual with disabilities.

At present, acceptance of the developmentally disabled population is broad and rights are advocated for, but state service systems are dwindling. As these services decline and caseloads of social workers, direct care staff, and skilled professionals rise, it is crucial to find ways to ensure the rights that were fought for in the 1960s and beyond, leading to normalization and inclusion in society, are not dishonored. If not, there is a risk of taking steps backward to a time in which developmentally disabled individuals were cast into the shadows of society.
Chapter 3

METHODOLOGY

This chapter discusses the research design as well as methodology used to complete this study. The purpose of the study was to describe the experience of parents and primary caregivers of individuals with developmental disabilities and to identify key factors which influenced their decision to care for the individual in-home or to opt for out-of-home placement. By identifying these factors, future evaluation of services offered to parents during the decision-making process can be more purposeful and potentially lead to improved services and interventions from social service agencies and professionals. Ultimately, the information gathered has the potential to lessen the stress and anxiety experienced by persons faced with such a complex decision, and can help ensure the decisions are made on an informed basis. This in turn will increase the likelihood the individual with developmental disabilities will live in a setting that fosters the greatest level of independence and well-being, which is without a doubt the common goal.

This researcher has 11 years of experience working in Yolo County with individuals who have been diagnosed with developmental disabilities, in both in-home and out-of-home settings. After observing individuals with developmental disabilities from a range of ages placed in community-based facilities, the researcher sought to answer the question: What are the key factors determining whether a parent or primary caregiver cares for an individual in-home, and for how long, or whether they seek out-of-home placement? Based on the relationships and rapport the researcher has established
with several families with developmentally disabled members in the Yolo County and greater Sacramento areas, as well as agencies that serve this population, it was the goal of the researcher to answer this question with regard to that population.

**Study Design**

Using a descriptive research design, this study sought to give a brief overview of the experience of parents and primary caregivers of individuals with developmental disabilities, and to identify the key factors that influence their decision to care for the individual in-home or to seek out-of-home placement. Descriptive studies aim to identify and illustrate the nature of relationships between variables in a certain situation, and can provide thorough information about these relationships (Yuen, Terao, & Schmidt, 2009). Researchers have identified a variety of factors influencing the decision to care for a developmentally disabled loved one in-home or to place the individual out-of-home. In the present study, the researcher identified would-be factors through a literature review and created a standardized survey given to a non-random, purposive sample. The goal was to discover an association between family, parent or primary caregiver characteristics, and the various factors identified as having influence during the decision-making process, as well as to identify trends in the decision-making process. Utilizing previous identified factors and eliciting non-identified factors from current study participants, this study attempted to describe the experience of individuals in the Yolo County and greater Sacramento areas.

**Sampling Procedures**

Subjects for this research study were 19 parents and family members of individuals
diagnosed as having a developmental disability. Criteria for inclusion in the study included the individual with developmental disabilities being alive during the study and living or having lived in the Yolo County or greater Sacramento area, at any point in time from October 2000 thru December 2011, regardless of length of stay or use of services offered or used by the individuals.

Using purposive and convenience sampling methods, participants were recruited from parents, family members and caretakers of individuals with developmental disabilities who are currently or have in the past, received services from Woodland Residential Services Inc., where the researcher served as a Qualified Mental Retardation Professional (QMRP) for six years. Additional participants were recruited using the same method from acquaintances known by the researcher to have a child with developmental disabilities. As specified previously, child refers to the relationship only, and parents, family members or other primary caregivers were eligible to participate without regard to the age of the individual with disabilities. Likewise, individuals were included in the sample without regard to current placement (in-home or out-of-home) of the individual with disabilities. In an effort to obtain a greater sample size, the snowball strategy was also used, as individuals already participating in the study informed acquaintances known by them to have a child with developmental disabilities meeting the aforementioned criteria of the study.

**Data Collection Procedures**

Data collection for this research study was done through mailed, standardized questionnaires which were developed by the researcher (see Appendix A). With
permission from the owner/administrator, contact information was gathered for the parents, guardians and family members of current or past Woodland Residential Services clients. Subjects were identified by the researcher as having met the criteria to participate and were then sent the following: a cover letter introducing the study (see Appendix B); a copy of the letter of support from Woodland Residential Services owner/administrator (see Appendix C); a standardized “Placement Decision Study Questionnaire”; consent to participate in the study, which also explained the purpose of the study and instructions for completing the questionnaire (see Appendix D); a declination form for those choosing not to participate (see Appendix E); and a self-addressed stamped envelope to return completed forms and/or questionnaires.

A total of 48 questionnaires were sent to individuals identified as meeting the criteria by the researcher. Of the 48 questionnaires sent, 19 were completed and returned. Three potential participants returned the declination form indicating they did not wish to participate in the study. One family member stated they did not have enough knowledge to accurately complete the questionnaire. One questionnaire was returned by the postal service as undeliverable. The researcher received no response from the remaining 24 individuals to whom questionnaires were mailed.

Instrument

The questionnaire employed both open- and close-ended questions, and was developed by this researcher based on the purpose of the research question and guided by current literature. The questionnaire consisted of 21 questions covering characteristics of both the respondent (parent, family member, primary caregiver, etc.) and the individual
with developmental disabilities, as well as key information directly related to the current living situation of the individual with developmental disabilities and the factors that influenced it and/or factors considered by those considering future living arrangements.

Questions 1–3 included characteristics of the respondent including relationship to the individual with developmental disabilities, the respondent’s age and their race. This information was collected to determine if relationship to the individual, age or race was, in any way, associated with the decision to place the individual in an out-of-home setting or to care for them in-home. Questions 4–6 consisted of characteristics of the family, including the total number of children raised in the family, the sibling rank of the individual with developmental disabilities and the number of children with developmental disabilities in the immediate family. The purpose of this information was to determine whether family dynamics play a role in the placement decision-making process. Questions 7–10 were related to information regarding the individual with developmental disabilities, including their primary diagnosis, level of mental retardation (if applicable), and ambulation status. The intent in gathering this information was to ascertain whether disability type and/or the individual’s ability to ambulate were associated with out-of-home placement or in-home care.

Questions 11–14 consisted of information about the current living situation of the individual with developmental disabilities, and were used to determine the type of placement the individual resides in, as well as the age the individual was placed in the out-of-home facility where applicable. Question 13 applied to parents or primary
caregivers who care for the developmentally disabled individual in-home and in an open-ended format, sought the reasons for this decision.

Question 15 listed potential factors influencing placement decisions and was based largely on factors identified in the review of literature. This question also allowed parents to write in additional factors not already listed. Questions 16–19 sought information about whom (professionals, family, friends, clergy, etc.) the respondent talked to about their decision to either place the individual out-of-home or to care for them in-home, which persons were most helpful or who they wish they had spoken to, and whether they felt well-informed during the decision-making process.

Question 20 asked for advice the individual would give to others faced with the decision-making process. Finally, question 21 allowed the respondent to state whether they would be willing to participate in follow-up questions to enable the researcher to get a more in-depth understanding of their experience, as well as contact information should they agree to further questioning.

**Data Analysis**

Upon receiving completed surveys and conducting follow-up interviews, the researcher completed a content analysis in which responses to open-ended questions and written-in answers were organized into categories. Data was then entered into the Statistical Package for Social Sciences (SPSS) program for statistical analysis. Descriptive statistics such as frequency distributions, measure of dispersion, measures of central tendency, as well as percentages, were used to understand what factors influenced a parent or primary caregivers’ decision of whether to place an individual with
developmental disabilities in an out-of-home setting or to care for him or her in-home. A Fisher’s exact test was performed to compare in-home and out-of-home placement, with the parent/primary caregiver’s gender and race. Data was presented through percentages, tables, graphs, and charts, which were created using both SPSS and Microsoft Excel.

**Protection of Human Subjects**

Prior to proceeding with any research for this study, a proposal was submitted to and approved as being of minimal risk to participants by the Committee for the Protection of Human Subjects at California State University, Sacramento. Additional approval was sought and granted by the owner/administrator of Woodland Residential Services, Inc., to contact parents and family members of individuals with developmental disabilities residing in their facilities in attempt to include them in the proposed study. After approval was obtained from both parties, letters introducing the study, along with questionnaires and informed consent forms, were mailed to potential participants identified as meeting criteria from Woodland Residential Services, Inc., and individuals known personally to the researcher.

Informed consent was obtained through the use of a written consent form and no data was considered without a signed consent. Participants were informed in writing of the study’s purpose and procedures. They were also notified that their participation in the study was voluntary, and that any information gathered would be kept confidential for the purposes of this research study only. In order to ensure identities remain confidential, no names or identifying information were used during the reporting of findings. Participants were also informed of a local mental health counseling resource available should they
experience any emotional discomfort as a result of answering questions for this study, and were advised that they could withdraw from the study at any time.
Chapter 4

STUDY FINDINGS AND DISCUSSION

Presented in this chapter are the findings from questionnaires completed by parents or primary caregivers who currently care for an individual with developmental disabilities in-home, or who have placed a developmentally disabled loved one in an out-of-home setting. For this study, placement factors for individuals already placed out-of-home, as well as reasons for keeping an individual in-home were explored with regard to basic demographics such as age, race, and gender of both the respondents and the individual with disabilities. Other aspects examined were disability type, family size, and support from others. Analysis of data from these questionnaires are presented in this chapter, along with graphs, charts, and tables, in an effort to easily depict findings and any relationships or trends related to key factors which determine whether a parent opts to continue in-home care or to pursue out-of-home placement.

Participant Demographics

This study included 19 participants, all of whom were the parent, primary caregiver or family member of an individual with developmental disabilities. Using purposive and convenience sampling methods, participants were recruited from parents, family members and caretakers of individuals with developmental disabilities who are currently or have in the past, received services from Woodland Residential Services, Inc., where the researcher served as a Qualified Mental Retardation Professional (QMRP) for six years. Additional participants were recruited using the same method from acquaintances known by the researcher to have a child with developmental disabilities.
Eight of the participants had a child or family member with developmental disabilities currently living in-home, and the remaining eleven participants had a child or family member who currently resides in an out-of-home setting (see Figure 2).

Figure 2. Child placement.

Respondents varied in age from 26 years to over 65 years, with the out-of-home respondents tending to be in the higher age ranges. All respondents reported their race as being either White or Hispanic/Latino. The number of children raised in each household, either presently if in-home, or in the past for individuals now residing outside of the home, ranged from no siblings to four siblings in addition to the individual with disabilities. Of the 19 respondents, 17 had only one child with developmental disabilities, while one family had two children with disabilities and another family had four children who had developmental disabilities. Both of the families that had more than one child with disabilities had placed these individuals out-of-home.
In-Home Respondents

Study participants who had a child or family member with developmental disabilities living in-home included three males and five females. All three males were biological fathers of the individual. Of the five female respondents, four were biological mothers and one was the biological sister of the individual (see Table 1). Respondents with individuals living in-home reported their race as either White (50%) or Hispanic/Latino (50%). Half of this group of eight respondents fell in the 26-35 age range. The remaining half were split equally in the 36-45 and 56-65 age ranges (see Table 2).

Of the respondents who have an individual with developmental disabilities living in-home, six had additional children in the home, and two reported the child with developmental disabilities being an only child. Of those with additional children, three had a total of two children including the developmentally disabled child, one respondent had a total of three children, and two respondents had a total of four children in the household.

Out-of-Home Respondents

Of the participants who had a child or family member with developmental disabilities living in an out-of-home setting, five were male and six were female. Three of the male respondents were biological fathers, one was a biological brother and one was the biological uncle of the individual with developmental disabilities living outside of the family home. Of the six female respondents from this group, five were the biological mothers of the individual with disabilities, and one was the biological sister of the
individual (see Table 1). Of the 11 respondents with a child or family member placed out-of-home, ten reported their race as White, while the remaining individual reported being of Hispanic/Latino origin. With regard to age, respondents in this group tended to be older in age overall, than the in-home respondents. Five of the 11 respondents in this group fell in the over 65 age range and the remaining six respondents reported being in the 56-65 range (see Table 2).

Of the 11 respondents who have a child or family member with developmental disabilities placed out-of-home, only one reported the individual as being the only child in the family. Four of the respondents reported the individual with disabilities being one of two children raised in their household. Three of the respondents reported a total of three children raised in the household. One respondent reported the child was one of four raised in the household, and the remaining two respondents reported the child with disabilities being one of five children raised in the household. As mentioned previously, in the family with four children, all four were diagnosed with developmental disabilities.

Table 1

<table>
<thead>
<tr>
<th>Gender Frequency of In-Home vs. Out-of-Home Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>In-Home</td>
</tr>
<tr>
<td>Biological Father</td>
</tr>
<tr>
<td>Biological Mother</td>
</tr>
<tr>
<td>Family Member - Male</td>
</tr>
<tr>
<td>Family Member - Female</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>
Table 2

*Frequency Distribution for Age of Respondents by Placement*

<table>
<thead>
<tr>
<th></th>
<th>In-Home</th>
<th>Out-of-Home</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>26-35</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>36-45</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>46-55</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>56-65</td>
<td>2</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Over 65</td>
<td>0</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>8</td>
<td>11</td>
<td>19</td>
</tr>
</tbody>
</table>

**Demographics of Individuals with Developmental Disabilities**

The individuals with developmental disabilities for which data was collected ranged in age from 4 years to 67 years old. Of the 19 individuals with disabilities, the race of 14 was White and the remaining nine individuals were reported to be of Hispanic/Latino origin. Ten of the individuals about whom questionnaires were answered were male and nine were female.

Of the 19 individuals, 11 lived in an out-of-home setting and nine live in-home with their parent(s) or family member(s). Ten of these individuals currently live in an Intermediate Care Facility for the Developmentally Disabled (ICF), while the remaining individual lives in his own apartment with supported living services.
The developmental disabilities of the individuals for whom data was gathered about included: autism, cerebral palsy, Down syndrome, mental retardation, and genetic disorders including Claire d’ Lange Syndrome CdLS and Agenesis of the Corpus Callosum, and developmental disabilities due to a massive stroke during childhood (see Table 3). The most common disability was cerebral palsy, comprising over 42 percent of the sample. In addition to their primary diagnoses, 17 of the 19 individuals were also diagnosed with varying degrees of mental retardation. Two of the 19 were diagnosed with mild mental retardation, five with moderate mental retardation, five with severe mental retardation, and five with profound mental retardation. Two of the individuals had not been diagnosed with any form of mental retardation.

Table 3

*Diagnosis of Individuals with Developmental Disabilities – Total Sample*

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism</td>
<td>3</td>
<td>15.8</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
<td>8</td>
<td>42.1</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>2</td>
<td>10.5</td>
</tr>
<tr>
<td>Genetic Disorder</td>
<td>5</td>
<td>26.3</td>
</tr>
<tr>
<td>Massive stroke at age 4</td>
<td>1</td>
<td>5.3</td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
<td>100.0</td>
</tr>
</tbody>
</table>

**In-Home**

Of the individuals with developmental disabilities living in-home, five were male and three were female. Four of these individuals were of Hispanic/Latino origin and four were White. The ages of in-home individuals ranged from 4 to 62 years (see Table 4).
Like their parents or family members who participated in the study, the individuals with developmental disabilities who lived in-home tended to be of a lower age than those who were placed out-of-home, though one exception was a 62-year-old female living in-home with her sister. Placed in an institution at a young age, her sister moved her in with her family as a result of repeated negative experiences in out-of-home settings.

Table 4

*Age of Individuals with Developmental Disabilities – In-Home*

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>9</td>
<td>2</td>
<td>25.0</td>
</tr>
<tr>
<td>31</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>62</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Diagnoses of individuals living in-home included, Down syndrome, cerebral palsy, autism and genetic disorders, with the most common being autism (see Figure 3). The level of mental retardation for individuals in this study who lived in-home included one individual with mild mental retardation, three with moderate mental retardation, two with profound mental retardation and the remaining two had not been diagnosed with mental retardation.
Out-of-Home

Of the individuals with developmental disabilities living in an out-of-home placement, five were male and six were female. Half of the individuals in this group were of Hispanic/Latino origin and the other half were White. The ages of individuals in this group ranged from 25 to 67 (see Table 5). The oldest individual, a female with cerebral palsy, lived in-home with her mother until she was age 65 when her mother passed away. The age at the time of out-of-home placement ranged from less than one year to age 65, with eight of the 11 individuals living in out-of-home settings being placed prior to age 20 (see Figure 4).
Table 5

Current Age of Individuals with Developmental Disabilities – Out-of-Home

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td>18.18</td>
</tr>
<tr>
<td>31</td>
<td>18.18</td>
</tr>
<tr>
<td>33</td>
<td>9.09</td>
</tr>
<tr>
<td>36</td>
<td>9.09</td>
</tr>
<tr>
<td>47</td>
<td>9.09</td>
</tr>
<tr>
<td>49</td>
<td>9.09</td>
</tr>
<tr>
<td>52</td>
<td>9.09</td>
</tr>
<tr>
<td>56</td>
<td>9.09</td>
</tr>
<tr>
<td>67</td>
<td>9.09</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>11</strong></td>
</tr>
</tbody>
</table>

Figure 4. Age of individual at time of out-of-home placement.
Diagnoses of the individuals currently living in out-of-home placements included cerebral palsy, genetic disorders called Claire d’ Lange Syndrome CdLS and Agenesis of the Corpus Callosum, and one child whose disabilities were the result of a massive stroke at the age of 4 (see Figure 5). The most common diagnosis for individuals placed out-of-home was cerebral palsy, with seven of the 11 having this as their primary diagnosis. The level of mental retardation for the individuals living out-of-home included one with mild mental retardation, two with moderate mental retardation, five with severe mental retardation, and three with profound mental retardation.

<table>
<thead>
<tr>
<th>Primary Diagnoses of Individuals Living Out-of-Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Massive Stroke at age 4</td>
</tr>
<tr>
<td>Genetic Disorder</td>
</tr>
<tr>
<td>Cerebral Palsy</td>
</tr>
</tbody>
</table>

*Figure 5. Primary diagnoses of individuals living out-of-home.*

**Placement Factors**

**Out-of-Home Placement Factors**

A total of 24 factors were listed in the Placement Decision Study Questionnaire (see Appendix A), with an additional option of “other” included to allow
respondents the opportunity to write in additional factors not listed by the researcher. Seven factors not listed on the questionnaire were listed by respondents in the “other” option. Of the 24 listed factors, a total of 21 factors were chosen by at least one respondent. Factors not chosen by any respondents were: cultural reasons; behaviors-aggression toward others; and behaviors- self-injurious behaviors. One respondent, a biological father did not select any factors and noted his former wife and mother of his child, placed their son in a care facility without his knowledge.

A content analysis was performed for placement factors written in by respondents in addition to the 24 factors listed by the researcher. All factors were placed into one of six factor domains (see Table 6).

Table 6

*Individual Placement Factors by Domain*

<table>
<thead>
<tr>
<th>Family Dynamic-Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>• I am/was a single parent</td>
</tr>
<tr>
<td>• Time demands took away from attention paid toward siblings</td>
</tr>
<tr>
<td>• Siblings were affected by behaviors of developmentally disabled child</td>
</tr>
<tr>
<td>• Marital Stress</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child-Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Individual with disability’s age (natural transition after school, etc.)</td>
</tr>
<tr>
<td>• Level of care necessary was beyond that which I could provide, physically</td>
</tr>
<tr>
<td>• Behaviors - Aggression toward others</td>
</tr>
<tr>
<td>• Behaviors – Self-injurious behaviors</td>
</tr>
<tr>
<td>• Medical/health of individual were beyond what I could handle</td>
</tr>
<tr>
<td>• The individual expressed the desire to move out</td>
</tr>
</tbody>
</table>
Health-Related (Mental or Physical Health of Parent or Primary Caregiver)
- My age
- Death of primary caregiver*
- Caregiver stress (feeling overwhelmed, etc.)
- My medical/health
- My mental health*

Social- or Cultural-Related
- My social life was affected/restricted
- Stigma (the way others respond to myself or the individual’s disability)
- Pressure from friends or family
- Religious or moral obligation
- Cultural reasons
- To promote independence/normalization of the individual

Financial- or Legal-Related
- My career was affected/restricted
- Legal reasons*
- Financial reasons

Service- or Support-Related
- Loss of trusted care provider*
- Distance of available out-of-home facilities – I am able to visit
- Distance of available out-of-home facilities – I am not able to visit
- Quality of facilities available in my area
- Knowledge of facility or agency*
- Relationship with facility/agency director*
- I am able to select or oversee the selection of caregivers*

Other
- Ex-spouse place child in out-of-home facility without respondent’s knowledge

*Answer was written in by respondent
The mean number of factors reported by participants as having an influence in their decision to place the individual with developmental disabilities in an out-of-home setting was 5.91. The most common number of factors identified by parents in the present study as impacting their decision to place the individual in an out-of-home setting was eight. These findings are in line with those found in the literature, which suggest the decision to seek out-of-home placement is often the result of a combination and build-up of factors. While some factors or factor domains may arise more often in decisions of out-of-home placement, there is likely no one in particular that leads to this decision.

**Relationship of Out-of-Home Placement Factors to Demographics**

Domains reported by study participants to have influenced their decision to place their child or family member with developmental disabilities in an out-of-home setting varied among the 11 respondents from this group. Biological mothers of these individuals reported more placement factors overall (34 total for 5) than did biological fathers (14 total for 3). The two male family members of individuals placed outside of the home reported a total of 16 factors or a mean of eight factors each. The only female family member reported just one factor in the placement decision (see Table 7).

Biological mothers reported family dynamic-, child-, caregiver health- and service- or support-related factors more than social- or cultural-, or financial- or legal-related factors. Biological fathers reported service- or support-related factors more than any other factor (see Table 7). The trend for mothers to report more factors overall and more factors from specific domains supports findings from the literature review, which assert mothers often have a greater role in the care of the developmentally disabled child.
Factor domains reported by age range of the respondents suggests service- or support-related factors were the most significant for parents or family members in the 56-65 age range, while the 65 or older range tended to report child- or caregiver health-related factors having the greatest impact. The 14 service- or support-related factors reported by the six respondent in the 56-65 age range as opposed to four service- or support-related factors reported by those in the 65 or older range (see Table 8) is suggestive of the increase in availability of services such as community-based facilities throughout the past half century. The respondents in the 56-65 may have had more services and supports available to them, or simply more knowledge of them.

Table 7

*Frequency of Out-of-Home Placement Factors by Relationship to Individual*

<table>
<thead>
<tr>
<th></th>
<th>Family Dynamic-Related</th>
<th>Child-Related</th>
<th>Health-Related</th>
<th>Social/Cultural-Related</th>
<th>Financial/Legal-Related</th>
<th>Service/Support-Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological Mother</td>
<td>6</td>
<td>8</td>
<td>9</td>
<td>1</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Biological Father</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Male Family Member</td>
<td>1</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Female Family Member</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>15</td>
<td>13</td>
<td>7</td>
<td>4</td>
<td>18</td>
</tr>
</tbody>
</table>
Table 8

*Frequency Distribution for Age of Respondent and Out-of-Home Placement Factors*

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Family-Related</th>
<th>Child-Related</th>
<th>Health-Related</th>
<th>Social/Cultural-Related</th>
<th>Financial/Legal-Related</th>
<th>Service/Support-Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>26-35</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>36-45</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>46-55</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>56-65</td>
<td>7</td>
<td>9</td>
<td>7</td>
<td>5</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Over 65</td>
<td>1</td>
<td>6</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>15</td>
<td>13</td>
<td>7</td>
<td>4</td>
<td>18</td>
</tr>
</tbody>
</table>

Reasons for Continuing In-Home Care

Of the eight respondents who currently care for their child or family member with developmental disabilities in-home, a total of 46 factors were reported as influencing the decision to continue this arrangement, with some reasons being reported by more than one respondent as playing a role. Reasons reported by this group of respondents were placed into the same six domains used for out-of-home placement factors: family dynamic-related; child-related; caregiver health-related; social- or cultural-related; financial- or legal-related; and service- or support-related. Domains reported by study participants to have influenced their decision to continue care of their child or family member with developmental disabilities in-home varied among the eight respondents from this group.
As with out-of-home placement factors, a content analysis was performed for reasons reported by parents or family members for continuing in-home care for their child or family member with developmental disabilities. All factors were placed into the same six domains used for out-of-home placement (see Table 6).

Table 9

*Reasons for Caring for Individual In-Home by Domain*

<table>
<thead>
<tr>
<th>Family Dynamic-Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Home environment/surroundings</td>
</tr>
<tr>
<td>• He is stable with his mother and brother</td>
</tr>
<tr>
<td>• He is my child/family</td>
</tr>
<tr>
<td>• He needs his family</td>
</tr>
<tr>
<td>• We will provide the best care for him</td>
</tr>
<tr>
<td>• I moved back to the area and was able to take care of her</td>
</tr>
<tr>
<td>• Elderly parents and family agreed it would be best if she lived with sister</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Child-Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>• He is a loner and does better on his own at home</td>
</tr>
<tr>
<td>• I need to know he is protected and cared for</td>
</tr>
<tr>
<td>• To promote independence/normalization</td>
</tr>
<tr>
<td>• She is my only daughter</td>
</tr>
<tr>
<td>• She has a small frame and is lightweight*</td>
</tr>
<tr>
<td>• He is still a child and is like any other child, but slower.</td>
</tr>
<tr>
<td>• I love my child*</td>
</tr>
<tr>
<td>• I know him better than anyone else</td>
</tr>
<tr>
<td>• I want to support him</td>
</tr>
<tr>
<td>• I understand him</td>
</tr>
<tr>
<td>• His age</td>
</tr>
</tbody>
</table>
• His level of independence
• He has a low level of aggression
• The individual wanted to live with her sister

Health-Related (Mental or Physical Health of Parent or Primary Caregiver)
• As long as I can care for him he will stay in his home
• I am able to care for him
• My age allows me to provide care
• I have nursing skills that help me take care of her
• I want to take care of him
• I have a tight bond with him

Social- or Cultural-Related
• I feel it is my moral responsibility to care for her
• I want to teach him
• I will never place him in a facility*

Financial- or Legal-Related
• I am financially able to stay home and care for her/him*
• General financial reasons
• The individual was abused in out-of-home placement

Service- or Support-Related
• I have experience working with developmentally disabled individuals
• Quality of facilities in my area
• I have a lot of family support*
• In-Home Support Services (IHSS) helps me
• Poor experiences with previous out-of-home placements
• Poor care in out-of-home setting

*Reason reported by more than one respondent
Biological mothers of these individuals reported more reasons overall for continuing in-home care (31 total for 4) than did biological fathers (7 total for 2). The sole female family member participant, who cares for her sister in-home, reported six total reasons for caring for her sister in-home (see Table 10). Biological mothers who are currently raising a child with developmental disabilities in-home reported child-related reasons more often than any other domain. Biological fathers also reported child-related reasons more than from any other domain, although their overall reported reasons were far fewer in all domains (see Table 10). This trend for mothers to cite child-related reasons most often and fathers to report fewer overall reasons is again suggestive of mothers playing a greater role in the care of their developmentally disabled children as has been consistently reported in literature.

Factor domains reported by age range of the respondents illustrate child-related factors as being the most significant reasons for parents or family members in both the 26-35 and 56-65 age range with an average of 2.25 and 2.5 child-related reasons, respectively, reported by each group (see Table 11). This is suggestive of the fact these parents or family members have not yet experienced situations in the remaining five domains as stressors to the point of considering outside placement. Similarly, the respondents in the 26-35 age range likely have children under the age of 18, which is a typical age for an individual to move outside of the family home. Therefore, placement may not yet have been considered.
Table 10

*Frequency of Reasons for In-Home Care by Relationship to Individual*

<table>
<thead>
<tr>
<th></th>
<th>Family Dynamic-Related</th>
<th>Child-Related</th>
<th>Health-Related</th>
<th>Social/Cultural-Related</th>
<th>Financial/Legal-Related</th>
<th>Service/Support-Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological Mother</td>
<td>4</td>
<td>12</td>
<td>6</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Biological Father</td>
<td>0</td>
<td>4</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Family Member Male</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Family Member Female</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>18</td>
<td>6</td>
<td>4</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>

Table 11

*Frequency Distribution for Age of Respondent and Reasons for In-Home Care*

<table>
<thead>
<tr>
<th></th>
<th>Family-Related</th>
<th>Child-Related</th>
<th>Health-Related</th>
<th>Social/Cultural-Related</th>
<th>Financial/Legal-Related</th>
<th>Service/Support-Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>26-35</td>
<td>1</td>
<td>9</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>36-45</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>46-55</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>56-65</td>
<td>3</td>
<td>5</td>
<td>3</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Over 65</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>6</td>
<td>17</td>
<td>7</td>
<td>4</td>
<td>4</td>
<td>6</td>
</tr>
</tbody>
</table>
In-Home and Out-of-Home Factors Compared

When out-of-home placement factors were compared with parent or primary caregiver reasons for keeping an individual with developmental disabilities in-home, all domains were reported as being important in the placement decision by at least one respondent. Biological mothers in both groups reported the highest number of overall factors influencing the decision to continue in-home care or out-of-home placement. Child-related and service or support-related factors were the most commonly cited overall with in-home and out-of-home respondents combined, with 29 and 28 reported respectively. The third most common factor domain cited was caregiver health-related, with 20 factors reported. Financial- or legal-related was the least commonly reported domain with regard to in-home care or out-of-home placement, with just eight total factors in this domain being reported (see Table 12). The most common domain reported by parents or family members of an individual with developmental disabilities living in-home was the child-related domain. Service- or support-related factors were reported most frequently as having an impact on the out-of-home placement of the individual with disabilities. This was followed closely by the child-related and caregiver health-related domains (see Figure 6). This finding highlights the vital need for services and supports offered to both the individual with developmental disabilities and their families. It suggests such services and supports must adequately address factors related to the child, as well as the physical and mental health of the caregiver, if and when in-home care is no longer a viable option.
Table 12

*Frequency of In-Home and Out-of-Home Factors by Relationship to Individual*

<table>
<thead>
<tr>
<th></th>
<th>Family Dynamic-Related</th>
<th>Child-Related</th>
<th>Health-Related</th>
<th>Social/Cultural-Related</th>
<th>Financial/Legal-Related</th>
<th>Service/Support-Related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological Mother</td>
<td>10</td>
<td>20</td>
<td>15</td>
<td>3</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Biological Father</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Family Member Male</td>
<td>1</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Family Member Female</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>14</strong></td>
<td><strong>29</strong></td>
<td><strong>20</strong></td>
<td><strong>11</strong></td>
<td><strong>8</strong></td>
<td><strong>28</strong></td>
</tr>
</tbody>
</table>

*Figure 6. Factor domains by placement.*
A Fisher’s exact test was performed to examine the relation between race of respondent (parents and family members) and placement choice (in-home or out-of-home). There was a statistically significant difference between Hispanic/Latino and Whites with regard to placement decision ($p = 0.071$, Fisher’s exact test) (see Table 13). This finding suggests that White respondents are more likely to place their child or family member with developmental disabilities out-of-home, than are Hispanic/Latinos. In-home care versus out-of-home placement for the Hispanic/Latino population in this study was 4:1, while it was 4:10 for White respondents (see Table 13). These findings are consistent with that of Heller et al. (2007) which found that minority groups are less likely to apply for or receive formal services for developmentally disabled family members, tend to care for the individual in-home, and rely more on other family members, possibly due to cultural belief that it is a family’s responsibility to take care of other members.

Table 13

**Fisher’s Exact Test: Race of Respondent by Placement of Individual**

<table>
<thead>
<tr>
<th>Current Living Placement</th>
<th>In-home</th>
<th>Out-of-home</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hispanic/Latino</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>White</td>
<td>4</td>
<td>10</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
<td>11</td>
<td>19</td>
</tr>
</tbody>
</table>
A Fisher’s exact test was also performed to examine the relation between gender of respondent and placement choice (in-home or out-of-home). There was no association found between gender of respondent and placement of the individual with disabilities (p = .66, Fisher’s exact) (see Table 14).

Table 14

**Fisher’s Exact Test: Gender of Respondent by Placement of Individual**

<table>
<thead>
<tr>
<th>Respondent's Gender</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Male</td>
</tr>
<tr>
<td>Current Living</td>
<td>In-home</td>
</tr>
<tr>
<td>Placement</td>
<td>Out-of-home</td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
</tr>
</tbody>
</table>

**Discussion of Placement Decision**

All respondents were given a list of potential persons with whom they discussed their decision to place or not to place their child or family member with developmental disabilities out-of-home. A total of nine choices were listed, with the option to fill in additional persons not listed. The nine choices were as follows: family members; friends; clergy or church members; school staff; medical staff; regional center service coordinator; other parents/guardians of developmentally disabled individuals; social worker; and the individual him/herself. All potential persons were chosen by at least one respondent in this study, and one respondent added *agency staff* as a person with whom they discussed the situation. One respondent reported not having spoken to anyone with regard to the decision. Other family members and regional center service coordinators
were reported as the most common individuals with whom parents or family members discussed their decision with (see Figure 7).

![Frequency Distribution for Discussion of Placement Decision](image)

**Figure 7.** Frequency distribution for discussion of placement decision

Of the parents or family members who placed an individual out-of-home, or 63.64%, felt they made an informed decision, or 27.27%, felt they were not informed of all options at the time of the decision. One respondent, or 9.09%, a sister of the individual with disabilities, was not the primary decision-maker and therefore did not answer this question (see Table 15).
Table 15

*Frequency of Informed vs. Not Informed Decision for Out-of-Home Placement*

<table>
<thead>
<tr>
<th></th>
<th>Informed</th>
<th>Not Informed</th>
<th>Not Primary Decision-Maker</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Biological Father</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Biological Mother</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>Family Member - Male</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Family Member - Female</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>7</td>
<td>3</td>
<td>1</td>
<td>11</td>
</tr>
<tr>
<td>% of Total</td>
<td>63.64%</td>
<td>27.27%</td>
<td>9.09%</td>
<td>100%</td>
</tr>
</tbody>
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**Advice to Other Parents**

Finally, all parents were asked if they had any advice to share with other parents or family members who may be deciding between in-home care and out-of-home placement for their loved one with developmental disabilities. While not all participants answered this question, those that did had a variety of responses that ranged from advising others to never place the individual outside of the home, to recommending they visit regularly if they do place the individual out-of-home, to ensure the individual’s well-being.

Parents or family members who have a loved one placed out-of-home tended to give advice related to researching the quality of facilities, checking in regularly, and maintaining good communication with the facility. Parents or family members caring for their loved one in-home offered guidance that included doing what is best for the
individual with disabilities, being realistic about their ability to care for the individual, and taking time to care for themselves.

Respondents from both the in-home and out-of-home groups urged parents to know their options whether they were related to in-home supports or out-of-home settings, as well as considering what is best for all involved— the individual with developmental disabilities, the caregiver, and any family members who may be involved.

**Summary of Findings**

Parents and primary caregivers face a variety of factors when caring for an individual with developmental disabilities. While some factors may influence the decision-making process of one caregiver, another may find the same factor irrelevant. Parent and primary caregiver demographics, as well as characteristics of the individual with developmental disabilities, are important areas to look at when determining factor significance in the process. Findings from this study, while on a small scale, are consistent with those in the literature review, which suggest it is a combination and accumulation of factors, combined with parent or primary caregiver demographics and ability to cope with these factors, that determine whether an individual with developmental disabilities will be cared for in-home or be placed in an out-of-home setting.

Finally, findings from this study show that parents or primary caregivers providing in-home care of an individual with developmental disabilities tended to cite child-related reasons, while respondents who were confident in the type and quality of care their children would receive out-of-home, opted for placement. This, again,
highlights the need for services and supports that address both in-home and out-of-home placement options in order to ensure the well-being and optimal level of functioning of the individual with disabilities.
Chapter 5

CONCLUSION

Individuals with developmental disabilities continue to be a vulnerable population in need of services and supports often provided by social workers. To better understand how the unique circumstances of each family result in a variety of outcomes with regard to placement, it is beneficial to take into consideration aspects from the various domains of life: family dynamics, child-related issues, caregiver health, social or cultural issues, financial or legal matters, and service- or support-related aspects. Doing so will allow social workers and other professionals to offer client-centered and situation-specific services.

In the present study, parents of younger children with developmental disabilities, who are still living in-home expressed a desire to continue caring for the individual at home either indefinitely or, in some cases, forever. Based on the literature review and findings from the present study, it is plausible to conclude that this may be the result of the parent or primary caregiver not having experienced the pile-up or accumulation of factors as stressors, as discussed in McCubbin and Patterson’s (1983) Double ABCX model of family behavior, and by Blacher and Baker (1994), who found that no one factor is responsible for out-of-home placement, but rather, an accumulation of factors leads to the decision. This could also be an indicator of more services or supports being utilized by these parents than those in the group who have already placed a child or loved one in an out-of-home placement. Additionally, this suggests that services such as respite care and Regional Center service coordination, combined with the shift toward
normalization, have made it more feasible to care for a child or family member in-home today, than it was for those in similar situations several decades ago, when the majority of the parents or family members of placed individuals made that decision.

**Study Findings**

Findings from this study support those from the literature review which assert that placement decisions made by parents or primary caregivers of individuals with developmental disabilities are made based on a variety of factors, and are usually the result of an accumulation of factors rather than any one factor in particular. While parents or primary caregivers caring for their family member in-home tended to cite child-related reasons for doing so, those who placed the individual out-of-home did so usually based on a combination of factors, of which family dynamic-, personal physical and/or mental health-, and service-related factors were reported to be most common. The respondents in the present study who were caring for their child or family member at home tended to be younger than those who had already placed their loved one out-of-home. This suggests, as do the findings in the literature review, that they may not have experienced many of the burdens that arise for aging caregivers in terms of physical care.

Findings from the current study suggest that unique qualities in each family system and culture determine how the family copes with the individual’s disability and ultimately whether they choose in-home care or seek out-of-home placement. The majority of respondents with a child or family member living in-home in the current study were parents or family members of individuals under the age of 18, a normal time for which an individual is expected to live in-home whether they have disabilities or not.
As discussed in the literature, normal launching years occur in late adolescence or early adulthood and since these individuals have not reached this stage, it is difficult to say whether or not they will eventually be placed in out-of-home settings, though studies support the notion that they will be.

The present study found that White respondents were significantly more likely to have placed a child or family member with disabilities out-of-home, while the Hispanic/Latino respondents tended to care for their loved one in-home. As Heller et al. (2007) demonstrated, minorities are less likely to place their child or loved one out-of-home possibly due to cultural beliefs that it is a family’s responsibility to take care of its members. Heller et al. (2007) further stated that these groups are less likely to apply for or receive formal services for family members with developmental disabilities and suggest this could be the result of distrust of formal service providers, as well as a tendency to rely more on other family members. With this trend, it is vital that service providers, including social workers, provide culturally competent services in which individuals with developmental disabilities and their families feel supported and empowered in whatever decision they make, be it in-home care or out-of-home placement.

To highlight the uniqueness of each individual’s situation, two individuals with developmental disabilities from the present study are considered in terms of similarities, differences and current placement. Both individuals are White, non-ambulatory females in their 60s, who have cerebral palsy as their primary diagnosis. Despite similarities in disability type, ambulatory status, age, and race, their placement outcomes were different.
The 62-year-old woman currently lives in-home with her sister after years of living in institutions and community-based facilities. The 67-year-old woman lived in-home with her mother until the age of 65, when her mother passed away, resulting in a sudden need for placement.

The difference in placement for these two women is likely due to the unique combination of factors. The respondent, whose 62-year-old sister currently lives in-home, reported her sister was placed in an institution at a young age, and after several bad experiences which included alleged abuse and neglect, her family came to the decision she would be better cared for in-home. To the contrary, the 67-year-old woman currently living in an out-of-home facility, was cared for in-home by her mother for 65 years, and was placed with some urgency after the sudden death of her elderly mother.

One factor that may account for the differing placements includes the presence of siblings. The 67-year-old woman, who was placed out-of-home suddenly, is an only child, while the 62-year-old woman living in-home with her sister is one of three children in the family. As the literature shows, siblings often take on the caregiver role once their parents are no longer able to do so (Freedman, Krauss, & Seltzer, 1997). Perhaps the presence of a sibling in the first case would have resulted in continued in-home care for the now placed woman. Another factor possibly influencing the difference in placement includes the level of mental retardation, and resulting level of function. The woman now placed out-of-home has a diagnosis of severe mental retardation, while the woman living in-home has a diagnosis of moderate mental retardation. As Haveman et al. (1997)
reported, the more dependent the individual with disabilities is, the more likely he or she is to be placed out-of-home.

**Implications for Social Work Practice**

As the field of developmental disabilities continues to grow, social workers will need to assist individuals with developmental disabilities and their families in areas such as placement, service coordination, individual counseling, and advocacy. Large-scale institutions specializing in custodial care are no longer accepted and have been replaced by a variety of community-based settings that are congruent with the normalization trend in which the least restrictive environment and greatest level of independence are promoted. Social workers must engage in client-centered and strengths-based practices that promote optimal level of functioning in the various settings now available to this population, whether it is in-home with family, in a community-based care facility, or in the individual’s own apartment.

Keeping in mind the uniqueness of each situation, trends in placement can serve to inform social work practice and the field of developmental disabilities by supporting individuals and their families, and coordinating services accordingly. Educating individuals with developmental disabilities and their families, with regard to in-home supports and community-based placement options is imperative to ensure informed decisions are made. Finally, recognizing the influence of culture in the placement decision can help inform the types of services offered to this diverse population.

Knowledge of culturally competent practices for people working with individuals with developmental disabilities and their families is vital.
Limitations

There were several limits to this study, one of which was the small sample size. Due to the purposive method used to recruit participants, and the small sample size, tests of significance were limited and cannot be generalized as being representative of the greater population. Related to the small sample size, is a relative lack of diversity in the sample; only White and Hispanic/Latino individuals were part of the present study.
APPENDIX A

Placement Decision Study Questionnaire

Research Question: What key factors influence the decision of whether to care for a developmentally disabled loved one in-home or to seek out-of-home placement?

Respondent’s Information:

1. Your relationship to individual with developmental disabilities:
   - Biological Mother [  ], Biological Father [  ], Adoptive parent [  ], Family member [  ]
   - Other [  ] Please explain: ________________________________

2. Your Age:
   - 18 – 25 [  ], 26 – 35 [  ], 36 – 45 [  ], 46 – 55 [  ], 56 – 65 [  ], Over 65 [  ]

3. Your Race:
   - American Indian or Alaska Native [  ], Asian or Other Pacific Islander [  ],
   - Black or African Descent [  ], Hispanic/Latino [  ], White [  ],
   - Other [  ] ____________________

4. Total number of children (biological or otherwise) raised in family: _______

5. Sibling rank of individual with developmental disabilities:
   - 1\textsuperscript{st} born [  ], 2\textsuperscript{nd} [  ], 3\textsuperscript{rd} [  ], 4\textsuperscript{th} [  ], 5\textsuperscript{th} [  ], 6\textsuperscript{th} [  ], ___\textsuperscript{th} [  ]

6. Number of children with developmental disabilities in immediate family: _______

Survey questions regarding individual with developmental disabilities:

7. Current age of individual with developmental disabilities: _____ years

8. Individual’s Primary Diagnosis:
   - Autism [  ], Cerebral Palsy [  ], Down Syndrome [  ], Genetic Disorder [  ],
   - Learning Disorder(s) [  ], Mental Retardation [  ], Other ____________________
9. Individual’s Level of Mental Retardation:
   Mild [   ], Moderate [   ], Severe [   ], Profound [   ], Other______________

10. Is the individual: ambulatory (walks) [   ] or non-ambulatory (does not walk) [   ]

11. Current living placement of individual:
   My Home [   ], Family Member’s Home [   ], Foster Care Home [   ]
   Independent Living Services (ILS) [   ], Supported Living Services (SLS) Home [   ]
   Adult Residential Facility (ARF) [   ], Skilled Nursing Facility (SNF) [   ]
   Intermediate Care Facility (ICF) [   ], Developmental Center (DC) [   ]
   Other [   ] Please explain: _____________________________________________

12. If the individual is currently living in your home, do you have plans to place him/her in an out-of-home care facility within the next year?:
   Yes [   ] No [   ] (answer question 13)

   Go to question 14

13. Please list key reasons you have chosen to care for the individual in-home. (use the back of this page for additional space)
   • ____________________________________________________________
   • ____________________________________________________________
   • ____________________________________________________________
   • ____________________________________________________________
   • ____________________________________________________________
   • ____________________________________________________________
   • ____________________________________________________________
   • ____________________________________________________________
   • ____________________________________________________________

14. If the individual is not living in your home, at what age was he/she placed in out-of-home care?:
   _____ years
15. The following factors were/are influential in my decision to place the individual in an out-of-home setting or to care for him/her in-home: (Please check all that apply)

- My age [  ]
- Individual with disability’s age (natural transition after school, etc.) [  ]
- Level of care necessary was beyond that which I could provide, physically [  ]
- My social life was affected/restricted [  ]
- My career was affected/restricted [  ]
- I am/was a single parent [  ]
- Siblings:
  - Time demands took away from attention paid toward siblings [  ]
  - Siblings were affected by behaviors of developmentally disabled child [  ]
- Marital stress [  ]
- Behaviors:
  - Aggression toward others [  ]
  - Self-injurious behaviors [  ]
- Caregiver stress (feeling overwhelmed, etc.) [  ]
- Financial reasons [  ]
- Medical/health of individual were beyond what I could handle [  ]
- My medical/health [  ]
- Distance of available out-of-home facilities:
  - I am able to visit him/her regularly [  ]
  - I am not able to visit him/her regularly [  ]
- Quality of facility or facilities available in my area [  ]
- Stigma (the way others respond to myself or the individual’s disability) [  ]
- Pressure from friends or family [  ]
- Religious or moral obligation [  ]
- Cultural reasons [  ]
- To promote independence/normalization of the individual [  ]
- The individual expressed the desire to move out [  ]
- Other [  ] Please list other factors that influenced your decision.
  - __________________________________________________________
  - __________________________________________________________
  - __________________________________________________________
16. Which of the following person(s) did you talk to about your decision? (Check all that apply)

Family members [ ], Friends [ ], Clergy or church members [ ], School staff [ ],
Medical Staff (doctors, nurses, etc.) [ ], Regional Center Service Coordinator [ ],
Other parent(s)/guardian(s) of developmentally disabled individual(s) [ ],
Social Worker [ ], The individual him/herself [ ], Other [ ] ______________________

17. Did you feel well-informed about placement options during the decision-making process?
Yes [ ], No [ ]

18. List the person(s) / professional(s) who were most helpful during the decision-making process.
a. ____________________________ b. ____________________________ c. ____________________________

19. List the person(s) / professional(s) who you wish you had spoken to during the decision-making process.
a. ____________________________ b. ____________________________ c. ____________________________

20. What advice would you give to an individual faced with the decision of whether to care for an individual with developmental disabilities in-home or to place him/her out-of-home?

• ______________________________________________________________
• ______________________________________________________________
• ______________________________________________________________
• ______________________________________________________________
• ______________________________________________________________

21. Are you willing to participate in a follow-up interview to allow the researcher to get a more in-depth understanding of your experience?
Yes [ ], No [ ]

• If yes, please check your preferred method of contact:
  Phone [ ], E-mail [ ], Written survey (such as this) [ ], In-person [ ]
Contact information for follow-up interview:
  Name: ________________________________
  Contact number and/or email: ________________________________

  ✷ ✷ ✷ ✷ ✷

Please return survey and consent form in the enclosed stamped envelope.
Thank You for participating in this study!
APPENDIX B

Introduction Letter to Potential Participants

December 18, 2011

Dear Family Member,

As many of you know, after serving as a QMRP with Woodland Residential Services for the past six years, I have begun pursuing my Master’s degree in Social Work. This course of study will further my ability to serve vulnerable populations including the developmentally disabled community which I hold dear to my heart. For my Master’s Thesis, I have chosen to research factors which influence the decision to care for a developmentally disabled loved one in-home or to place them in and out-of-home care setting. My hope is to identify areas of need to assist families facing such a decision in the future. In an effort to gain the greatest insight, I have chosen to gather data from individuals who have first-hand experience, the families of Woodland Residential Services clients.

I am enclosing a letter of support from Shelly Kenealy, Administrator/Owner of Woodland Residential Services, a consent form, as well as a questionnaire that should take a short amount of your time to complete. Please return the completed and signed consent form and questionnaire in the enclosed stamped envelope. If for any reason you choose to not participate in the study, please send the “decline to participate” form in the enclosed stamped envelope.

Please feel free to contact me at (XXX) XXX-XXXX with any questions regarding the research study.

Thank you in advance for your support in my research endeavor!

Sincerely,

Rachael A. Bernath
APPENDIX C

Letter of Support from Administrator of Woodland Residential Services, Inc.

Woodland Residential Services, Inc.
1381 East Gum Avenue
Woodland, California 95776

5 October 2011

Committee for the Protection of Human Subjects
California State University, Sacramento
6000 J Street
Sacramento, California 95819

Dear Committee for the Protection of Human Subjects,

I am writing this letter in support of Rachael Bernath’s Master Thesis research proposal to explore key factors in the decision-making process parents/guardians experience when determining whether to care for their developmentally disabled child in-home or to consider out-of-home placement. Rachael worked as a Qualified Mental Retardation Professional (QMRP) for Woodland Residential Services, for six years and prior to this worked as a Program Counselor in a local Adult Residential facility for five years. As such, she has proven to have a great care for and, desire to improve services for the developmentally disabled community.

I understand that she will be contacting families of WRS clients, participation will be voluntary and participants will remain confidential, and may drop out of the study at any time. All HIPPA laws will be strictly adhered to as well. After discussing the proposal with Rachael, I am confident her study has the potential to contribute to and improve services rendered by Woodland Residential Services, and other community-based care facilities, as well as to parents in the community who are caring for their child in-home and may be considering placement options.

Sincerely,

Shelly Kenealy
Owner/Administrator
Woodland Residential Services, Inc.
APPENDIX D

Consent to Participate in a Research Study

I ____________________________ have been asked to participate in a Master Thesis research study under the direction of Rachael A. Bernath, a graduate student in the Master of Social Work program at Sacramento State University, who can be reached by phone at (XXX) XXX-XXXX, or by email at xxxxxx@xxxxx.com.

Purpose:
I understand that the purpose of this study is to identify key factors which influence a parent’s/guardian’s decision to care for their developmentally disabled child in-home or to place the child in and out-of-home setting. I also understand that the data collected may be used in determining whether there is a need for additional resources to assist future parent(s) or guardian(s) in making such a decision in the future.

Duration and Location:
I understand that I am being given the opportunity to complete the survey in a location of my choosing and at my leisure, and that the survey should take less than 60 minutes of my time. I also understand there may be a follow-up interview in-person, via telephone or electronic mail. The length of follow-up interviews will depend on the nature of the questions developed by the researcher, but it is expected this will take no more than 60 additional minutes of my time.

Procedures:
I will be asked to complete a written survey and to return my completed survey to the researcher in-person or via U.S. postal service in a self-addressed stamped envelope which is being provided to me. I also have the option of requesting to fill out the survey electronically and e-mailing my responses to the researcher, by request, if I so choose. Should I choose to not participate in the study, I will return the “decline to participate” form in the self-addressed stamped envelope provided. I understand I have the opportunity to participate in a follow-up interview based upon my survey answers, and can indicate this on my survey. Follow-up interviews will occur in-person, via telephone or via electronic mail, at my convenience.

Risks/Discomforts:
I have been informed that some survey and/or interview questions may cause discomfort due to the nature of the subject being studied. I have been advised by the researcher, that I may discontinue my participation in the study at any time. I have also been informed that should I feel the need to discuss my feelings with someone, I can contact Sacramento County Mental Health at (916) 875-1055 or visit the department at 2150 Stockton Blvd. in Sacramento.
**Benefits:**
I understand my participation in this study may help researchers better understand the key factors which influence parents of developmentally disabled children in their decision to care for their child in-home or to consider out-of-home placement, and may be used to identify resources that may benefit others faced with this decision, as well as professionals who work with them.

**Confidentiality:**
I am aware that my information and responses will be confidential and will be known only to the researcher for the purpose of follow-up interviews. I understand that only group information will be reported.

**Compensation:**
I understand that this research study is for the purpose of increasing awareness of and need for resources with regard to in-home or out-of-home placement of developmentally disabled children, and as such, I will not be compensated for time spent filling out the survey or participating in interviews.

**Right to Withdraw:**
I understand that my participation in the research study is voluntary and I may withdraw from the study at any time by notifying the researcher in writing.

**Signatures:**
I have read and understand this consent form in its entirety and by signing below am voluntarily agreeing to participate in this research study. I will be provided with a copy of this consent and have been advised that I may contact the researcher, Ms. Rachael Bernath, at (XXX) XXX-XXX or her Master Thesis advisor, Dr. Francis Yuen, DSW at (XXX) XXX-XXXX, to discuss any part of the research process.

_________________________________________  __________________
Signature                                           Date

_________________________________________            
Print Name
APPENDIX E

Research Study Declination Form

I have been informed of the opportunity to participate in a research study under the direction of Rachael A. Bernath, a graduate student in the Master of Social Work program at Sacramento State University. At this time, I do not wish to participate in this study.

Name: _________________________________    Date: ____________________
REFERENCES


*The state of the states in developmental disabilities: 2005.* Department of 
Psychiatry and Coleman Institute for Cognitive Disabilities, University of 

Braddock, D., (2002). Public financial support for disability at the dawn of the 21st 


*Deinstitutionalization and community adjustment of mentally retarded people* (pp. 

placement for young children. *Mental Retardation, 38*(1), 50-60.

Developmental Disabilities Services Act.* Retrieved November 11, 2011, from 

Chan, J.B. & Sigafoos, J. (2001). Does respite care reduce parental stress in families with 
developmentally disabled children. *Child & Youth Care Forum, 30*(5), 252-263.


