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## Understanding the experience and needs of foster parents caring for medically fragile children

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UNDERSTANDING THE EXPERIENCE AND NEEDS OF  
FOSTER PARENTS CARING FOR MEDICALLY  
FRAGILE CHILDREN

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A Project  
Presented to the  
Faculty of  
California State University,  
San Bernardino

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In Partial Fulfillment  
of the Requirements for the Degree  
Master of Social Work

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by  
Ana Maria Baisley

June 2003

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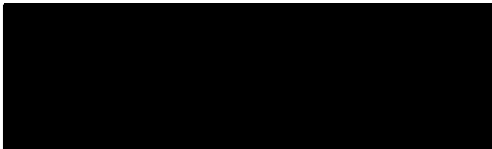
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Approved by:

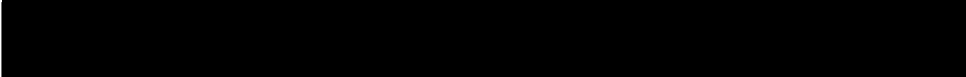


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*May 22, 2003*  
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## ABSTRACT

Large numbers of foster children with significant medical problems continually enter the child welfare system even though there is a shortage in the number of foster parents with both the ability and willingness to care for them.

The purpose of this study was to develop a better understanding about the experiences and needs of foster parents who care for medically fragile children and to identify characteristics related to providing quality care. The study was intended to generate knowledge about services medically fragile children are receiving in foster care in an effort to improve their medical condition and provide stability of placement. The study looked specifically at the specialized medical training, the amount of services provided to the children and the coping ability of the foster parents.

The research employed quantitative and qualitative research design utilizing a personal interview questionnaire and a 22-item Likert Scale questionnaire. The sample consisted of 26 foster parents caring for 76 medically fragile children in Los Angeles County.

The results of the study supported the hypothesis that the specialized medical training, and the number of years foster parents spent caring for medically fragile children was related to the on going length of time particular children remained in their care (stability of placement). The amount of services medically fragile children received and coping ability of the foster parents had little correlation with the stability of placement.

## ACKNOWLEDGMENTS

I want to thank Dr. Ray Liles, my faculty advisor for his guidance in the project. Your expertise provided invaluable support and is greatly appreciated.

## DEDICATION

I would like to dedicate the thesis to my husband Daryl R. Baisley and my two daughters Natalia V. Baisley and Deidre N. Baisley who supported and stood by me during the challenges of the Master in Social Work program. I would like to also dedicate the thesis to my parents Vincenzo and Dosolina Scopino who have taught me to persevere and strive to be the best.

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## CHAPTER ONE

### INTRODUCTION

#### Problem Statement

According to Simms (2000), children in foster care are the least healthy and most needy group in the United States. Despite efforts to prevent child abuse and neglect and decrease the rate of out of home placement of maltreated children, the number of children in foster care has risen steadily over the past two decades.

Between 1986 and 1995, the number of children nationwide in foster care rose from 280,000 to 494,000, which is an increase of 76% (Chua, 1999). The nearly half million children in out of home care suffer from serious, often chronic, medical problems, including asthma, malnutrition, anemia, neurological disabilities and HIV infection. Many experience mental health and emotional problems, as well as delayed growth and development. Appropriately, 20% have developmental disabilities such as mental retardation or cerebral palsy or suffer from speech, hearing or vision problems (Chua, 1999).

The Child Welfare League of America (1998) indicates that the number of children in foster care increased,

providers steadily decreased from 147,000 in 1985 to only 125,000 in 1994. There is not only a shortage in the overall number of foster families, but there is also a shortage of foster families with the ability and willingness to parent medically fragile children. The Center of Social Services Research University of California, Berkeley reported in July 2001 that children who entered foster care remained in care an average of two and one half years and they are more likely to experience three or more replacements.

Hughes and Rycuss (1998) reported that the recent era of child welfare has been characterized by increasing caseloads, growing numbers of infants and toddlers entering care, reduction on the available foster homes and large numbers of children in ill health.

According to Ruptier (1997), children are entering the foster care system in large numbers, at earlier ages and with higher frequencies and severities of health problems than ever before. Further, Ruptier stated the health problems of children in foster care, which are most related to pre-placement circumstances (lack of prenatal care, drug exposure, lack of preventive and illness care, inadequate nutrition, abuse and neglect),

impose an increasing responsibility on public agencies to address the foster child's health needs. Once the child enters dependency, the health care received may not improve. Child protective agencies have been characterized as lacking coordination, continuity and documentation.

The health care system has not responded to the special needs of children in foster care. Fragmented by changes in health care financing, and lacking influence on the child welfare policies and practices, health care providers struggle with inadequate information about the children, inability to follow up on intervention and limitations in the types of services and consultation the children may receive (Simms, 2000).

Halfon and Klee (1987) studied health services used for California's foster children. The organization of health services demonstrated a high degree of variability between counties. Seven of the 14 counties report that all children received an initial medical evaluation, whereas the remaining seven counties report providing this service only to children who are abused, neglected, ill or injured. Eight of the 14 counties have designated examination sites, and three counties in which children

pass through a shelter, an on-site nurse performs the evaluation. The remaining counties rely on staff physicians in county hospitals and clinics. Although some counties initially evaluate all children by using specific protocols and examination sites, services are often poorly organized, fragmented and inadequate for the health care needs of the children.

The passage of P.L. 96-272, the Adoption Assistance and Child Welfare of 1980 (Groze, Haines-Simeon, & Barth, 1994), established a national policy affecting permanency initiatives for children in the foster care system and those at risk of entrance into the Child Welfare System. The legislation emphasized preservation of the family at risk of disintegration, reunification of children with the biological family if children are in out of home care, promotion of adoption if reunification cannot be achieved guardianship and long-term foster care. Child welfare service providers were legally mandated to provide effective and timely permanency planning of these options. This legislation has particular relevance for children with special needs. The term "special needs" has been defined to include older children, adolescents, handicapped children, sibling groups, children with

emotional and behavioral problems, and children of minority or biracial heritage (Groze et al, 1994).

Bonner and Crow (1997) stated that researchers define disability using the Americans with Disability Act of 1990 (ADA: PL101-336-7/90). According to the ADA the term disability means that an individual has a physical or mental impairment that substantially limits one or more of the individual's major life activities, has a record of such impairment or is regarded as having such impairment. This definition includes children and adolescents with all types of disabilities, including intellectual, or learning disabilities, physically disabling conditions, motor and sensory disabilities, mental illness or any other kind of physical, mental or emotional impairment.

Established by the Department of children and Family Services in the assessment of and services for medically fragile children, specialized medical placement units were created to place medically fragile children that were referred to the Department of Children and Family Services for abuse and neglect, in foster homes instead of long term hospital institutionalization. Placement in the homes of specially trained foster parents is used



whenever it is deemed to be the best interest of the child.

The Bates bill (AB636) was enacted into law in California on February 22, 1993. It provides funding for services for children with specific medical problems. It amended the definition of children with special health care needs and broadened the scope of medical conditions that required in home health care. It also authorized the placement in specialized foster care of children with medical conditions requiring in home health care who are either dependents of the Juvenile Court, or in the custody of the county welfare department (voluntary placements) or receiving Regional Center services.

The Bates Bill also defined "medically fragile children" as children with special health care needs or medical conditions or symptoms, which require special procedures, equipment, devices, therapies or ongoing medical care and assessments. In order to qualify under the Bates regulation the child must have one or more of the following conditions: 1) a chronic disease or illness (e.g. diabetes, HIV/AIDS, sickle cell anemia, organ failure, etc) that, without proper care, could rapidly lead to permanent injury or death; or 2) depend on some

type of technology (e.g., apnea monitors, oxygen, feeding tubes, pulmoaids, medication regimens, including injection, intravenous medication, etc.). The terms medically fragile child and Bates eligible are often used interchangeably by DCFS. A variety of factors must be considered in determining Bates eligibility, including the actual medical diagnosis, life threatening illnesses, developmental delays and dependence on technologies.

Foster parents of medically fragile children must be trained to recognize the onset of symptoms requiring the intervention of health care professionals. It is essential for training to occur prior to foster placement to ensure adequate health services are provided. No more than three medically fragile children can reside in a specialized foster care home with the exception under special circumstances and approval from their supervisor. The Bates legislation is designed to insure that these vulnerable children receive the best care in the least restrictive, most family-like setting.

As noted above, Ruptier (1997), and Halfon and Klee (1987) state that foster parents experience problems dealing with the health care system due to the complex medical needs of the children, lack of resources in the

community, fragmentation and poor coordination of services. Since the daily care of medically fragile children is a very demanding and taxing experience, there are limited numbers of foster parents willing to take the challenge and accept chronically ill children into their homes. One study found that the number of available foster homes decreased from 147,000 nationwide in 1987 to approximately 100,000 three years later (Chua, 1999).

Tavormina, Hampton, Grieger, and Tedesco, (1977) stated that the needs of the handicapped are greater, as is the burden placed upon their prospective caretakers. Aside from the "normative" social and emotional stresses of the typical foster child, handicapped children addition stressors of day-to-day management, re-socialization, and remedial requirements, all of which tax the strength of the foster parent. Consequently, such children have become difficult to place.

Medical foster parents must be trained specifically on the care of each child before placement can occur, as per the Bates' bill. Often times children are ready for discharge from the hospital before a foster home can be located and training arranged. The availability of medical placement foster homes in Los Angeles County has

been very limited. According to statistics from the County of Los Angeles, Department of children and Family Services, March 2002, there are 32,780 children in out of home placement and 6,982 beds available in foster homes. There are 2,038 medically fragile children receiving specialized care rates in out of home placement. Currently, the number of medical foster placements homes is close to 300 homes. The recruitment of foster parents to care for seriously ill children is difficult due to the extensive requirements and specialized training involved. At this time, there are not enough medical foster parents willing to take medically fragile children.

The purpose of the current study is to develop a better understanding about the experiences and needs of foster parents who care for medically fragile children. Specifically, this study focused on documenting the services medically fragile children are receiving in foster care in an effort to improve their medical stability of placement. Furthermore, the study identified obstacles and problems that foster parents face in providing the best care possible for medically fragile children. The study examined how the medical placement

units in the Department of Children and Family Services could improve service delivery to the medically fragile children who are coming into the system in large numbers due to abuse and neglect and are placed in these medical placement foster homes.

Due to the complexity of caring for a medically fragile child and the extensive coordination of services in the health care system, foster parents face a heavy burden when they try to care for medically fragile children. Melnyk and Feinstein (2001) state a commonly cited source of stress for parents was the "arduous day to day treatment" (p. 574) described as the "chronic burden of care" (p. 574). The authors explain that the day-to-day challenges frequently affect parental relationships and family life. Balancing the competing demands from the child's chronic illness daily responsibilities is challenging and exhausting.

As reported by the Department of Children and Family Services (2002), there were 2,038 medically fragile children entering foster care in Los Angeles and there are not enough available medical foster homes to properly care for these children with severe medical needs. Kirk (1998) stated children used to remain in unnecessary

extended hospitalizations or placed in facilities where the care provided was not adequate. Medical advances have led to the emergence of a group of chronically ill children who are dependent upon technology for their survival. There is also evidence that the technologically dependent child's quality of life, physical functioning and overall development may improve as a direct result of being cared for in the home.

Another significant reason for this project is to look for ways of lowering risk of abuse or abuse of the medically fragile children. Sullivan and Knutson (1998) collected data from 35 Child Protective Services agencies selected to be nationally representative of U.S. counties. Results indicated that 14.1% of the children whose maltreatment was substantiated by Child Protective Services Workers had one or more disabilities. Additionally, 47% of cases involved children with disabilities and CPS workers reported that, in their opinion, the disability either led to or contributed to the abuse.

Foster parents who are caring for medically fragile children need to be properly trained to care for the children and to deal with various service providers and

bureaucracies. When recruiting foster parents, social workers need to assess the ability of these foster parents to adequately address the medical needs of the children and participate in an array of services of hospitals and other institutions (Luginbill & Spiegler, 1989). Medical foster parents need supportive services to manage the complexity of caring for children with medical needs such as: respite care, specialized equipment, on-going medical treatment, special education, physical therapy, recreational outings and involvement with parents. Foster parents need to understand how the services are obtained and work in expanding services available to children in their care.

The findings of this study will help Child Protective Services better understand how medically fragile children should be cared for in a medical foster home and identify characteristics of medical foster parents which are related to providing quality care. This study hopes to change how child welfare agencies and social workers work with medically fragile children and the foster parents in Child Protective Services. Learning about how foster parents care for the medically fragile

children will provides more knowledge on the standard of care for these children.

In addition, this study could help maintain stability in placements and decrease the number of re-placements. Social workers may gain additional information working with medically fragile children and medical foster parents. As a result, policies regarding the placement and the care of medically fragile children in foster care might change. Agencies involved in the care of medically fragile children could use the findings of this study in the training of professionals and foster parents.



CHAPTER TWO  
LITERATURE REVIEW

Introduction

The literature associated with the health care system and foster care was reviewed. Studies that focus on selection and training of specialized foster parents to care for medically fragile children at home were evaluated. Literature associated with the child protective system, children with disabilities and placement stability was also reviewed. In addition, the care of children with chronic illness, technology dependency and life expectancy was assessed. Information regarding medical foster parents caring for medically fragile children and how child protection agencies are assisting with coordination of services and service delivery was reviewed.

Needs of Children Entering  
Foster Care

Hochstadt, Jaudes, Zimo, and Schachter, (1987) looked at abused and neglected children entering the foster care system. They found no studies comparing the health status of abused children in foster care with

those in the care of their natural parents. However, they did find studies that indicated that children in foster care have increased incidence of chronic medical problems, developmental delays school problems, psychiatric problems and behavioral disorders. The estimated three to four hundred thousand children in foster care represent a population high in medical and psychological problems. Problems are compounded by the lack of adequate resources available to them while in foster care. The researchers screened 149 abused and neglected children. The goal was to generate a profile of medical and psychosocial needs of children entering the foster care system as a step towards developing a better service care delivery system. Results indicated that these children have a much greater incidence of chronic medical conditions, higher incidence of developmental delays and mental deficits in adaptive behavior and have a larger number of behavioral problems often associated with psychiatric disorders.

Ackert, Flaherty, Harisiades, and Hart, (2000) stated that the integrity of medical care is severely compromised as many children in foster care moved from one foster home to another. The authors indicated "foster

children are among the most vulnerable individuals in the welfare population. As a group they are sicker than homeless children living in the poorest sections of our inner cities" (p. 3). The authors stated that information about the foster children previous medical problems and physical and psychological needs typically fails to move with them from medical care provider to medical care provider. Even when the medical needs of the child are documented, foster families may not have access to appropriate care and services. This is further exacerbated by the trend towards managed care, in which fewer providers authorize the specialized treatments foster children require.

#### Specialized Foster Care

According to Hawkins and Breiling (1989), therapeutic or specialized foster family care serves a wide variety of children and adolescents, including the retarded, the moderately disturbed, the severely disturbed, the delinquent and the medically fragile. All therapeutic foster families seem to have certain general characteristics in common:

- (a) They involve a youngster being placed out of home with an alternative family;
- (b) the

alternative family, is more carefully selected than are regular foster families; (c) the family is given some kind of pre-service education or training and often in-service education as well; (d) the family is supervised and/or assisted more intensively than regular foster families, with about six to 20 families per professional and (e) the family is reimbursed at a rate between the reimbursement rate of regular foster parents and the salaries of the professional staff members who supervise them. (p. 30)

Specialized foster home care has been defined as "Specialized family care for children with developmental disabilities: the Finnish experience" by Szymanski and Seppala (1995) as "a residence owned or rented by a family as their home, with one or more persons with mental retardation living as family members" (p. 367). In earlier years, this type of care was primarily custodial; later, it was expected to include active treatment plans. The general tendency was to place in foster homes persons who were older and had a significant degree of retardation, although all ages have been represented. The average stay of persons with mental retardation in specialized foster homes is usually longer than in-group homes and thus the foster home placement are more stable. It was described: "incorporation of the fostered individual into the family, and into the community, with

use of community resources; the provision of a personalized home environment and improvement on adaptive behaviors" (Szymanski & Seppala, 1995).

Lunginbill and Spiegler (1989) reported in their article called "Specialized foster family care" that the Medical Foster Parent Program of the Children's Home and Aid Society of Illinois and La Rabida Children's Hospital and Research Center in Chicago was designed to locate families and achieve permanency planning for a small number of seriously ill children who had been residing at the hospital. The authors explained the children were under the custody of Illinois Department of Children and Family Services and the recruitment of specialized foster families was done from the general population as well as the existing pool of licensed foster families. Training for specialized foster parents focuses on their role as part of the child's health care team, emotional factors involved in caring for serious or chronically ill children, care of children with specific medical problems or disorders, and community resources that might be helpful, as well as other areas included in the agency's regular foster parent training course. In addition to the intensive training, the project provides foster parents

with a number of other support services, including nursing care based on the individual child's needs; medical equipment and supplies; coordination of social and medical services; follow up medical care and a specialized foster care board rate.

#### Selecting and Training Foster Parents

According to Tavormina et al, (1977), when selecting and screening foster parents, there are a number of conditions that need to be followed. The authors stated that the research demonstrated that selection-screening criteria are necessary for optimal placement success and that foster parent variables such as age, education, motivation and capabilities to accept and adequately deal with specific children should enter into the process. The effectiveness of foster care lies in the therapeutic abilities of the foster parents. The authors concluded that it stands to reason that a multi-problem client who will be more of a burden on his caretakers will need to be placed with parents who have had more systematic training, evaluation and maintenance to deal with such children.

Orme and Buehler (2001) critically reviewed the literature on family foster care and integrated key findings with research information on how family life affects children's social and emotional adjustment in the general population. Influential factors include parenting, the family home environment, family functioning, marital functioning, family demography, personal temperament, parent's mental health and social support. The researchers found that 15-20% of the approved foster parents and families have problems in their home environment, family functioning and parenting. The authors were not able to estimate the proportion of parents and families with problems in terms of parental mental health, marital conflict, social support and general temperament. However, the results of the study suggested a link between foster parents and family characteristics and behavioral and emotional problems of foster children. Specifically, foster children's socio-emotional well being is better when foster parents are more accepting, authoritative and discipline using non-power assertive strategies.

Smith (1996) reported that in 1988 the Cabinet for Human Resources initiated a foster care program for

children with moderate to severe medical conditions. In response to increasing referrals by hospitals around the state for sick children and birth parents unable to provide the necessary care. Smith said the underlying concept of foster care is that children thrive in families and that children with long hospital stay lose out socially and emotionally. The author indicated that her experience has shown that children in medically fragile foster homes require fewer hospitalizations and tend to do well developmentally. Nurses as foster parents play a vital role and the nursing skills are used to perform daily care needs and to provide emotional stability and support. The Cabinet for Human Resources needs more foster parents with pediatric nursing background and with the ability to work in a team with child welfare professionals.

#### Permanency Planning

Groze, Haines-Simeon, and Barth (1994) reported foster families serve an important function in the permanency planning of all children; however, there are unique aspects to fostering drug exposed and HIV infected children. One of the issues that go beyond the discussion



of these medically fragile children is the lack of available foster homes in general. The growing crisis in the child welfare system is attributed to the growing needs of drug-exposed children. Connected to this growing population of children needing foster care is a growing crisis in the number of foster families. The authors cited that the GAO study (1990) specified this growth. In New York, referrals increased by 268% over 4 years between 1986 to 1989. In Los Angeles referrals increased by 342% and in Chicago by 1,735%. The researchers indicated that the number of foster parents has fallen by 34% since 1992. Issues of difficulties in providing care for the children are related to foster families' concerns about the extent of developmental and neurological damage to the affected child. This is directly related to the impact of the child upon the foster family and the foster family's ability to provide services equivalent to the child's needs. Limited resources of the child welfare system also affect the child prior to arrival into the foster care system. The authors referred to statistics given by Child Welfare League of America (1992) study of hospitals with resident babies, 90% of the hospitals cited the child welfare system as a major contributor to

the occupancy baby problem. Due to the shortage of trained foster parents, understaffed agencies with overwhelming caseloads and no weekend services, medically cleared infants were often forced to extend their stay at hospitals.

#### Home Care of Medically Fragile Children

Patterson, Leonard, and Titus (1992) studied the health status of 48 families providing home care for their medically fragile children. They measured adaptation by looking at the demands and capabilities of the parents. The authors found that more families are providing a level of care in their homes that previously was done only in hospitals or nursing homes. Contributing to this growing trend toward home care for medically fragile children are (1) improved survival of children with serious pediatric diseases, (2) rising hospital cost, (3) reduced payments for inpatient care by private and public payers, and (4) concern about adverse developmental consequences for children in prolonged institutional care. Although early clinical reports suggest that medically fragile children do as well or better at home, reports of the impact on the family from

providing this level of care are only now beginning to emerge. The long-term impact on the family that care for technology assisted children suggest that parental coping declines over time.

#### Management of Chronic illness

Singer and Farkas (1989) stated that successful adaptation to chronic illness or disability for infants is an important factor of the family's ability to cope with the stresses involved. There are few guidelines for practitioners interested in strengthening parents' ability to manage their care giving roles. An understanding of the caretakers' perceptions of the stresses related to such care is essential to foster caregiver coping and to avoid prolonged hospitalizations for children. Greater understanding of the stresses that caregivers have caring for developmental disabled or chronically ill infant can aid family workers who must provide support to caregivers. The authors stated the use of mutual help approaches to improve social supports as an effective way to develop and enhance coping skills. Mutual help involves the use of peer counseling, educational seminars, small groups and social support

with or without professional leadership. Mutual help does not take the place of services from professionals; however, the strength of mutual help in promoting mastery involves elements of social support.

Kirk (1998) stated that parents caring for technologically dependent children are faced with trying to find professionals in the community that are trained for the special needs of the children. Services are often fragmented, duplicated and poorly coordinated between the community and the specialist. There is evidence of confusion over medical responsibility with parents being unclear whether the primary care physician or specialist is responsible for the child's care. Obtaining the equipment required and the services to support its use in the home can be problematic. Parents can experience problems in getting their child's needs assessed, with transportation to school and with educational provision for children with such specialized needs.

#### Technology Dependent Children

According to Cohen (1993), biomedical and technological advances have improved the life expectancy of children with chronic, life threatening illnesses.

Long-term survival is expected for most children, for others, there exists the potential of permanent cure. Consequently, the illness experience for the families of these children has been significantly altered and the tasks required of parents are categorically different. Cohen stated that to live with a child who has a life threatening, chronic illness is to live with sustained uncertainty.

According to Cohen and Martinson (1988) chronic uncertainty is the greatest psychosocial stressor confronting families who have had a child diagnosed with a life threatening illness. For families living with a child whose condition are both chronic and life threatening, uncertainty is a constant, for even if the disease is under control or in remission; parents know that it can reoccur with little or no warning. It is this knowledge that keeps the threat of loss always in awareness. Parents have described the experience as "living with a time bomb" (p. 66) never knowing when it is going to go off (Cohen, 1995).

Melnyk and Feinstein (2001) discussed the stressors of caring of a child who is chronically ill and interventions to enhance coping. The authors stated that

even though the stressors are multiple and on-going they can be categorized as those the parents experience: (a) at the time of diagnosis; (b) during developmental transitions; (c) that are related to the ongoing health care needs of the child and (d) as their child experience illness exacerbations and hospitalizations. Melnyk and Feinstein defined coping as "Constantly changing cognitive and behavioral efforts to manage specific external and internal appraised as taxing or exceeding the resources of the person" (p.574). The authors stated that previous studies of interventions can be divided into four categories: (a) disease specific educational interventions; (b) stress point intervention; (c) problems solving skills training; (d) educational-behavioral intervention to enhance coping.

#### Placement Stability In Foster Care

Mack and Boehm (2002) reported that most foster parents of children with disabilities receive training in an effort to prepare them for medical and other needs of children in their care. Other supports may be scarce for foster and adoptive parents who are caring for children

with disabilities, but organizations like National Foster Parent Association (NFPA) and the National Counsel on Adoptable Children can be resources for these children. One support that is on the rise is respite care and crisis care, allowing parents to take time off to rest and recuperate from the stresses of parenting children with disabilities. Designed to support the family stability, prevent future problems such as abuse and neglect, and avoid out of home placement and hospitalizations, such programs have proven to be critical in caring for children with disabilities.

According to Mack and Boehm (2002), one program that deals with the issues affecting children with disabilities is called New Alternatives for Children (NAC) in New York City. When NAC began in 1982, children with disabilities used to spend years in the hospital, and few agencies were working to reunite them with their families or place them in foster care or adoptive homes, or to preserve families and help them care for their children with disabilities. NAC began moving children out of hospitals through foster care, adoption or reunification with the birth family. The organization added post adoption, and prevention programs to help

families cope with crises and difficulties of disabilities. To help families with less intensive step down services, NAC added post- prevention services such as transportation, recreation and education. One of the areas NAC worked on was the creation of continuous care to have families remain connected with the same medical team to better coordinate the care and avoid fragmentation of services.

#### Theories Guiding Conceptualization

Thurman (1997) stated the term ecology was originally used in the biological sciences to denote the study of interactive systems or the mutual effects of organisms and their environments. Thus, rather than focusing on a single organism, ecology is concerned with the total system in which the organism lives and how it affects its environment and in turn how its environment affects it. Ecology is concerned with the interaction of a system. Ecology is consistent with general systems theory in that it recognizes the interrelationship of each part of a system creates a whole that is greater than the sum of those parts. Ecology is more concerned with understanding mutual effects of individuals and



environments than is general systems theory, which is more concerned with the description of whole systems and the prediction of their behavior.

The social-ecological perspective (Bronfrenbrenner, 1979) is defined as the study of the relation between the developing human being and the settings and context in which the person is actively involved. The model proposes that the child is at the center of a series of concentric circles, which represent settings that have bidirectional influences on the child. The concentric rings that are further away from the child are those that represent societal values and culture, whereas those closer to the child indicate settings of smaller scale, such as family neighborhood, and school (Kasak, 1989).

The social-ecological theory is relevant to children with chronic illnesses placed in foster care as it helps to understand how the foster parents adapt and cope with the children and their mutual effect on each other. This model examines how the other systems such as child protective agencies, health care facilities interact and influence each other. In this model the child is the center of the system, the health of the child has an affect on the health and functioning of the members of

the same family. The service providers are also affected by the health of the child and in turn they impact the child and the family. The social-ecological perspective will provide a framework in this study to help better understand how the medical placement foster parents are able to coordinate and access services, to obtain medical training specific for the child's needs and to cope with the uncertainty of the child's chronic condition.

#### Summary

In summary, there are thousands of medically fragile children with complex medical care entering the foster care system. There is also a shortage of foster homes that are able to care for these children needs. Foster families are having difficulties accessing appropriate care for the children due to fragmentation, duplication and poorly coordinated services in the health care system. Legislation has been passed to provide a clear definition of "special needs" children and the provision of services for the special health care needs while in the child welfare system. Medical placement foster parent is one of the answers to place medically fragile children in home care and to provide an alternative to

hospitalization. The care of the children lies in the foster parents ability to cope over time for children with chronic illness and technology dependency. Foster parents that are properly trained and have medical expertise may be better able to endure the stresses and demands of the daily care of the medically fragile children and provide permanency for the children who are not going to be able to return home. The child welfare system and the medical providers need to work together to support and advocate for the children. Foster parents will be impacted positively by the coordination of services and they will be able to better provide for the children's needs. In turn, the medically fragile children will have placement stability. It is important to monitor across time how medical foster parents are coping with the medically fragile children so the social worker can help them adjust and intervene to ensure the children care is enhanced and obstacles removed. The social-ecological perspective studies the relationship between the person and the setting and context in which the person is involved. This theory will help guide and provide a framework to conceptualize the study.

## CHAPTER THREE

### METHODS

#### Introduction

The purpose of this study is to develop a better understanding of the care of medically fragile. This study looked at the health care system in foster care, access and coordination of services, specialized medical training needed to care for medically fragile and how medical placement foster parents cope with children with chronic illness. The researcher learned about the actions medical placement foster parents are taking to help improve children with the medical conditions and provide placement stability and permanency planning.

This chapter describes the study design, sampling, data collection/instruments, procedures, the protection of human subject and the data analyses.

#### Study Design

This study employed a quantitative and qualitative research design, utilizing a personal interview questionnaire to talk to medical placement foster parents who are presently caring for medically fragile children in their homes. Potential participants for the study were

selected from a list of medical placement foster parents in the Department of Children and Family Services in Los Angeles County. The researcher then requested their participation by phone.

The rationale for choosing these approaches was that the quantitative data provided information that can be interpreted in an objective manner, and the results tested by using numerical data that can be analyzed. An exploratory design was used to gain information regarding the characteristics of medical placement foster parents to help medically fragile children improve their health and increase their survival. Using a qualitative approach for this population provided insights into the attitudes, perceptions and opinions of the participants. Qualitative methodology allowed the researcher to interact directly with the participants and to get to have an opportunity for clarification as well as for follow up questions. The qualitative approach also was advantageous because it provided the chance to obtain large amount of data in the participants' own words.

The hypothesis of this study is as follow:  
Placement stability is related to the number of years of experience foster parents have in the care of medically

fragile children, the medical training for the child's specific needs, the services received and the ability to cope with child's chronic condition.

### Sampling

The subjects of this study were 230 medical placement foster parents in Los Angeles County. The participants were selected from a list of foster parents that have completed specialized training for medically fragile children and have at least one year of experience taking care for medically fragile children in their homes.

Children placed with medical placement foster parent have in the files documented medical problems that require specific care activities on the part of the caregiver. The medical conditions include physical handicaps, severe medical problems (acute or chronic) or developmental disabilities (including developmental delay under age three). Documentation in the files includes the diagnoses, prognoses, treatment indicated and the specific medically related activities to be performed by the foster parent.

The list of foster parents included the address, the number of children previously placed in the home and presently living in the home. Further, it included related trainings foster parent completed to be eligible to care for medically fragile children and any medical experience before becoming a foster parent. All the foster homes selected for this study are licensed through Los Angeles County and have a home study approved by the Department of Children and Family services social worker from the foster care recruitment program. All records and information regarding medical placement foster homes are held in a centralized unit in the Medical Placement Program responsible for placing all medically fragile children in Los Angeles County.

#### Data Collection and Instruments

This researcher personally interviewed all the medical placement foster parents who agreed to participate in the study at their homes. Quantitative questions asked consisted of demographics, ethnicity, education, hours of employment, income level, marital status, length and amount of children placed in their homes, age and diagnosis of the children. Qualitative

open-ended questions were also asked about the motive to become foster parents for medically fragile children, specialized training received, services received by the children and problems accessing and coordinating services (See Appendix C for English version interview questionnaire and Appendix D for Spanish version interview questionnaire). Questions were designed to elicit information from participants about their experiences dealing with child protective services, the health care system and other services provided for the medically fragile children in their care.

A 22-item Likert scale was also administered at the end of the interview to assess the coping abilities to deal with the children's chronic illness and the foster parents skills used to manage their on-going care (See Appendix E for English version questionnaire and Appendix F for Spanish version questionnaire).

The dependent variable in this study was the stability of placement in the medical placement foster parents. The independent variables were the foster parents length of time caring for the children, the amount of services received, the specialized medical training, and the ability to cope with children's chronic



conditions. The independent variables were measured by using the data from the questionnaire and scale. This researcher used parametric level of measurements.

The first variable was the number of years of experience foster parents have in the care of medically fragile children. This variable was measured by asking the foster parents how long they have been caring for medically fragile children.

The second variable was specialized medical training for the child's specific medical needs and was measured by asking what specialized trainings foster parents had to prepare them to care for the medically fragile children.

The third variable was the amount services children received and it was measured by asking the foster parents what services the medically fragile children were receiving.

The fourth variable was the ability to cope with children's medical chronic conditions. This variable was measured by using a 22-item Likert scale that ranked the values from strongly agreed to strongly disagreed and from all of the time to none of the time.

This researcher constructed the 54-item instrument using personal experience and knowledge learned by working with medically fragile children in the Department of Children and Family Services. To create questionnaire, this researcher reviewed other literature and studies on this topic.

In addition, this researcher used a simplified and shorten 22-item scale from the "CHIP-Coping health inventory for parents: An assessment of parental coping patterns in the care of the chronically ill child", developed by McCubbin, McCubbin, and Cauble, (1983) to measure a family's coping with chronic illness of a child. This scale was developed to record what parents find helpful or not helpful to them in the management of family life when one or more of its members is ill for a brief period or has a medical condition which calls for continued medical care. Coping is defined as personal or collective efforts to manage the hardships associated with health problems in the family. This scale was found to have good internal consistency with alphas of .79 for the first two factors and .71 for Factor III. No data on stability were available. The CHIP has fair concurrent validity with several correlations with the Family

Environment Scales. The CHIP also has good known-group validity, significantly discriminating between high and low conflict families.

This researcher translated into Spanish the instruments for the monolingual Spanish speaking foster parents. The researcher then asked a Spanish speaking person to translate the questionnaire back into English to ensure that it was properly translated.

The researcher gave each foster parent a written informed consent to read and to place a mark at the bottom of the page. The content of the informed consent was verbally explained to the foster parents by this researcher (Appendix G for English version and Appendix H for Spanish version).

The researcher believes the instruments used had reliability and validity. The personal interviews results measured accurately what it claimed to measure and it was consistent every time. The experiences of the medical placement foster parents were consistent and the results of the interview questionnaires and 22-item Likert scales showed the questions to be reliable and valid. The limitation was that the sample population of 230 foster parents caring for medically fragile children was small.

One of the logistical problems of this study was that the medical placement foster parents were busy with the care of the children and appointments were scheduled around the children's needs and services providers visiting the children. Further, the children's care demanded time from the foster parents and distracted them while answering some of the questions. One of the strengths was that the medical foster parents have a very close-knit group and they advocate and help each other. The foster parents told other foster parents about the study and it encouraged greater participation in the research. Another strength was that the interviews were done at the foster parents homes and they did not have to take time away from the children or arrange for somebody to watch them during the interview. Foster parents were open to discussing issues around their experience and needs caring for the medically fragile children in the comfort and safety of their own homes. In some cases the researcher was able to observe the foster parents relationship with the children and the medical care of the children. The researcher saw the high level of competency of the foster parents in dealing with the

medical problems and treatments and the close bonding that existed between them.

### Procedures

The researcher conducted all the personal interviews at the foster parents home between January and March 2003. All appointments were set up by calling the foster parents homes and requesting their participation in the study. The researcher explained that the personal interview would take one hour to one and half hours to complete and their participation was voluntary. (See Appendix A for English version on the request of participation and Appendix B for Spanish version on the request of participation). The study was being conducted for a school project in California State University San Bernardino (CSUSB) and under the approval of DCFS, Medical Placement Unit. Appointments were scheduled within a week or two of the initial phone calls and depended upon the foster parents time availability and schedule.

Prior to the interview, the researcher explained the purpose and nature of the research to the foster parents and provided them with informed consent form. The

participants were reminded that the responses would be kept absolutely confidential, and told that there were no right and wrong answers and that they should not hesitate to ask questions and ask for clarification at any time. All the answers to the questions were written on the questionnaire by the researcher.

This researcher called 62 medical placement foster parents that are residing in the east side of Los Angeles to request their participation in the study. The researcher personally interviewed 26 participants who agreed to be part of the study. During the request, appointments were set up at the foster parents home at their convenience. Most medical placement foster parents preferred an appointment in the morning during the weekdays after the children went to school. There were six foster parents that declined participation due to personal problems and busy schedule. Ten foster parents called to reschedule the appointments and four changed their minds and canceled the appointments. Phone messages were left in 15 homes but only two called the researcher back. Three foster parents were interested in participating but did not have medically fragile children

placed in their home. The researcher was not able to reach others by phone to request participation.

#### Protection of Human Subjects

A written consent form was given to each participant to mark and return back to the researcher. Informed consent provided information regarding the nature and purpose of the study, research methods and research participation time. Those surveyed were guaranteed confidentiality and the right to withdraw their participation without any penalty. The researcher utilized a numeric coding system that was known only to the principal investigator. All completed interview questionnaires were kept in a locked drawer in the researcher's office. The researcher only had access to the information.

A debriefing statement was provided to desensitize the participants. The debriefing gave two referrals in the community in case participation in the study brought up any personal issues such as feelings of loss and pain. The debriefing statement explained the purpose of the research, how to obtain general results and the person to contact if the participants had any questions or concerns

(See Appendix I for English version and Appendix J for Spanish version).

### Data Analysis

The sample was collected from the pool of medical placement foster parents in the Department of Children and Family Services in Los Angeles County. The population was taken from a list of foster parents that completed specialized care training and had at least one-year experience caring of medically fragile children. The sample population consisted 230 foster parents that are currently licensed or had medically fragile children placed in their home in the past.

The researcher found that the sample was sufficiently large and representative of the population to achieve a normal distribution. Given the qualitative nature of the data that was gathered, a considerable amount of personal judgment was involved in the researcher's interpretation and analysis. Data gathered from the interviews and all verbal responses from the open-ended questions were recorded on the questionnaire by the researcher as the participants spoke. The researcher grouped the answers into categories according



to similar content, themes and patterns in order to be able to analyze all responses. The frequency of both the quantitative and qualitative responses were obtained, as well as for each independent variable, mean and standard deviation.

Parametrical statistical tests were used to examine the relationship between the variables. The researcher used correlation analysis to find the degree of association between or among the variables. In order to find out if the independent variables could have sampling error, this researcher used parametric tests: one way ANOVA, Pearson and multiple linear regression. Significance was found using one-way ANOVA, Pearson and multiple linear regression tests.

#### Summary

The study consisted of quantitative and qualitative questions, which included nominal, ordinal, interval and ratio levels of measurements. This study used personal interviews and a written questionnaire to collect data from the medical placement foster parents. The participants were selected from a list of foster parents that had completed medical training and had medically

fragile children placed in their homes for a year. The sampling was 230 medical placement foster parents in Los Angeles County. The objective of the study was to develop a better understanding about the experience and needs of medical placement foster parents. Specifically, the study focused on the medical foster parents knowledge and experience on how to coordinate and access health care services, specialized medical training, the ability to cope with the child's chronic conditions and stability and permanency plans. The study was strictly confidential and the researcher did the data collection. Informed consent and debriefing provided to the participants. The data analyses used were parametric statistical analysis to examine the relationship between independent variables. Significance was found using one- way ANOVA, Pearson and multiple linear regression.

## CHAPTER FOUR

### RESULTS

#### Introduction

This study focused on the experience and needs of medical placement foster parents caring for medically fragile children at home. The information presented in this chapter has been gathered from the personal interviews and written questionnaires given to the foster parents who participated in the research. Results of the data were analyzed in four areas: the specialized medical training, the coordination and access of health care services, the stability and permanency of placement, and the ability to cope with the child's chronic conditions. The findings are reported via these categories.

#### Presentation of the Findings

##### Demographics

The following information describes the sample of medical placement foster parents who cooperated in this research. Twenty-six medical placement foster parents participated in the personal interviews and written questionnaires. Fourteen foster parents were English speaking and twelve foster parents were monolingual

Spanish speaking. Out of the 26 foster homes 7 had licenses for Small Family Homes where they can have up to six children placed in their home. All 26 foster parents interviewed were females and the primary caretakers of the children. Seven foster fathers were present during the interview and assisted the foster mother with the care of the children and with some of the answers.

The mean age of the participants was 50, with the ages ranging from 39 to 75. Fifteen of the participants were Hispanic (58%), three were African American (11%), seven were Caucasian (27%), and one was Pacific Islander (4%). Twenty-three were not employed and three were employed part time. Five had attended some high school (19%), eight had completed high school (31%), two had vocational technical skills (8%), and eleven had attended some college or had a college degree (42%). The household income not including foster care payments were eleven less than \$30,000 (42%), four between \$30,000 and \$40,000 (15.5%), five \$40,000 to \$50,000 (19%), four \$50,000 to \$60,000 (15.5%) and two were more than \$60,000 (8%). Twenty-three were married (88.5%), two never married (7.7%) and one divorced (3.8%). The mean for the length of time licensed foster parent was 14.1, ranging from 1

to 31 years (SD 8.5). The average number of medically fragile children placed in the foster parents homes was 26.1, ranging from 1 to 122 (SD 31.34). Foster parents who were caring for medically fragile children between one to ten years had 42 children, ten years to eighteen years had 23 children and twenty one to thirty one years had 11 children.

There were 76 children placed in the twenty-six foster homes. Three foster homes had one child, five foster homes had two children, twelve foster homes had three children, four foster homes had four children, one foster home had five children and one foster home had six children. The children's ages ranged from two months to 17 years. The time foster parents spend caring for the children placed in their home ranged between one day and 13 years. There were 20 African American children (26%), 13 Caucasian children (17%), 40 Hispanic (53%) and 3 Asian (4%) in placement with these foster parents. Twenty-three out of 26 foster parents have cared for technology dependent children and they reported to have cared for a total of 224 technology dependent children during the time they have been licensed. Sixty-eight of the children had prognosis of hope for survival (89%), three had

Table 1. Characteristics of Foster Parents Caring for Medically Fragile Children (N = 26)

Characteristics	Frequency	Percent	Mean	SD
Age (in years)			50	7.9
Gender				
*Female		100		
Ethnicity				
*African American	11	3		
*Caucasian	27	7		
*Hispanic	58	15		
*Pacific Islander	4	1		
Hours/week employment				
*Full Time				
*Part Time	3	11		
*Not employed	23	89		
Education				
*Some H.S.	5	19		
*H.S.	8	31		
*Vocational	2	8		
*College	11	42		
*Graduate				
Income				
*<30,000	11	42		
*30,000 to 40,000	4	15.5		
*40,000 to 50,000	5	19		
*50,000 to 60,000	4	15.5		
*60,000>	2	8		
Marital Status				
*Married	23	88.5		
*Never married	2	7.7		
*Divorced	1	3.8		
*Widow				
Length of time licensed				8.5
Time caring for medical fragile children				31.34

prognosis of not sure (4%) and five had prognosis of no hope for survival (7%).

The number of years in placement of the 76 children reported by the foster parents was 38 children (50%) between one week to two years, 22 children (29%) between two to five years, and 16 children (21%) between five to 13 years.

When foster parents were asked about their motivation for becoming foster parent for medically fragile children, eleven stated they had previous experience caring for children with disabilities and they wanted to help the children, two said they were working in a hospital and they wanted to make the transition from hospital care to home care, three said they enjoyed caring of the medically fragile and it was very rewarding, five stated that friends and social workers told them to switch from taking care of foster children to medically fragile children and they wanted to try something different, three stated that their own children grew up and moved away and they wanted to have more children at home, and two said they wanted to adopt children (see Appendix K).

#### Specialized Medical Training

During the time the foster parents had been caring for medically fragile children, foster parents of 9

children had two specialized trainings, foster parents of 8 children had three specialized trainings, foster parents of 11 children had four and five specialized trainings, foster parents of 16 children had six to seven specialized trainings, foster parents of 13 children had eight to nine specialized trainings and foster parents of 19 children had ten to thirteen specialized trainings. The children's diagnosis were as followed: 11 had cerebral palsy, 2 had autism, 5 had fetal alcohol syndrome, 25 had drug exposed symptoms, 2 had Down syndrome, 3 had heart problems, 8 had asthma, 1 had brain injury, 1 had diabetes, 1 had cancer, 1 had skin problems and allergies, 1 had tumors, 3 had cleft palate, 2 were oxygen dependent and 10 had other diagnosis. When the foster parents were asked if the training to become a medical placement foster parent prepared them to be a caretaker of medically fragile children the majority responded that the medical training prepared the foster parents to care of medically fragile children but it is necessary that foster parents get child specific training before bringing a particular child home from the hospital. The foster parent should go to the hospital and get familiar with the care of the child, get a nurse to



come to the home for follow up if necessary and get referrals from the doctor. Five foster parents said "the F-rate training is a good class because it explains what to do in case something bad happens" (F-rate training is a 16 hour class to prepare foster parents who want to care for medically fragile children). One foster mother said "more training in the regions is needed, the regional center offered training but now they are charging \$10 dollars per class, Children's Hospital of Los Angeles is not offering the medical training like they used to". Two foster parents said "the training helps but foster parents should prepare themselves by looking in the Internet before making the decision to take the child home". One foster parent said "classes help foster parents find out about the places and people that can help". One foster parent said "the training gave her a base but foster parents should continue to go to community colleges and foster parents support groups for on going training and support". Four foster parents said "I was scared at first but I felt prepared after the training". One said "the F-rate training is good but there is nothing like learning from direct practice". One foster mother said "a child had seven replacements due

previous foster parents lack of medical training" (see Appendix K).

All foster parents reported they are required to perform multiple tasks. There were three nurses out of 26 foster parents. The time required in a day caring for the children ranged from three hours to 24 hours.

Twenty-three children required care twenty-four hours a day. Trips to the doctor per month ranged from one to six, one child required six trips, three required five trips, four required four trips, fifteen required three trips, twenty-nine required two trips and twenty-four required one trip. Fourteen children had one hospitalization per month, two had two hospitalizations, six had three hospitalizations and seven had no hospitalizations. Foster parents stated that hospitalization occurred more frequently when they were initially placed.

#### Coordination and Access of Services

When foster parents were asked how many services children in their care were receiving, nine said no services, 25 said one service, 22 said two services, 9 said three services, 6 said four services, 2 said five services, and 3 said six services. When asked what type

of services the children were receiving, 37 stated Regional Center services, 18 California Children Services, 7 vocational rehabilitation, 4 early Intervention, 9 other services such as mental health, 1 respite care, 12 home attendance, 11 recreational and 6 said transportation services.

When foster parents were asked if these services were helpful, all the foster parents stated the services were helpful because they provided education to the foster parents on how to deal with the children. The children conditions improved greatly due to professional therapy and equipment provided to the children's needs. Three foster parents stated the services provide them with time to take care of other responsibilities such as taking another child to the doctor and other activities, and to go out shopping. Four foster parents were concerned that children would not get the services needed if the foster parents would not strongly advocate on their behalf and due to budget cuts (See Appendix K).

All the foster parents responded that their family members helped them with the care of the children except for one foster parent. Twelve foster homes said that they had a home attendant to assist them with the care of the

children and house keeping. The hours the home attendant was available per week ranged from 2 to 25 hours, the mean was 11.92 hours. When foster parents were asked the number of doctors each had 17 children had one doctor, 20 children had two doctors, 21 children had three doctors, 11 children had four doctors, 6 children had five doctors and one had seven doctors.

When asked what services they are having problems accessing the responses were as followed: 8 respite care, 1 day care, 1 home attendant, 2 CCS, 5 School District, 1 dental services (braces), 3 mental health services, and 2 health care. When asked who helped coordinate services 6 responded the child's social worker, 3 the Regional Center social worker and 17 stated they coordinate all the services themselves. When the foster parents were asked what are the impediments to receive services out of the 76 children 15 reported lack of resources, 10 fragmentation of services, 7 lack of coordination, 5 inadequate information, 7 problems with medical, 2 lack of knowledge on the services available and 21 stated the following responses: "school district don't want to pay for services", "the paper work takes too long", "there is not enough doctors in major hospitals and the waiting

list is three to six months long", "the court is a problem and children suffer discrimination because they are disabled and foster children".

#### Stability and Permanency Plans

Thirteen foster parents stated that the reason they asked for a child to be removed from their home was due to behavior problems and four stated for severe medical problems, the rest of the foster parents said they never asked for a child to be removed. As per what efforts were made to prevent re-placement, one foster parent said "wrap around services were put in place for the child", two said "I took more training classes on how to deal with behavior problems", four said "the social worker from regional center put more services in place", and one stated "I have a nurse to come to the house". When asked what would have helped make the decision to keep the child in your care, six said support services, one said help with access of services, and four said improve health of the child and three said the children's social worker assistance. Foster parents reported that the child's social worker supports the current placement by visiting every month (65%), set up training (4%) and provide with on-going support (31%).

Twenty-three foster parents received specialized care rate (F-rate) as the foster care payment for the children, two are getting regional center rate and one is receiving regular foster care payments (AFDC-FC). When asked if the level of funding was able to meet the needs of the children, twelve said no and fourteen said yes. The explanations given by the foster parents who answered "no" were that "the care of the children is 24 hours a day, the special equipment, the medication, the multiple doctor appointments, the need to have a reliable car and the child-care are very expensive. Medical does not cover for some medication and other important things the children need for their care". All the respondents indicated that the care of medically fragile children is a lot of work and responsibility and they are not able to get away from the on-going care due to lack of respite care and trained staff available to help them. The foster parents that responded "Yes" to the question stated that they thought it was a fair amount and enough money, however they all agreed that the children were a lot of work and they did not do the job for the money (See Appendix K).

When foster parents were asked if a child died while placed in their care 4 stated, "yes" and 22 stated "no". Two children died in the hospital and two at the foster home. The four foster parents reported feeling devastated with the death of the children and that it took them a long time to deal with the loss due to the on-going investigations and questions asked of them while grieving for the child.

When foster parents were asked if a child had been removed from their care where they did not request to be removed 6 responded "yes" and 20 said "no". One foster parent stated that " I don't want to say the reason", two foster parents said "I was not able to properly take care of the medical needs and the social worker placed the children in another home with more experience in the medical area", two foster parent stated "the child had severe medical problems and the social worker placed them in a skilled nursing facility until they became stable medically", and one foster parent said " my natural son hit the child to defend himself and the foster child told his attorney that he was abused in my home".

When foster parents were asked what permanency plan the children were receiving, 16 children were receiving

family reunification services, 22 children were in long term foster care, 22 children in legal guardianship and 16 children in adoption. Four foster parent stated that the reason for the selection of the long term foster care permanent plan was that "I am looking in the future and the problems the children might have when they become teenagers", two said that "the children's parents are still involved they might get a chance to get them back", two stated "there are not enough homes for the medically fragile children and I would continue to care for them as long as necessary until a more permanent plan is set up for the children". The reasons given for selecting legal guardianship, four said "the children have severe medical problems and they prefer to stay involved with DCFS and get services and support", one stated "the court will not let me adopt now but I might adopt in the future". The reason given for selecting the adoption permanent plan were that they loved the children and wanted to keep them under their care (See Appendix K).

All foster parents answered "yes" when asked if they intended to continue to care for the children. The majority stated they really enjoyed caring for the medically fragile children and they would continue to do



it as long as they were capable physically and emotionally. Many felt caring for the medically fragile was their call in life and they want to give a stable home to the children. Foster parents were concerned that as they became older they were not going to be able to care of the children anymore and they were worried about what would happen to the children in their care.

When making the decision to keep the children under their care, twelve foster parents said " the children social workers can assist them by giving them support and information", one said " the children social worker need to give more time to make the decision about what permanent plan they want to select", two said " the children social workers need to spend more time communicating with the foster parents and speak to the children alone", four said "there was nothing children social worker could do", three said " the children social workers should look for services and foster parents should get involved in the foster care association and take classes to learn how to deal with the children", one said "the county can provide respite care", one said "the children social workers should give referral and provide answers when needed", one said "foster parents should

continue to take classes and review the doctor's orders to make sure that it is done right. It is very stressful to have to make the decision to keep them or not", one foster parent said "the adoption division places a lot of responsibility on the adoptive parents and nobody is there to really help if there are problems" (see Appendix K).

#### The Ability to Cope with Chronic Illness

When the foster parents were asked what stressors they were facing, seven stated problems with the child welfare system, one stated problems with access of services, three stated problems with health care system, one stated problems with coordination of services, one stated lack of resources, three stated communication problems with the providers, two stated family problems, one stated financial problems, five stated problems with the school system and two stated they had no stressors.

When looking at the results from the 22 item Likert scale to assess the coping abilities to deal with the children chronic illness and the foster parents skills used to manage their on-going care, 85% to 90% of the foster parents responded that they strongly agreed with

the items. The only question that 13 foster parents circled "disagree" was question number 7 which stated, "I am able to get away from the home care tasks and responsibilities".

On items 23-26, all of the foster parents (100%) checked "true" in all of the items.

#### Recommendations

When foster parents were asked what recommendation they have for DCFS to improve the services to the medical placement foster parents caring for the medically fragile children, the following responses were given: six stated "the medical placement unit is doing a better job now and they have more resources than other agencies", eight stated "more communication, training, and respite care is needed", five stated "the children social workers are over burden with cases and they lack the time to properly serve the children, and to help the foster parents obtain resources", three stated "F-rate classes need to be improved", six stated "foster parents need a better support systems to help them to care of the children if they get burned out, or need to help and relief, DCFS should provide more foster parents association for

support groups, and training", two stated "children should get the appropriate foster care rates", one stated "the system need to review the policies and regulations that are not the best for the children", one stated "the health system needs to be improved and to be more open", and one stated "the F-rate classes are good for the new foster parents but boring and repetitive for the foster parents with a lot of years of experience and they should be revised and improved" (see Appendix K).

The hypothesis of this study was supported statistically when the number of years children were in placement (stability of placement) was correlated with the number of specialized trainings received by the foster parents. The Pearson correlation significance was .325. When the numbers of years children were in placement was correlated with the number of years of being a foster parent, the significance was .425. When the number of years of being a foster parent and the number of services received by the children was correlated, the significance was .265. There was no significant correlation between the number of years in placement and coping skills.

Table 2. Coefficients for the Effect on Child's Placement Stability

Variables	n	M	SD	r	p*
Years foster parent	76	10.66	8.23	.425	.000
Specialized Training	76	6.53	2.97	.325	.004
Services received	76	1.95	1.45	.187	.106
Coping Skills	76	12.17	1.94	.149	.198

\*two tailed tests

The one-way ANOVA examined the relationship between the independent variable, the number of years being a foster parent, with the number of specialized trainings, the number of services received and the coping skills (sig.000a) (F=6.719).

#### Summary

In order to analyze the data from the personal interviews and 22-item scale, the results were categorized in four major areas; the specialized medical training, the coordination and access of health care services, the stability and permanency of placement and the ability to cope with the child's chronic conditions. The results supported the hypothesis that foster parents with more specialized medical training will be able to adequate care for the children, administer all medical

treatments and ensure the children safety and stability in placement. The on-going training prepared them to confront the daily challenges of caring for medically fragile children. The amount of services the children were receiving showed to improve the children's medical condition; however, it had a small correlation with the stability of placement. The coping ability of the foster parents in dealing with the children's chronic illnesses did not show correlation with the stability of placement.

## CHAPTER FIVE

### DISCUSSION

#### Introduction

The goal of the study was to develop a better understanding about the experiences and needs of medical placement foster parents. The exploratory study used qualitative and quantitative approaches to obtain more information about the characteristics of the foster parents and to find out what they are doing to provide stability and permanency of placement. This study examined the complexities of caring for medically fragile children, the specialized medical training, the extensive coordination and access of services, and the management of the demands and heavy burden of care of the medical needs by the medical placement foster parents.

#### Discussion

The researcher called 62 medical placement foster parents to request participation in the study and to explain the nature of the study. All of the foster parents who agreed to participate were very interested in discussing their experiences and eager to openly talk about their perspective and opinions in working with the

medically fragile children in Los Angeles County. This researcher met face to face with the 26 foster parents at their home. All foster parents were friendly, polite and respectful during the interviews and excited about being heard. The researcher found that the foster parents had extensive knowledge in the health care field gained by taking care of the medically fragile children. It was apparent that they have a deep understanding of how the different systems that the children were involved worked and how they interacted with each other. The results indicated that the foster parents had many years of experience caring for children and some foster parents were teaching classes such as F-rate training and MAPP training. They all had much insight into the problems associated with the service delivery breakdown and they had been fighting to make changes to improve them. All the foster parents had a lot to offer to this research and it became clear to the researcher by the amount of information given regardless of the time constraints and busy schedules. In this researcher's opinion the foster parents answered all the questions sincerely and they all understood the questions.



The findings showed that the participants in the study were representative of the large population of medical placement foster parents. The majority had three children in their care and they had been caring for the medically fragile an average of 15 years. The researcher found out that many foster parents started caring for regular foster children and later they became aware of the need to care of the medically fragile. They became involved with the medical placement units to work solely with this population of children coming into the system. The familiarity with the different diagnosis and the tasks involved in the care was evident and the experience not only help them with the decision to accept children in their home but also with the decision to keep them under a permanent plan. Many struggled with letting the children leave to another home when they no longer could take care of them. During the interviews, foster parents stated that working with the medically fragile population, accelerated the bonding process which lead to quicker attachments to the children. No wonder, the children stayed in their homes longer and obtained more stability and permanency. The appeal to work with the most needed, and difficult children to care stemmed from

the desire to alleviate the pain and suffering of the most vulnerable of them all.

The researcher could not help feel bewildered by the many sacrifices these foster parents made to continue to care of these children and to observe the lack of privacy and leisure time. It was found out that the medical placement foster parents are with the children all the time; they cannot go on vacation, or take time off unless a substitute caregiver is found and trained. The demands and on going treatment the children need 24 hours a day are exhausting. The foster parents barely complained and they happily said they would not do it any other way.

The results of the study supported that having child specific specialized training done at the hospital suggests that the foster parents are going to know how administer all medical treatments and ensure the children's safety in the home. The on-going training done in community colleges and at DCFS to prepare foster parents to confront the challenges of caring for the medical fragile children and to learn how to work the different bureaucracies to obtain services was reported to be adequate. This means that foster parents need to be ready to respond immediately to the medical care needs of

the children and to treat the different diagnosis the children have. The foster parents have to balance the multiple task required for the children, the large number of doctor appointments and hospitalizations.

The findings demonstrated that the medical placement foster parents are left to advocate for the children on their own most of the time. As reported, they need to coordinate the different appointments with service providers and make sure that all the information is recorded in the children's records. They also need to know what services are available and how to acquire them. All the foster parents expressed that the services provided to the children by DCFS and regional center benefited them and improved their conditions. All the foster parents depended on the family support and help to be able to continue to care for the children. Some were able to afford a part time home attendance to provide some relief from the daily tasks, but most of them provided the care on their own. Impediments in obtaining services were found to support the literature. There is lack of resources, fragmentation and lack of coordination of services to access the health system. In addition, many foster parents reported major problems trying to

obtain services with school district and mental health system.

The results showed that the amount of services the children received did not correlate with the stability of placement. The more severe medical and psychological problems the children had the more services they received. One possible explanation that the amount of services did not correlate with placement stability could be that the sicker the children they more likely they would be hospitalized or placed on a more restricted placement environment to deal with the unstable chronic medical conditions. In addition, foster parents had to advocate with all services providers along with extensive coordination of services to make sure that the proper services were provided to the children. Literature reviewed stated the stresses for the foster parents to access the services needed for the medically fragile children are greater. Foster parents were more likely to let the children with more severe medical problems and mental health issues go to other placements.

In regards to the stability of placement and permanency plans, children who had dual diagnosis were at higher risk of replacements than the children who had

medical problems only. Provision of services reduced the possibility of removal and stabilized the placement. The researcher found that medical placement foster parents felt very strongly about receiving the correct amount for specialized rates. They felt insulted by the social workers that expressed opinions such as "you are only doing it for the money". They all felt the money received could not come close to the amount of work and responsibility required to care of the children on the daily basis.

The findings showed the selection of a permanent plan such as adoption was done according to the child's prognosis for the future, the amount of family support system and the degree of attachments to the children based on length of time placed in the home. Foster parents reported that service provision to play a strong role on the decision to keep the children under their care long term and the child's social worker support and assistance was critical.

The successful adaptation to care for the chronic illness or disabilities was an important factor on the ability to cope with the daily stresses. The results indicated most of the medical placement foster parents

had a positive outlook on life, they believed that the children would get well and they were receiving the best care possible. Foster parents used peer counseling, educational seminars, support groups and health care staff to deal with the heavy burden of care of the medically fragile children. Foster parents were strong advocates for the children and their ability to manage the child's condition and coordinate services increased their independence and self esteem as a person.

The results indicated the ability to cope with the child's chronic conditions did not correlate with stability of placement. One possible reason for the lack of correlation could be that the parental coping decreases over time due to the long-term impact on the family care for the medically fragile children.

#### Limitations

The following limitations apply to the project:

1. The data collected from the interviews was very extensive and some foster parents opinions and experiences did not quite fit within the categories given. It was not possible to measure every variable.

2. Another limitation of the study was that even though the foster parents appeared to be honest and open, some of the information given could have been answers that the foster parents thought the researcher wanted to hear. The foster parents expression of their opinion and spontaneity could have been limited.
3. As explained above, due to the qualitative nature of the data gathered, the interpretation of the information and analysis involved a significant amount of subjectivity.
4. The foster parent population interviewed was small and the results might not be able to be generalized in to the larger population.

#### Recommendations for Social Work Practice, Policy and Research

This study assessed the existing service delivery to assist the medically fragile children in foster care. Understanding the specialized medical training foster parents are receiving, the coordination and access of services in the health care system and the foster parents ability to cope with the uncertainties of chronic illness can ensure that medically fragile children will not be re

abused while in foster care and will increase the stability of their placements.

The researcher's recommendations are that more attention should be given to the suggestions medical foster parents made regarding the training for foster parents before a medically fragile child is placed in their home. More medical trainings, parenting classes for special needs children and support groups are needed. Mandatory F-rate trainings are beneficial however, for those foster parents that have been caring for the medically fragile for many years the same repetitious training is not necessary and a more sophisticated and broaden curriculum should be designed and put in place. Further, a uniform, structured curriculum for F-rate training should be used for new foster parents wanting to care of the medically fragile. Child specific training before a child is placed is the best guarantee that the placement will succeed and it should be implemented through out all the county offices.

Lists of specific trainings dates and topics related to the care of medically fragile children should be provided to all foster parents and they should be encouraged to attend. Medical placement foster parents



can benefit from a liaison between the health care providers and DCFS to set up more training in the needed areas and provide a support system to the foster parents. Foster parents can be taught how to navigate through the health care system and obtain the services for the children rapidly to prevent children deterioration in their health. Literature reviewed indicated that involving the major hospitals to work more closely with the medical placement and set up training will enhance greatly the competencies of the foster parents and will help foster parents with documentation of the health logs for case records. The outcome will be that the children's health will improve and have less doctor appointments and hospitalizations. The collaboration between the hospital, the foster parents and DCFS will improve and less fragmentation, duplication and poor coordination of services will occur.

Another recommendation is that foster care recruitment staff in DCFS can utilize the information gained in this study to increase competent recruitment of foster parents to medically fragile children. Additional training for social workers to develop proper assessments skills can be created to discern the

abilities/characteristics in potential foster care parents. Support services like respite care for this particular population needs to be set up and be utilized more frequently when foster parents are experiencing increased stress in their lives. Home attendances are a great source of assistance and foster parents should be able to have access to help at home with the care of children. Transportation is another area identified as problematic. Foster parents are responsible for transporting the children to all medical appointments and other services. If foster parents cannot afford a wheelchair van, they are restricted in the ability to transport the children that are not ambulatory placed in their homes. Assistance should be provided to help foster parents obtain transportation for the children to attend the multiple appointments and services needed.

The researcher is recommending more training for social workers to learn how to work with this population and ensure safety for the children in placement. Social workers carrying a caseload of medically fragile children need to have more time to be able to assist the foster parents to coordinate and access services, to provide on going support and training. Social workers will also need

to have more support staff to assist in all the tasks related to servicing medically fragile children such as f-rate assessments.

### Conclusions

The study places attention on the care and treatment medically fragile children are receiving while in foster care. One way of ensuring that the children entering the system will be properly cared and safe is by making certain delivery of services are granted. The literature reviewed pointed out that the children coming in the foster care system in large numbers and with higher frequencies and severity of health problems than ever before while foster parents are decreasing in numbers. The health care system is not responding to the special needs of the children and foster parents are having problems accessing appropriate services due to fragmentation, duplication and poor coordination.

Foster parents who accept medically fragile children have extensive experiences in dealing with the complexity of caring for chronically ill children and how to coordinate and access service. These foster parents have a wide-range of training in medically related issues and

are able to perform tasks that are required to provide care for the medically fragile children. Their knowledge and concerns were openly shared during the interviews. The commitment and dedication to the most needed children in the county of Los Angeles was surmountable.

It was evident in the findings of the research that improvement in the areas of training, coordination and access of services are necessary to provide more stability and permanency in placement. The opinions and experiences shared by the foster parents increases the understanding of what is like to take care of medically fragile children. On the other hand, this study has pointed out the existing strengths that can be built on to ensure the safety and health of all medically fragile in foster care.

Medical placement foster parents are a great resource for medically fragile children and they play an important role dealing with the health care system. The results of the study showed that foster parents take a proactive stance in trying to obtain services for the children and to eradicate the break down in services to the medically fragile children. DCFS is instrumental to provide services and support to the medical placement

foster parents in an effort to create and maintain stable placements.

APPENDIX A  
REQUEST FOR PARTICIPATION  
(ENGLISH VERSION)

## REQUEST FOR PARTICIPATION

My name is Ana Baisley and I am a student in the Master of Social Work Program at Cal. State University San Bernardino (CSUSB). You have been selected to participate in a research study designed to learn more about the experience of a medical placement foster parent caring for the medically fragile children.

Your name was randomly selected from a list of medical placement foster parents who have been caring for medically fragile children through the Medical Placement Unit in the Department of Children and Family Services (DCFS).

The interview will take place at your home for approximately one hour and 30 minutes of your time. I will be personally conducting the interview. The interview will consist of questions about your experience as a medical placement foster parent, the health and status of the children in your care, the services the children are receiving, the training you have completed, your coping ability to care for chronically ill children, placement stability and permanency plans.

I want to assure you that your name and any information you provide will be held in strict confidence by me. When the results of the research are published or discussed, no information will be included that would reveal your identity.

Your participation in this study is absolutely volunteer and if you accept to participate you may withdraw at any time without any consequences of any kind. You may refuse to answer any questions you don't want to answer and still remain in the study. The agency will not know you are participating.

Your participation in this study is very important because it will benefit the public child welfare and DCFS-Medical Placement Program in many ways. The objective of this study is to assess the enhancements needed to be made to the Medical Placement Program in order to better meet the needs of the medical placement foster parents and the medically fragile children under their care.

I would like to offer you an appointment to come to your home for an interview at a convenient time and date. I also want to thank you for your time and consideration.

APPENDIX B  
REQUEST FOR PARTICIPATION  
(SPANISH VERSION)



## Permiso de participación

Mi nombre es Ana Baisley y soy una estudiante en California State University San Bernardino (CSUBS) en el programa de Maestría de Trabajadores Sociales. Usted ha sido seleccionado a participar en un estudio de investigación diseñado para aprender más acerca de las experiencias de los padres de crianza en la ubicación medica cuidando niños medicamente frágiles.

Su nombre ha sido elegido de una lista de padres de crianza en la ubicación medica que cuidan a niños medicamente frágiles a través de la unidad de ubicación medica en el Departamento de Servicios para Niños y Familias (DCFS).

La entrevista va a tomar lugar en su casa por una hora y media de su tiempo aproximadamente. Yo voy a conducir la entrevista personalmente. La entrevista consistirá de preguntas sobre su experiencia de padre de crianza en la ubicación medica, la salud y el estado de los niños en su cuidado, los servicios que los niños están recibiendo, el entrenamiento que usted ha completado, sus habilidades de enfrentar el cuidado de niños enfermos crónicamente, la estabilidad de la ubicación y planes de permanencia.

Yo quiero asegurarle que su nombre y cualquier otra identificación que usted provee será mantenida con la más estricta confidencialidad por mí. Cuando los resultados de la investigación sean publicadas o platicadas, ninguna información será incluida que revela su identidad.

Su participación en este estudio es absolutamente voluntaria y si usted acepta participar puede retirarse en cualquier tiempo sin ninguna consecuencia. Usted puede negarse de contestar cualquier pregunta si no quiere contestar y todavía quedarse en el estudio. La agencia no va a saber de su participación.

Su participación en este estudio es muy importante porque va a beneficiar en muchas maneras el sistema público de bienestar de niños y el programa de Ubicación Medica en el Departamento de Servicios de Niños y Familias (DCFS). El objetivo de este estudio es de asesorar los realces que son necesarios para que el programa de ubicación medica mejore para dar por las necesidades de los padres de crianza y los niños medicamente frágiles que están bajo su cuidado.

Me gustaria ofrecer una cita y venir a su casa para entrevistarle en un día y hora conveniente. También, yo quiero darle las gracias por su tiempo y consideración.

APPENDIX C  
INTERVIEW QUESTIONNAIRE  
(ENGLISH VERSION)

## INTERVIEW QUESTIONNAIRE

- 1) What is your age? \_\_\_\_\_
- 2) What is your sex?
  - 0) Male
  - 1) Female
- 3) What is your ethnicity?
  - 1) African American
  - 2) Caucasian
  - 3) Hispanic
  - 4) Native American
  - 5) Asian
  - 6) Pacific Islander
  - 7) Other
- 4) Hours/week employed:
  - 1) Employed full time
  - 2) Employed part time
  - 3) Not employed
- 5) Education:
  - 1) Some High School
  - 2) Finished High School
  - 3) Vocational Technical
  - 4) College/University
  - 5) Graduate/ professional
- 6) What is your household income not including Foster Care Payments?
  - 1) < \$30,000
  - 2) \$30,000-40,000
  - 3) \$40,000-50,000
  - 4) \$50,000-60,000
  - 5) > \$60,001
- 7) Marital Status:
  - 1) Married
  - 2) Never Married
  - 3) Divorced
  - 4) Widow

- 8) Number of children under 18 years old in your household. \_\_\_\_\_
- 9) Number of adults in your household. \_\_\_\_\_
- 10) How long have you been a licensed foster parent? \_\_\_\_\_
- 11) How long have you been caring for Medically Fragile children? \_\_\_\_\_
- 12) How many Medically Fragile Children have been placed in your home?  
\_\_\_\_\_
- 13) How many medically fragile children are you caring for now? \_\_\_\_\_
- 14) How long have you been caring for each child?  
 Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
 Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
 Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_
- 15) What are some of the reason that made you decide to be a foster parent for medically fragile children?
- 1) I want to help children with medical problems.
  - 2) I have personal experience in the medical field
  - 3) I am a nurse and want to transition from hospital care to home care.
  - 4) Children were placed in my home without proper assessment of their medical problems.
  - 5) Children became ill while under my care.
  - 6) I enjoy caring of children with disabilities.
  - 7) Other reason \_\_\_\_\_
- 16) What are the children's ages?  
 Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
 Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
 Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_
- 17) What is the ethnicity of the Children?  
 Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
 Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
 Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

- 18) What are the children's diagnoses?  
 Child #1: \_\_\_\_\_  
 Child #2: \_\_\_\_\_  
 Child #3: \_\_\_\_\_  
 Child #4: \_\_\_\_\_  
 Child #5: \_\_\_\_\_  
 Child #6: \_\_\_\_\_
- 19) Have you cared for Technologically Dependent children?  
 1- Yes \_\_\_\_\_ 2- No \_\_\_\_\_
- 20) How many technologically dependent children have you cared for?  
 \_\_\_\_\_
- 21) What is the prognosis of the children in your care?  
 1) Hope for survival  
 2) Not sure  
 3) No hope for survival  
 Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
 Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
 Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_
- 22) What specialized training have you had to prepare for the care of medically fragile children?  
 1) Cardiorespiratory (apnea) Monitor  
 2) Aerosol treatment  
 3) Internal feeding tube  
 4) Tracheostomy  
 5) Colostomy/ileostomy  
 6) Shunt care  
 7) Diabetes  
 8) Spina Bifida  
 9) Renal Failure  
 10) Oxygen dependency  
 11) Urinary catheterization  
 12) Ventilator dependency  
 13) Special medication regimes(e.g.,injections, intravenous and/or oral medication)  
 14) Other \_\_\_\_\_

23) Did the training to become a medical placement foster parent help you prepare you to be a caretaker of medically fragile children?

1- Yes \_\_\_\_\_ 2- No \_\_\_\_\_

Explain \_\_\_\_\_

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24) What tasks is required for the children in your care?

- 1) Eating
- 2) Hygiene
- 3) Ambulation
- 4) Vision/Hearing
- 5) Surgical/wound care
- 6) Respiratory care
- 7) Drug/medical/developmental treatment
- 8) Life threatening illness
- 9) Communicable disease risk
- 10) Infant behavior associated with prenatal drug exposure
- 11) Disabilities
- 12) Emotional problems
- 13) Other

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

25) Are you a nurse?

1- Yes \_\_\_\_\_ 2- No \_\_\_\_\_

26) How much time in a day you spend on home care?

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

27) How many trips do you take to the Doctor per month?

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

28) How many hospitalizations and /or urgent care visit per month?

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

29) What services the medically fragile children are receiving?

- 1) PHN
- 2) Vocational Rehabilitation
- 3) Regional Center
- 4) California Children Services
- 5) Early Intervention
- 6) Home health nurse
- 7) Other

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

30) What support services are you receiving?

- 1) Respite Care
- 2) Recreational
- 3) Day care
- 4) Home attendance
- 5) Transportation
- 6) Regional Center
- 7) Vocational Rehabilitation
- 8) Other

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

31) Were these services helpful?

1- Yes \_\_\_\_\_ 2- No \_\_\_\_\_

Reason \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

32) Does your family help you with the care of the children?

1- Yes \_\_\_\_\_ 2- No \_\_\_\_\_

33) Do you have a home attendance to assist you?

Child #1: Yes \_\_\_ No \_\_\_  
Child #2: Yes \_\_\_ No \_\_\_  
Child #3: Yes \_\_\_ No \_\_\_  
Child #4: Yes \_\_\_ No \_\_\_  
Child #5: Yes \_\_\_ No \_\_\_

34) If you have a home attendance, how it is helpful to you?

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35) How many hours per week is the home attendance available?

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36) How many doctors does each of your children have?

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

37) What services are you having problems accessing?

- 1) Respite Care
- 2) Recreational
- 3) Day care
- 4) Home attendance
- 5) Transportation
- 6) Regional Center
- 7) Other \_\_\_\_\_

38) Who has helped you coordinate services?

- 1) Children's social worker.
- 2) Regional Center social worker.
- 3) Hospital social worker.
- 4) Doctor/nurse.
- 5) PHN
- 6) Other \_\_\_\_\_

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_



39) What are the impediments for your children to receive services?

- 1) Lack of resources.
- 2) Fragmentation of services.
- 3) Lack of coordination.
- 4) Inadequate information.
- 5) Problems with medical.
- 6) Lack of knowledge on what services are available
- 7) Other reason \_\_\_\_\_

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_

Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_

Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

40) What are some of the reasons you asked a child to be removed from your care?

- 1) Behavior problems.
- 2) Problems accessing services.
- 3) Severe medical problems.
- 4) Lack of support system.
- 5) Inadequate health services.
- 6) Other \_\_\_\_\_

41) What efforts were made to prevent a re-placement?

Explain \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

42) What would have helped you make the decision to keep the child in your care?

- 1) Support services
- 2) Access of services
- 3) Coordination of services
- 4) Improve health of the child
- 5) Improve behavior of child
- 6) CSW assistance
- 7) Other

43) How is the CSW helping you support current placement?

- 1) Visits every month
- 2) Follows up with all phone calls
- 3) Provides me referrals
- 4) Helps me with access of services
- 5) Helps me coordinates services
- 6) Set up training
- 7) Set up appointments with health providers
- 8) Attends all appointments for the child
- 9) Provides me with on-going support
- 10) Other

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

44) What foster care payments are you receiving?

- 1) AFDC-FC
- 2) F-Rate
- 3) Regional Center rate
- 4) SSI
- 5) None
- 6) Other

45) Are you able to meet the needs of the children in your care with this level of funding?

Explain \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

46) Have you had any child die while placed with you?

Yes \_\_\_\_\_ No \_\_\_\_\_

Reason \_\_\_\_\_

47) Have any child been removed from your care where you did not request to be removed?

Yes \_\_\_\_\_ No \_\_\_\_\_

Reason \_\_\_\_\_

48) What is the current permanency plan?

- 1) Long Term Foster Care
- 2) Legal guardianship
- 3) Adoption

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

49) How long has the current permanency plan been in place?

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

50) What is the reason this permanent plan was selected?

Child #1: \_\_\_\_\_ Child #4: \_\_\_\_\_  
Child #2: \_\_\_\_\_ Child #5: \_\_\_\_\_  
Child #3: \_\_\_\_\_ Child #6: \_\_\_\_\_

51) Caring for medical fragile children can be very difficult. Do you intent to continue to care for the child on a long-term basis?

1- If yes,

Why \_\_\_\_\_  
\_\_\_\_\_

2-If no,

Why \_\_\_\_\_  
\_\_\_\_\_

What stressors are you facing now?

- 1) Problems with Child Welfare System.
- 2) Problems with access of services
- 3) Problems with health care system.
- 4) Problems with coordination of services.
- 5) Lack of resources.
- 6) Communication problems with providers
- 7) Family problems.
- 8) Financial Problems
- 9) Other \_\_\_\_\_

52) How can the Children Social Worker assist you in your decision to keep the child under your care?

Explain

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53) What recommendations do you have for the DCFS to improve the services to the medical placement foster parent caring for the medically fragile children?

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APPENDIX D  
INTERVIEW QUESTIONNAIRE  
(SPANISH VERSION)

### Cuestionario de entrevista

- 1) Cuantos años tiene Ud.? \_\_\_\_\_
- 2) Cuál es su sexo?
  - 0- Hombre
  - 1- Mujer
- 3) Cuál es su etnicidad?
  - 1- Africano Americano
  - 2- Caucasico
  - 3- Latino
  - 4- Nativo Americano
  - 5- Asiatico
  - 6- Isleno del Pacifico
  - 7- Otro \_\_\_\_\_
- 4) Horas de trabajo per semana
  - 1- Todo el dia
  - 2- Parte del dia
  - 3- Sin trabajo
- 5) Educación
  - 1- Algo de secundaria
  - 2- Graduado de secundaria
  - 3- Tecnico vocacional
  - 4- Universidad/colegio
  - 5- Graduado/profesional
- 6) Cuales son sus ingresos sin incluir los pagos de padres de crianza?
  - 1- <\$30,000
  - 2- \$30,000-40,000
  - 3- \$40,000-50,000
  - 4- \$50,000-60,000
  - 5- >60,000
- 7) Estado civil
  - 1- Casado
  - 2- Soltero
  - 3- Divorciado
  - 4- Viudo

- 8) Cuantos niños menores de 18 años vivén en su casa?  
\_\_\_\_\_
- 9) Cuantos adultos vivén en su casa?  
\_\_\_\_\_
- 10) Por cuanto tiempo ha tenido licencia de padre de crianza?  
\_\_\_\_\_
- 11) Por cuanto tiempo ha cuidado niños que son medicamente frágiles?  
\_\_\_\_\_
- 12) Cuantos niños medicamente frágiles han sido colocados en su casa?  
\_\_\_\_\_
- 13) Cuantos niños fragiles esta cuidando ahora?  
\_\_\_\_\_
- 14) Por cuanto tiempo ha estado cuidando a cada niño?  
Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_
- 15) Por cuales razones Ud. decidio ser Padre de Crianza para niños medicamente frágiles?
- 1- Quiero ayudar a los niños enfermos.
  - 2- Tengo experiencia personal en el campo de medicina.
  - 3- Soy enfermero(a) y quiero hacer la transición del cuidado en el hospital al cuidado en casa.
  - 4- Los niños fueron colocados en mi casa sin haber tenido un diagnóstico medico.
  - 5- Los niños se enfermaron durante el tiempo que estaban bajo mi cuidado.
  - 6- Me gusta cuidar niños con desabilidades.
  - 7- Otras rezones \_\_\_\_\_
- 16) Que edad tienen los niños en su cuidado?  
Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_
- 17) Cuál es la etnícidad de los niños?  
Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

- 18) Cuales son los diagnósticos?  
 Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
 Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
 Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_
- 19) Ha cuidado de niños dependientes en tecnología?  
 1- Si \_\_\_\_\_ 2- No \_\_\_\_\_
- 20) Cuantos niños dependientes en tecnología están bajo su cuidado?  
 \_\_\_\_\_
- 21)Cuál es el pronóstico de los niños en su cuidado?  
 1- Esperanza de sobrevivir  
 2- No estoy seguro  
 3- No esperanza de sobrevivir  
 Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
 Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
 Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_
- 22) Que entrenamiento especializado ha tenido para prepararlo con el cuidado de los niños que son medicamente frágiles?  
 1- Cardiopulmonar  
 2- Tratamiento de aerosol  
 3- Tubos internos de alimentación  
 4- Traqueotomía  
 5- Colostomía/ileostomía  
 6- Cuidado del tubo de desviación  
 7- Diabetes  
 8- Espina bifida  
 9- Falla del Rinon  
 10- Dependencia de oxígeno  
 11- Catecterización urinaria  
 12- Dependencia de ventilador  
 13- Regimen especiales de medicina (inyecciones, intravenoso, y/o oral)  
 14- Otros \_\_\_\_\_



23) Ha el entrenamiento de ser padre de crianza preparado a Ud. para saber cuidar niños medicamente frágiles?

1- Si \_\_\_\_\_ 2- No \_\_\_\_\_

Explique \_\_\_\_\_

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24) Cuales son las tareas requeridas para los niños en su cuidado?

1- Alimentación

2- Higiene

3- Ambulación

4- Vision/ oidos

5- Cuidado despues de operaciones y heridas

6- Cuidado de respiración

7- Medicinas/ tratamiento de desarrollo

8- Enfermedades que amenazan la vida

9- Riezgo de comunicación de enfermedad de epidemia

10- Conductas de infante asociada a la exposición de drogas antes de nacer

11- Desabilidades

12- Problemas emocionales

13- Otros \_\_\_\_\_

Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_

Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_

Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

25) Es usted una enfermera(o)?

1- Si \_\_\_\_\_ 2- No \_\_\_\_\_

26) Cuando tiempo por dia pasa en el cuidado en casa?

Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_

Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_

Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

27) Cuantos viajes por mes toma para llevar los niños al doctor?

Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_

Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_

Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

28) Cuantas hospitalizaciones y/o visitas a la sala de emergencia por mes?

Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_

Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_

Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

29) Que servicios estan recibiendo los niños medicamente fragiles?

1- Enfermera de salud pública

2- Rehabilitación vocacional

3- El centro regional

4- California Children Services

5- Intervencion temprana

6- Enfermera de salud en casa

7- Otros \_\_\_\_\_

Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_

Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_

Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

30) Que servicios de apoyo esta recibiendo los niños?

1- Cuidado de respiro

2- Recreacionales

3- Guarderia

4- Asistencia en casa

5- Transportación

6- El centro regional

7- Rehabilitacion vocacional

8- Otros \_\_\_\_\_

Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_

Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_

Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

31) Fuerón los servicios provechosos?

1- Si \_\_\_\_\_ 2- No \_\_\_\_\_

Explique \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

32) Le ayuda su familia a cuidar los niños?

1- Si \_\_\_\_\_ 2- No \_\_\_\_\_

33) Tiene un asistente en casa?  
Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

34) Si tiene un asistente, como le es de ayuda para Ud.?  
Explique \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

35) Si tiene un asistente, cuantas horas a la semana esta disponible?  
\_\_\_\_\_

36) Cuantos doctores tiene cada uno de sus niños?  
Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

37) Que servicios tiene problemas de acceso?  
1- Cuidado de respiro  
2- Recreacionales  
3- Guarderia  
4- Asistencia en casa  
5- Transportacion  
6- El centro regional  
7- Otros \_\_\_\_\_  
Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

38) Quién le ha ayudado a cordinar los servicios?  
1- El trabajador social del condado  
2- El trabajador del centro regional  
3- El trabajador del hospital  
4- El Doctor o la enfermera  
5- La enfermera de salud publica  
6- Otros \_\_\_\_\_

- 39) Cuales son los impedimentos para que los niños reciban servicios?
- 1- Falta de recursos
  - 2- Fragmentación de servicios
  - 3- Falta de coordinación
  - 4- Información inadecuada
  - 5- Problemas con el medical
  - 6- Falta de conocimiento de servicios obtenibles
  - 7- Otras razones
- Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
 Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
 Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_
- 40) Cuales son algunas de las razones que ud. pidió que sacaran a un niño de su casa?
- 1- Problemas de conducta
  - 2- Problemas accediendo los servicios
  - 3- Problemas medicos severos.
  - 4- Falta de un sistema de apoyo.
  - 5- Servicios de salud inadecuados.
  - 6- Otros \_\_\_\_\_
- 41) Que esfuerzos se han echo para prevenir una re-ubicación?  
 Explique \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_
- 42) Que hubiera ayudado a hacer la decisión de mantener el niño bajo su cuidado?
- 1- Servicios de apoyo
  - 2- Acceso de servicios
  - 3- Coordinación de servicios
  - 4- Mejoramiento de la salud del niño
  - 5- Mejoramiento de la conducta del niño
  - 6- Ayuda del Trabajador social
  - 7- Otros \_\_\_\_\_

43) Como el trabajador social esta apoyandolo a mantener la ubicación del niño en su casa?

- 1- Visita todos los meses.
  - 2- Me regresa todas las llamadas telefonicas
  - 3- Me provee referencias
  - 4- Me ayuda a acceder los servicios.
  - 5- Me ayuda cordinar servicios.
  - 6- Me ayuda areglar los entrenamientos
  - 7- Va a todas las citas del niño
  - 8- Me da apoyo todo el tiempo.
  - 9- Otros \_\_\_\_\_
- Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_  
Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_  
Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

44) Que pagamentos esta recibiendo?

- 1- AFDC-FC
- 2- F-Rate
- 3- La tarifa del centro regional
- 4- SSI
- 5- Ninguno
- 6- Otro \_\_\_\_\_

45) Puede Ud. satisfacer las necesidades de los niños con el nivel de pagamentos que recibe?

Explique \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

46) Ha tenido algun niño morirse mientras estaba ubicado en su casa?

1- Si \_\_\_\_\_ 2- No \_\_\_\_\_

Razon \_\_\_\_\_  
\_\_\_\_\_

47) Ha sido algun niño sacado de su casa en que Ud.no pidio que lo sacaron?

1- Si \_\_\_\_\_ 2- No \_\_\_\_\_

Razon \_\_\_\_\_

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48)Cuál es el plan de permanencia ahora?

1- Largo termino

2- Tutela legal

3- Adopción.

Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_

Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_

Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

49) Por cuanto tiempo este plan ha estado en efecto?

Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_

Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_

Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

50)Cuál es la razon que selecciono este plan?

Niño #1 \_\_\_\_\_ Niño #4: \_\_\_\_\_

Niño #2 \_\_\_\_\_ Niño #5: \_\_\_\_\_

Niño #3 \_\_\_\_\_ Niño #6: \_\_\_\_\_

51) Cuidar a un niño medicamente frágile es muy dificil. Tiene intenciones de continuar cuidando al niño a largo termino?

1- Si \_\_\_\_\_

Porque \_\_\_\_\_

---

2- No \_\_\_\_\_

Porque \_\_\_\_\_

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- 52) Que stresses se enfrenta Ud. ahora?
- 1- Problemas con el sistema de beneficencia para niños.
  - 2- Problemas de accesos de servicios.
  - 3- Problemas con el sistema de salud
  - 4- Problemas de cordinación de servicios
  - 5- Falta de recursos
  - 6- Problemas de comunicación con los proveedores de servicios.
  - 7- Problemas de familia
  - 8- Problemas financieros
  - 9- Otros \_\_\_\_\_

- 53) Como puede el trabajador social ayudarlo con la decisión de mantener el niño bajo su cuidado?  
Explique \_\_\_\_\_

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- 54) Qué recomendaciones tiene ud.para DCFS para mejorar los servicios para los padres de crianzas cuidando niños medicamente frágiles?

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APPENDIX E  
QUESTIONNAIRE  
(ENGLISH VERSION)



## QUESTIONNAIRE

For the following questions, please circle 1 through 4 as applicable:

1= Strongly Agree 2= Agree 3= Disagree 4= Strongly Disagree

	Strongly Agree	Agree	Disagree	Strongly Disagree
1- I believe that things will always work out.	1	2	3	4
2- I believe my child(ren) will get better.	1	2	3	4
3- I take good care of the medical equipment at home.	1	2	3	4
4- I believe the children are getting the best care possible.	1	2	3	4
5- I believe the medical center hospital has the children best interest at heart.	1	2	3	4
6- I encourage the child(ren) with medical condition to be more independent.	1	2	3	4
7- I able to get away from the home care tasks and responsibilities.	1	2	3	4
8- I have become more self reliant and independent.	1	2	3	4
9- I keep myself in shape and well groomed.	1	2	3	4
10- I talk to someone about how I feel.	1	2	3	4
11- I talk to other foster parents in the same situation and learn about their experiences.	1	2	3	4

	Strongly Agree	Agree	Disagree	Strongly Disagree
12- I talk to medical staff when we visit the medical center.	1	2	3	4
13- I read about the medical problems that concern my children.	1	2	3	4
14- I am sure prescribed medical treatments for child(ren) are carried out at home on daily bases.	1	2	3	4
15- I talk with the doctor about my concern about my child(ren) with the medical condition.	1	2	3	4

For each of the following questions, please check the box for the one answer that comes closest to you.

	All of the time	Most of the time	Some of the time	None of the time
16- I manage my child's chronic condition.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17- I provide general health care.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18- I help with the coordination of services.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19- I communicate with other providers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20- I am able to answer questions about the condition of my child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21- I receive guidance and information regarding my child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22- I am comfortable with the training I received about My child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please answer true or false on the following questions.

	True	False
23- I believe my child(ren) survival depends on the coordination of services.	<input type="checkbox"/>	<input type="checkbox"/>
24- Support services allow me to spend more time caring for my child(ren).	<input type="checkbox"/>	<input type="checkbox"/>
25- The medical training I received has prevented my child(ren) going to the hospital.	<input type="checkbox"/>	<input type="checkbox"/>
26- I believe my child(ren) have less doctor visits due to the training I received.	<input type="checkbox"/>	<input type="checkbox"/>

APPENDIX F  
QUESTIONNAIRE  
(SPANISH VERSION)

### Cuestionario escrito

Paras las siguientes preguntas por favor ponga un circulo entre el 1 a 4 como aplica:

1= Fuertemente de acuerdo 2= De acuerdo 3= Desacuerdo 4= Fuertemente desacuerdo.

	Fuertemente de acuerdo	De acuerdo	Desacuerdo	Fuertemente desacuerdo
1- Yo créo que las cosas siempre van a trabajar.	1	2	3	4
2- Yo creo que los niños van a mejorar.	1	2	3	4
3- Yo cuido muy bien los aparatos de los niños en casa.	1	2	3	4
4- Yo creo que los niños estan recibiendo el mayor Cuidado posible.	1	2	3	4
5- Yo creo que el centro medico/Hospital tiene el mejor interes de los niños.	1	2	3	4
6- Yo aliento a los niños con condiciones medicas que séan más independientes.	1	2	3	4
7- Yo puedo dejar de hacer tareas de casa y responsabilidades.	1	2	3	4
8- Yo me siento más seguro de mi e independiente.	1	2	3	4
9- Me mantengo en linea y bien presentable.	1	2	3	4
10- Yo hablo con algien en como me siento.	1	2	3	4

	Fuertemente de acuerdo	De acuerdo	Desacuerdo	Fuertemente desacuerdo
11- Yo hablo con otros padres de crianza en la misma situación y aprendo acerca sus experiencias.	1	2	3	4
12- Yo hablo con empleados medicos cuando visito al centro.	1	2	3	4
13- Yo leo acerca de problemas Medicos que conciernen los niños.	1	2	3	4
14- Estoy segura que todos los tratamientos prescritos son llevados en mi casa diariamente.	1	2	3	4
15- Yo hablo con los doctores acerca de mis preocupaciones sobre la condicion medica de los niños.	1	2	3	4

Por cada una de las siguientes preguntas, por favor marque la caja con la respuesta mas cercana a la suya.

	Todo el tiempo	Casi todo el tiempo	Algo del tiempo	Ninguna parte del tiempo
16- Yo manejo la condicion cronica de los niños.	( )	( )	( )	( )
17- Yo proveo cuidado de salud general.	( )	( )	( )	( )
18- Yo ayudo a cordinar los servicios.	( )	( )	( )	( )
19- Yo me comunico con otros proveedores de servicios.	( )	( )	( )	( )
20- Puedo contestar preguntas a cerca de la condiciones de los niños.	( )	( )	( )	( )
21- Yo recibo guianza e informacion sobre los niños.	( )	( )	( )	( )
22- Yo estoy comodo sobre el entrenamiento que recibí sobre los niños.	( )	( )	( )	( )

Por favor conteste verdad o falso en las siguientes preguntas.

	Verdad	Falso
23- Yo creo que la supervivencia de los niños depende en la coordinación de servicios.	( )	( )
24- Todos los servicios de apoyos que reciben los niños me dejan pasar mas tiempo para cuidarlos.	( )	( )
25- El entrenamiento Medico que recibí ha prevenido mis niños que vayan al hospital.	( )	( )
26- Yo creo que los niños tienen menos visitas con los doctores por el entrenamiento medico que he recibido.	( )	( )



APPENDIX G  
INFORMED CONSENT  
(ENGLISH VERSION)

## Informed Consent

The study in which you are invited to participate is designed to learn more about your experience as a medical placement foster parent caring for the medically fragile children. The study is being conducted by Ana Baisley who is a student in the Master of Social Work Program at Cal State University, San Bernardino, California (CSUSB). Mrs. Baisley is under the supervision of Dr. Ray Liles, Assistant professor at CSUSB. The Department of Social Work Sub-committee of the Institutional Review Board of California Sate University, San Bernardino, and the Department of children and Family Services have approved this study.

In this study you will be asked to participate in a personal interview at your home regarding your foster care experience as medical placement foster parent. The questions will be about the health of the children placed in your home, the services the children are receiving, training you have received, your coping ability to care for chronically ill children, placement stability and permanency plans. The entire interview will take approximately one hour and 30 minutes.

Please be assured that your name and any information you provide will be held in strict confidence by this researcher. When the results of the research are published or discussed, no information will be included that would reveal your identity.

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so. The agency will not know about your participation.

If you have any concerns after you have completed the study, about your participation, please do not hesitate to call Ana Baisley at (626) 938-1761. Thank you for your time and consideration.

I acknowledge that I have been informed of, and understand the nature of this study. I freely consent to participate as indicated by my signature below. I acknowledge I am at least 18 years old.

\_\_\_\_\_  
Mark

\_\_\_\_\_  
Date

APPENDIX H  
INFORMED CONSENT  
(SPANISH VERSION)

## Consentimiento de información

El estudio que usted es invitado a participar está diseñado para aprender más acerca de la experiencia de padres de crianza que cuidan a niños que son medicamente frágiles. El estudio esta conducido por Ana Baisley quién es un estudiante en el programa de Mastestria de Trabajadores Sociales en La Universidad del Estado de California San Bernardino (CSUSB). Sra. Baisley esta bajo la supervisión del Dr. Ray Liles, Asistente Profesor en CSUSB. El sub-comite de la Junta Institucional de Examinación de California (IRB) en el Departamento de Trabajadores Sociales y el Departamento de Servicios de Familias y Niños (DCFS) han aprobado el estudio.

En este estudio, usted va hacer pedido que participe en una entrevista personal en su casa sobre su experiencia de padre de crianza de niños medicamente frágiles. Las preguntas serán acerca de la salud de los niños ubicados en su casa, los servicios que estan recibiendo los niños, entrenamiento que usted ha recibido, sus habilidades de manejar el cuidado de niños enfermos crónicos la estabilidad y planes de permanencia de los niños. Toda la entrevista tomara aproximadamente una hora y media.

Por favor, este asegurado que su nombre y cualquier información que usted provée será mantenida bajo estricta confidencialidad. Cuando los resultados de la investigación sean publicados or platicados, no información será incluida que revelara su idéntidad.

Usted puede elegir si quiere ser parte del estudio o no. Si usted quiere voluntariamente entrar en este estudio, usted puede retirarse en cualquier momento sin ninguna consecuencia. Usted puede negarse de contestar cualquier pregunta si usted no quiere contestar y todavia puede quedarse en el estudio. El investigador puede sacarlo del estudio si hay circunstancias en que es necesario hacer eso. La agencia no va saber si usted participó.

Su participación y contribución son apreciados grandemente. Usted puede obtener una copia final del reporte si usted desea ponerse en contacto con California State University San Bernardino, Departamento de Trabajadores Sociales al (909)880-5800 despues de Junio 2003.

Si tiene alguna preocupación despues de haber completado el estudio sobre su participación, por favor llame a Ana Baisley al (626) 938-1761. Gracias por su tiempo y consideracion.

Yo declaro que he sido informado y entiendo la naturaleza del estudio. Yo libremente consiento de participar como indicado por mi marca abajo. Yo declaro que tengo 18 anos de edad.

\_\_\_\_\_  
Marca

\_\_\_\_\_  
Fecha

APPENDIX I  
DEBRIEFING STATEMENT  
(ENGLISH VERSION)

## Debriefing Statement

The study you have just completed was designed to investigate the experience and needs of medical placement foster parents caring for medically fragile children in Los Angeles County, Department of Children and Family Services. The study is looking in particular at the coordination and access of services, specialized training and ability to cope with the children's chronic conditions.

Thank you for completing the survey in this study. Your participation and contribution to this study is greatly appreciated. You may obtain the results of this study by contacting California State University, San Bernardino, Department of Social Work at (909) 880-5800 after June 2003.

If you have or experience any personal issue that this study has brought about, you may contact a local agency that is available in your community. The following are community agencies that can assist you: Visiting Nurse Assistance/ Counseling (626) 967-9311 and USC Humans Relations Center (213)740-1600.

To ensure that the results not be influenced by participants being aware of the purpose of this study, please do not discuss the nature of this study to other potential participants.

APPENDIX J  
DEBRIEFING STATEMENT  
(SPANISH VERSION)

## Declaración de Instrucciones Sobre la Investigación

El estudio que recién usted ha completado está diseñado para investigar las experiencias y necesidades de los padres de crianza en la ubicación medica que cuidan niños medicamente frágiles en el Departamento de Servicios para niños y familia en el condado de Los Angeles. El estudio esta mirando en particular a la cordinación y acceso de servicios, entrenamiento especializado y la habilidad de manejar las condiciones cronicas de los niños.

Gracias por completar la entrevista en este estudio. Su participación y contribución a este estudio es apreciado grandementé. Usted puede obtener los resultados de este estudio llamando la Universidad del Estado de California San Bernadino al Departamento de Trabajadores Sociales al (909) 880-5800 despues de Junio 2003.

Si usted tiene o este estudio le ocasiona alguna cuestión personal, usted puede ponerse en contacto de una agencia local en su comunidad que esta disponible a ayudarle. Las siguientes agencias de la comunidad pueden asistirle: Visiting Nurse Assistance/Counseling (626) 967-9311 y USC Humans Relations Center (213) 740-1600.

Para asegurar que los resultados no sean influenciados por los participantes conociendo el proposito de este estudio, por favor no hable de la naturalesa de este estudio con otro participante potencial.



APPENDIX K  
RESPONSES FROM THE PERSONAL  
INTERVIEW QUESTIONNAIRE

## Responses from the personal interview questionnaire

What are some of the reasons that made you decide to be a foster parent for medically fragile children?

- 1- *I was working with disabled adults, I knew somebody who was taking care of medically fragile children and began to help out.*
- 2- *I began working on a facility that cared for disabled children and adults. I did not like how the children were cared so I got a license to care of them at home.*
- 3- *I was working and I found out that a 5 years old girl needed a home to be cared for other than the state hospital. I decided to take care of the 5 years old and to stay home and care for children with disabilities.*
- 4- *My mother and grandmother were foster parents. After I graduated from high school, I helped my grandmother care for the disabled children and started volunteering in a facility that cared for children with handicapped.*
- 5- *My mother in law had the home and I took it over.*
- 6- *I was working in a hospital as a nurse and taking care of medically fragile children. Parents of the children I was caring, encouraged me to get my license and they assisted me financially to buy a house.*
- 7- *I began taking care of terminal children as an alternative to provide them a home instead of ending up in a hospital or institution. I give normalcy and advocate for them. The children need somebody to bond with instead of having people coming in at different shift. I believe the quality of life improves at home.*
- 8- *My parents were foster parents and I grew up in a family that took care of foster children. My husband grew up in a large family and has a lot of experience caring for children. My first medically fragile child was by accident and the child was brought to me with cranium problems. I went to training to get licensed for medical fragile children after this child.*
- 9- *I find caring for medically fragile children to be rewarding and its great to see the children leave healthy. Children are innocent and I like to rescue the children from their situations.*
- 10- *I was doing childcare and a friend became a foster parent and told me how to get license.*

- 11- *A friend told me about getting a license to be a foster parent after I lost my job. Caring for the medically fragile, I see it as a blessing.*
- 12- *I learned about taking care of medically fragile children when I took a MAPP class with the other foster parents who were doing it. I was ready to try something different. I began by caring of emotionally disturbed children but it was very hard to deal with the behavior. Then I switched to medically fragile children.*
- 13- *A social worker told me about taking care of medically fragile children and explained the procedure to me. I went to get the county license. I am a CNA and I work in a facility part time caring for sick people.*
- 14- *My brother had a syndrome and I grew up caring for him. After I began working as a teacher for LA County Education I decided to get licensed as a foster parent to take in a boy who had the same syndrome as my brother.*
- 15- *My children grew up and moved away and I wanted to continue to care for children.*
- 16- *I was working for Foster Family Agency as a foster parent and I accepted a child who needed to go to the hospital three times a week. I decided to get the county license and take care of medically fragile children. I was also interested in caring for D rate children and the money was an incentive but after the child with schizophrenia was placed in my home and learned I could not handle the behavior problems and decided to care of the medical fragile children instead.*
- 17- *I helped my sister take care of medically fragile children and I learned a lot from the experience. Then I decided to get a foster care license and take care of the children with medical problems. I like it a lot.*
- 18- *I wanted to be useful and spend more time with my son at home.*
- 19- *After my children moved away I felt lonely and wanted to adopt more children.*
- 20- *I have a CNA license and wanted to stay home and care of my children.*
- 21- *My only son needed a playmate and I saw on television advertisements on how to become a foster parents. Other foster parents told me about caring for the medically fragile children and I liked it.*

22- *I wanted to adopt children but decided to foster children when I learned that social workers were not telling the complete truth about what the children's problems were.*

23- *I like to care of sick children and I find them easier to care for. I like it because the medical field tells the truth about the children and train me how to care for them.*

24- *I started taking care of teenagers and then other foster parents told me about medically fragile children. I was scared to care of the very sick children so I only care one child at the time with not severe medical problems.*

25- *I had a day care license and my neighbor told me about getting a foster care license.*

26- *I enjoy caring for the medically fragile children.*

**Children's Diagnoses:**

- *Cerebral Palsy, non ambulatory, orthograposis*
- *Autistic, Mental retarded, ADHA, hydrocephalic*
- *Drug and alcohol exposed, developmental delays, apnea monitor, laser eye surgery, asthma*
- *Fetal alcohol syndrome, Cerebral Palsy, Obsessive compulsive behavior*
- *Brain injury, shunt, dementia*
- *Right hemi, Mental Retardation*
- *Spinal bifida, shunt, non ambulatory*
- *Legally blind, Moderate developmental delays*
- *Down syndrome*
- *Learning handicapped*
- *FAS, throat enlargement,*
- *Charge Syndrome, one kidney, micro cephalic head*

- *Heroin addict*
- *Epileptic seizures*
- *Pancreatic, ADHD*
- *C.P., MR, G-tube, gaseophagal, presbiopia, undescendent testacles*
- *Osteogeneses imperfecta Type II*
- *Hydroencephelic, (no brain) microcephalic*
- *Micro cephalic, blind, hard of hearing, CP, pulmonary dysphasia, G-tube, oxygen dependent*
- *Bacterial meningitis*
- *Diabetes insipidis*
- *Down syndrome, asthma, webbing, high blood pressure*
- *Intestinal surgery*
- *Lupus, MR*
- *Heart problems, legally blind*
- *Major heart and lung surgery, drug exposed, G-tube*
- *CP, hydrocephalic, stiff legs and arms, DD*
- *Nephritic syndrome, NG-tube*
- *Heart surgery, genetic belocardi facial, deletion chromosome 22,*
- *De George syndrome*
- *Asthma*
- *Skin problems and allergies*
- *Burn victim*
- *Shunt and DD*

- Tumors in the head
- Leukemia in remission
- Cleft palate, DD,
- Charge syndrome, oxygen dependent, G-tube, intestine and anus surgery
- Brain injury, femur fracture, behavior problem

Did the training to become a medical placement foster parent help you prepare to be a caretaker of MFC? Explain

- *It really helped. I get a lot out of the training. I also look in the Internet to prepare before I make the decision to take the child.*
- *I always had the gift to take care of anything that is helpless. I grew up taking care of others. The training teaches how to deal with the children's behavior and techniques. The regional center has good workshops and conferences.*
- *The training prepares you but you need to get specialized training for that one child before bringing home. RC is offering for other type of kids but now they are charging \$10 dollars, CHLA is no longer offering the medical training like they used to.*
- *The F-rate training is a good class but there is the need of more specialized medical training for the kids.*
- *I have taken classes in college that are helping me.*
- *Training should be child specific with the child doctor and nurses that are familiar and help you with the needs of the child.*
- *I am a nurse and do not require a lot of training. When I picked up the child, I had to train for the child specific. It is good because the medical field is always changing and you never know the new developments.*
- *It is important that the foster parents get training by the hospital before taking the child home. For the new foster parents, it is imperative that they have a visiting nurse after the child is discharged or they might hurt the child. However, some nurses don't know and don't have experience. Some hospitals do better than others. You need to look for the person who took care of the child the most at the hospital and look for the doctor interns to get as much information. Get referrals from the doctor and ask a*

*lot of questions. You need to do detective work and spend time in the hospital, wait and see. Ask for the discharge summary, history and other information before leaving the hospital with the child.*

- *The trainings help but I also done a lot on my own like the Internet. The hospital training is good but when you get home you panic and it is easy that you become overwhelmed. I had a 7month old child that had 7 replacements before coming to my home. The FFA placed the child with a 22-year-old foster parent who had no experience. She took the child to the hospital and refuses to take him back. I went to pick up the child at the hospital and received the training. It is important that all foster parents receive the individual training before taking the child home. All children are different.*
- *You are forced to go to the hospital and get the training until you are comfortable before taking the child home. Going to the hospital you meet the child's doctor and nurses and you get a nurse to come to your home if you need it. The only child I requested a nurse was one with a central line. The nurse was an RN and she worked with us for a week. Nothing scares us now after that experience.*
- *I go to the hospital all day and find out a lot about the kids. Classes help me find out about the places and people you can get help from. I like the seminars because I learn so much information.*
- *At first I had no training and I had to call the nurse and doctor to show me how to use the g-tube.*
- *I took classes for the medically fragile children that help me train before taking the child home. At first I was scared but you catch on really fast and it becomes second nature. I tend to take children with the same diagnoses.*
- *I was scared before taking the child home but after the nurse show me and I saw it was easy I was ok with the training. I am determined to do a good job.*
- *Social workers and nurses in some hospitals are great. F-rate training is not helpful for foster parents that have been doing this for many years.*
- *I learned a lot from f-rate training and individualize training by the doctor.*

- *Training is good but there is nothing like the direct practice. I participate on going in a support group and other trainings in the community to get more knowledge.*
- *The training gave me a base but I go to weekly training at community college and attend foster parent support groups.*
- *Training help me learn what I have to do and how to do it.*
- *I learned a lot. First I am a little scared but later I feel OK. I feel sometimes I know more than the nurses and they ask me questions on how I do things.*
- *I have taken more classes than it is required and I have more hours than I need. Child specific training is very important.*
- *I didn't like taking the severe medical problem children because I didn't feel capable. I gradually learned to care of the children and now I take many classes to help me feel sure of myself. I see a big difference on how children do in a hospital like facility and in a foster home. I believe is best for the children to be in a foster home.*
- *Training helps me became more secure about the skills and care of the children.*
- *The training to care of the children helps me with my own children.*
- *Training explains what to do in case something bad happens and what to do.*
- *CHLA has a great training before releasing the children.*

Were these services helpful? Explain

- *I see a lot of improvements and progress. The professional therapy helps the children and teaches us how to work with the kids at home.*
- *Very helpful.*
- *Equipment wise like wheelchairs, leg braces. The children have nothing without it but it takes time to get it. The foster parents need to speak up and advocate for the services.*
- *They are helpful, I educate the service providers on the children's needs*



- *It gives me time to take the kids to the doctor and other appointments.*
- *They provide sensory integrated services. The therapist comes to the house to work with the children and they have a wealth of information and resources to help out.*
- *Therapy and medication helps the children make a lot of improvements.*
- *Regional center is helpful dealing with the schools.*
- *CCS and regional center are helpful but I need to push the worker and advocate getting what I need. Pomona district had a great early intervention and that is why I live here.*
- *Services are not available for budget cut and no services for foster parents.*
- *My kid is doing better since Occupational therapy started. The shoulders and arms are no longer stiff.*
- *They tell me what should be done and then I have to do it. We discuss the child a lot.*
- *Yes, the therapist knows my child and the medical needs and tries to help a lot.*
- *Some services are not helpful. Services are turned down because we are foster parents not the children's parents.*
- *Yes, they play with the children and I can use the time to go out to doctor visits, shopping and the children get a lot more activities.*
- *Yes, they pay for everything medical don't pay such as bi-pack, oxygen, and pediasure.*
- *They provide services right away and come twice a week to help the children.*
- *They are OK under certain circumstances. The children with CP and MR have too many problems and they need a lot of help.*
- *They give me time to go out.*
- *Helps the children with developmental delays.*

- *The occupation therapy and speech therapy at home is very helpful and they help the children emotionally and physically. I have a lot of problems with the school district and they help with the communication.*

Are you able to meet the needs of the children in your care with this level of funding?

Explain

- *No, They are a lot of work and they are very sick children.*
- *Yes, I think is enough money.*
- *I am barely doing it.*
- *The only need you cannot meet is the transportation. I need a van for wheelchair. It also depends on the age of the child. There is a need for better clothing allowance. Clothes are expensive. I have three medications I pay for. Foster parents are not supposed to take care of children for the money.*
- *No, because is 24/7 day care of the children, the special equipment, the multiple doctor appointments, reliable car, and child care if you need it. I don't do it for the money.*
- *Not really. If I want to work outside I can't afford decent childcare. Medical does not cover some medications. I suggest that if the medical does not cover the medication, the money should be increases accordingly and decreased when it not needed anymore.*
- *Sometimes, it depends on the problems the child has.*
- *I don't think is enough money.*
- *I think it's fair. I get F4 and it's enough but the children are a lot of work.*
- *No because there are a lot of doctor appointments and it's expensive to take them to 3 to 4 times a week.*
- *I don't think is enough money because I like them to wear good clothing.*
- *For teenagers all the money goes to personal things and they need more help with counseling.*

- *There is a lot of work involved in the daily care specially when they are sick. It takes two weeks at least to get better and watch them day and night.*
- *I think is good because when I was in FFA they did not pay enough. I use the money to buy what they need. I like them to dress well.*
- *It is not enough for the amount of work that the children need.*
- *I believe that it is not enough. It is a lot of work and responsibility that one has to take and we should not negotiate over a child. There are no funds for respite care and other services.*
- *Social workers don't properly evaluate and they give you wrong rates.*

*What efforts were made to prevent a re-placement? Explain*

- *Wrap around services. Reg. Center does not have services like DCFS to prevent replacement.*
- *I had children with MR and behavior problems and I took behavior modification classes to deal with children that their functioning was not enough to understand regular discipline.*
- *I give my best effort and try everything I can before asking a child to be removed.*
- *The RC gave us a person to watch the child at night but we decided that we did not wanted and let the child go to a temporary placement to help him with behavior problem. He is back at my house and we want to adopt him.*
- *The social worker worked with me and provided a lot of support and I decided to keep the child.*
- *The doctors were helpful and supportive and the CSW was very understanding.*
- *I had a child removed due to being very ill and I felt I could not provide the best care the child needed. I did not take care of anybody for six months. Each case needs to be determined individually and it depends on what is going on.*
- *I specialize in drug babies and they all leave when the court makes the determination and it's time.*

- *The CSW talked to me but I did not want the teenagers to model bad behavior to my other kids. I felt bad with the child who the other kids did not get along and I had to let him go. I told myself I would try to teach kids to share. I would also look at the whole household and see what is best for the whole house.*
- *I resolved it by talking to the CSW and arranged somebody else to monitor visits.*
- *No, there is nothing anybody can do when I make up my mind.*
- *The hospitals send me a nurse and it helped me keep the child.*
- *They said it was my problem and nothing could be done.*
- *Nothing they can do. I only take children that I know I can handle to avoid problems later on.*
- *The CSW and I felt the child needed to go to another home*
- *The children needed a higher level of care like a group home due to behavior problems they acted out a lot.*
- *I got somebody to help me with the house so I can supervise the children all day.*
- *I am having the problem right now and I am looking at options on what to do with the social worker and therapist.*
- *I looked for recreational activities, sports, counseling and medication to prevent re-placement.*

What is the reason for the permanent plan selected?

- *If the kids have parents that care, I give them back. I don't want them to be re-abused. If they don't have anybody, I keep them because I don't want them to bounce from one place to another. I fall in love with them.*
- *I have legal guardianship of the children. I don't want to adopt because I am not sure the AAP services are working and they don't guarantee the services.*
- *I have LTFC and legal guardianship because there are not enough homes and as long as I able I will take care of them.*

- *I want to keep them here with me long term under adoption first and if not legal guardianship.*
- *I want to adopt and keep them under my care.*
- *I adopted three children and became legal guardian of two others. I could not see them leaving because I love them. They have nobody else in the world.*
- *I want LTFC for now. We look at the future and the problems they are going to have when they become teenagers. I may consider legal guardianship and adoption later on.*
- *I only take terminal children. I don't want forever kids or raise them to adulthood. I am a worrier and did not want kids to be taken away from me. When children are terminal you know where they are going.*
- *I have adopted three children and I have legal guardianship of one. The reason I selected this plan is due to the child's medical needs and the mother being in prison. It was very difficult to obtain approval for surgeries and mother agreed that the best plan was legal guardianship. Also because of her age and her medical problems she would have been put for adoption and removed from me. In the future, mother might get her life together.*
- *I don't want to adopt anymore and start over raising children. I adopted one child but now we are getting old and we are considering taking time off.*
- *I adopted 5 kids, 4 boys and 1 girl. I decided to adopt as soon as I found out he could sleep in the bedroom with the other two kids. I decide to adopt them by looking at the bond that exist with them and that is how I know which one is the one I want.*
- *I adopt them because I love them. I have legal guardianship with one because parents and siblings are part of his life and I want share with the parents.*
- *I don't want legal guardianship because parents love him and want to get him back.*
- *I only want legal guardianship because they have severe medical problems and I learned from the children I adopted.*
- *I feel that if I adopt I am going to lose the services I have now.*

- *I only want legal guardianship because I will like to give them a stable place to live and help.*
- *If other families don't adopt the children, I will keep them under legal guardianship.*
- *I might consider legal guardianship because it is reversible and I will have services and support. Nobody wants to help you once you adopt a child.*
- *I want to keep the child under legal guardianship because it is reversible. We might change our mind and adopt.*
- *I decided to keep her under legal guardianship because she never had a family and the lady who had her since she was a baby did not want her anymore.*
- *I love her very much and she is a good girl. I want to adopt her but I can do legal guardianship if the court does not want to let me.*
- *I adopted two children and I am legal guardian of one. Parents did not want them and I have the children over a year.*
- *I prefer legal guardianship because DCFS is involved and provide services. I have to look at the future and consider my whole family before making the decision to adopt.*
- *In adoption, all services are cut. I want legal guardianship to get help needed for the children.*
- *I felt it was better emotionally for the child to adopt but the social worker said it was better to have legal guardianship. I am adopting the other children because I love them and they are part of my family. If something happens to me, my children will care for them.*

How can the CSW assist you in your decision to keep the child under your care?

- *The CSW can give me time to make the decision and let me keep the child under LTFC.*
- *The CSW can help me with the decision by giving me support and information.*
- *I don't think CSW need to come every month if the children are stable and the relationship with the CSW is strong.*

- *By providing support.*
- *The role of the CSW is instrumental to help make the decision. I like MPU because they have more connections and the support system is there. Adoption puts a lot of stress and places all the responsibility on the adoptive parents. Post adoption assistance does the re-determination by filling out forms every two years but the child continues to have the same problems. If there are problems and there is no regional center involved, I don't know who to call for help. When the children get 7 or 8 years old and they have school problems and nobody to help its very difficult. A lot of foster parents tell me that I am stupid to adopt because there are no CSW helping and the pay goes down. In my house it takes two to care of the children.*
- *The CSW are supportive when things need to be done.*
- *The CSW can help by listening and giving support. They should ask, "What can I do to help?"*
- *CSW do not always have the time to help and to go to appointments with me. The license workers have penalized me for silly staff.*
- *CSW can help with support and services and to provide more resources if needed for the children.*
- *CSW can give me advice.*
- *Support and help.*
- *Nothing*
- *CSW should communicate more with foster parents and then speak to the children alone. They should evaluate the children appropriately for the foster care rate.*
- *CSW should talk to the children and make sure the children get the services they need.*
- *CSW should give me referrals and provide answers when needed. The responses of CSW when investigate a referral should be better.*
- *The CSW cannot do anything once I make a decision.*
- *I look for services. I am involved in foster care association and take classes to learn how to deal with children in my home.*

- *The county can provide respite care. Since I have been a foster parent I get a letter every year that I can get 3 days but they have never paid.*
- *I continue to take classes and review the doctor orders to make sure that I do it right. I hope that the children get a good family to adopt them. I was very stressed when I have to make the decision to keep them or not but I have to make sure all the children at my house are safe to prevent something from happening.*
- *The CSW comes to get the medical forms and deals with the children's parents. I don't call the CSW if it is not important. I try to stay neutral with reunification services and never speak badly about the parents in front of the children.*
- *I want CSW to give the right information.*
- *I would like CSW to help me when there are serious problem and to take interest.*
- *CSW to worry about the children and provide services.*

What recommendation do you have for the DCFS to improve the services to the medical placement foster parents caring for the medically fragile children?

- *MPU is doing great. DCFS has better resources than other agencies and they work on making a permanent plan for the children.*
- *CSW need to have more time to help the children. MPU is doing OK. I had no bad experiences.*
- *I never got a bad CSW and I got along with them. The foster parents used to have to do a lot more like the referral to Regional Center. I take the children to all the doctor appointments, transport them and attend IEP's. DCFS should give a list of foster parents to call and names and addressed and qualifications. Medical foster parents should have a foster parent organization for advice and assistance. Right now it's done informally.*
- *Court should get things done instead of picking in little things.*
- *More communication is needed between the CSW and the foster parents.*
- *Foster parents should have a place to call if they need relief and help. There is no time to go out and we always have to take them with us. Foster parents get burned out. I can't make plans because I don't know what is going to happen with the children. Foster parents should attend*



*the foster parent association and attend classes through the consortium on going.*

- *Help foster parents get the appropriate rates for the children and medical. DCFS should raise the rates. If the children are from LA foster parents should get LA rates.*
- *The F-rate training should be done by MPU staff, PHN and experienced foster parents. Other regions should know what CSW at medical placement do. DCFS staff and foster parents should train together. A lot of new CSW don't know how to fill out F-rate and get the diagnoses for the children*
- *The system is set up with a lot of policies and regulations that are not the best for the children.*
- *The CSW are over burden with cases. The health system needs to be improved and more open.*
- *MPU is doing a good job and I like the classes and seminars provided.*
- *It is much better now than before. CSW visit monthly and I get the checks with no problems.*
- *I would like help with getting respite care and babysitting so I can attend meetings. There are not enough post adoption meetings in the areas outside LA. The f-rate classes are good for the new foster parents but not the ones with years of experiences. They are really boring. MAPP classes are something else. Foster parents that teach them have less experience than the ones attending and they talk about older children not babies with medical problems.*
- *MPU is doing well but CSW need to take MAPP training.*
- *Foster parents should have more access to CSW when needed. DCFS should provide more foster parents associations for support groups, parenting classes, communication and other topics.*
- *More support is needed from the system. We need more support groups. I don't like CSW to jump to conclusions without properly evaluating the situation at home.*
- *More training is needed to learn how to deal with medically fragile children.*

- *I think more communication is needed. I have good experiences so far with CSW, they listen to complains and help.*
- *More attention and time is needed to follow up the children and their needs.*
- *The foster parents need more help to care of the children, I can't leave them anywhere and they are always with me.*
- *DCFS should provide health care for foster parents.*
- *MPU is doing well with foster parents, but more training and services are needed. I learned from other foster mother with experience and she helps me work through fears to care of medically fragile children. May be have mentors for foster parents*
- *There are problems with some CSW giving services and the payments-rate training need to be improved. Foster parent are not getting the information needed.*
- *DCFS, MPU should have good connection with other systems.*
- *More training for new foster parents, many don't attend training. I get a lot of calls from other s who need help and support*

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