

EXPLORATORY STUDY OF MEDICALLY FRAGILE
CHILDREN IN UTAH'S CHILD WELFARE SYSTEM

by

Trudi D. Moore

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STATEMENT OF DISSERTATION APPROVAL

The dissertation of Trudi D. Moore
has been approved by the following supervisory committee members:

Norma Harris, Chair 2/8/2012
Date Approved

Frederick V. Janzen, Member 2/8/2012
Date Approved

Larry L. Smith, Member 2/8/2012
Date Approved

Cheryl Wright, Member 2/8/2012
Date Approved

Becky Christian, Member 2/8/2012
Date Approved

and by Jannah Mather, Chair of
the Department of Social Work

and by Charles A. Wight, Dean of The Graduate School.

ABSTRACT

Children in foster care are a vulnerable population. They are typically in poorer health and experience higher rates of mental health issues and developmental delays. Medically fragile children in foster care are even more vulnerable. They have significant health care needs and require specialized services. Because of these needs, it is critical that medically fragile children in foster care are appropriately identified.

The primary purpose of this qualitative, exploratory study was to increase the understanding of medically fragile children served by the Division of Child and Family Services (DCFS) in the State of Utah and propose a definition of medically fragile children for DCFS consideration. There are many definitions used to describe medically fragile children. These definitions vary from broad to restrictive in nature. It is critical to identify criteria to accurately describe a medically fragile child because it will increase the likelihood that these children are appropriately identified. This will result in appropriate services provided to this population and increase the likelihood of their needs being met.

Telephone interviews were conducted with 26 participants who had experience working with medically fragile children. Based on the participants' responses, a new definition of a medically fragile child was created. In addition to a medical and/or mental health diagnosis, level of oversight, level of health care needs, level of assistance with daily activities, cognitive delays, developmental delays, and the impact of

psychosocial stressors were included in the new definition. Use of this definition may result in children being assessed in a more holistic manner.

In addition to incorporating the proposed definition, it is suggested that DCFS provide the following services to improve the care of medically fragile children in foster care: a) appropriate reimbursement to foster parents for caring for medically fragile children, b) qualified respite providers, c) training for foster parents' support system to assist in respite care, d) alternative support services, e) attendance of a DCFS nurse at all child and family team meetings, f) assistance to foster parents in coordination of health care services, and g) necessary medical information to foster parents prior to a child's placement.

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CHAPTER 1

STATEMENT OF THE PROBLEM

Because of the variety of definitions used to define a medically fragile child, it is difficult to determine the number of medically fragile children and their needed services in the United States. According to van Der Lee, Mokkink, Grootenhuis, Heymans, and Offringa (2007), the number of children with a chronic health condition is increasing in frequency. Many studies show that approximately 10% to 15% of children have chronic health problems (Gortmaker & Sappenfield, 1984; Harvey, 1991; Pless & Perrin, 1985; Yost & Hochstadt, 1987). Of these children, 10% have a severe chronic illness (Harvey, 1991; Yost & Hochstadt, 1987). Based on these findings, approximately 1 and 2% of all children have a severe chronic illness that interferes with their daily age appropriate functioning. Many of the children served in child welfare systems are identified as medically fragile and this is the primary focus of this dissertation.

van der Lee et al. (2007) reviewed definitions of childhood chronic conditions and determined the prevalence rate varied from .22% to 44%. Newachek and Halfon (1998) reviewed studies on the prevalence of childhood chronic conditions and determined that the number of children afflicted with a chronic condition ranges from less than 5% to more than 30%. Depending on the definition of a chronic condition, Perrin, Newachek, Pless, Drotar, Gortmaker, Leventhal, et al. (1993) determined the prevalence varies from .6% to 31%. Similarly, Harris-Wehling, Ireys, and Heagarty (1995) reported that the

estimated prevalence of children with special health care needs varies from 2% to 31%. Higher estimates of chronic childhood conditions are found in studies that use a liberal definition (Perrin et al., 1993) and “include conditions that have modest effects on children’s activities and use of medical care” (Newacheck & Halfon, 1998, p.615). Lower estimates of chronic childhood conditions are found in studies that used a more restrictive definition (Perrin et al., 1993) and only included conditions that caused “some level of disability” (Newacheck & Halfon, 1998, p.615). The differences in the findings on the prevalence of childhood chronic conditions further illustrate the difficulty in developing a definition that accurately defines this population.

With the numerous definitions and criteria used to identify medically fragile children, it is difficult if not impossible to determine the number of children who are in need of or qualify for specialized services. These various definitions also raise questions about the services being provided and if they are appropriate and/or adequate.

Defining Medically Fragile Children

Medically fragile children are described as medically complex, medically fragile, technologically dependent, handicapped, chronically ill, children with special health care needs, and children with chronic health conditions (Capen & Dedlow, 1998; Fleming, Challela, Elan, Hornick, Johnson, Martinson et al., 1994; Harrigan, Ratliffe, Patrinos, & Tse, 2002; Hill, 1993; Hill, Hayden, Lakin, Menke, & Amado, 1990; Horner, Rawlins, & Ghiles, 1987; Silver, DiLorenzo, Zukoski, Ross, Amster, & Schlegel, 1999; Thomas, 1984; van Der Lee et al., 2007). Because of these different classifications and lack of consensus on the definition of a medically fragile child, it is difficult to determine the number of medically fragile children in the United States and more specifically, the

number of medically fragile children in the child welfare system. Because there is so much variation in classifications and definitions, it is difficult to determine what services, treatment strategies and other resources are needed. As a consequence, it is unknown if children with these needs are receiving adequate care. Of particular concern are medically fragile children who are placed in foster care systems and how vulnerable they are.

A review of relevant literature reveals that a standardized set of criteria for identifying medically fragile children does not exist. Researchers, medical professionals, and social workers use definitions that vary from broad to specific in nature making it very difficult to determine if these children are receiving needed services.

A variety of health care conditions were included in the following definitions of medically fragile children. Children with mental health disorders or developmental issues were rarely included in the following definitions and/or research. This further complicates the issue of accurately defining a medically fragile child.

Definitions

The Office of Technology Assessment (OTA) (1987) defines a technology-dependent child as “one who needs a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability” (p.3). This definition is further divided into four categories. The first group of children is dependent for at least part of the day on mechanical ventilators. The second group of children requires prolonged intravenous administration of nutritional substances or drugs. The third group of children is dependent on other device-based respirator or nutritional support. The last group requires prolonged dependence on other medical

devices that compensate for vital body functions that require daily nursing care. “Under a very strict definition of technology dependence, this fourth group might not be included. OTA has included it to demonstrate how rapidly the technology-dependent population grows as additional groups are included in the definition” (OTA, 1987, p. 4). In a literature review on the stress experienced by families with medically fragile children completed by Ratliffe, Harrigan, Haley, Tse, and Olsen (2002), the authors defined medically fragile children by the criteria established by the OTA. However, they noted that children who are not dependent upon technology can also be considered medically fragile, further illustrating the confusion in defining a medically fragile child.

Thomas (1984) prefers to identify children with health care issues as children with chronic health conditions instead of chronically ill children. His justification in identifying them as children with chronic health conditions is that this definition reinforces the concept that a chronic condition does not necessarily affect all areas of a child’s ability to function. Thomas defines a chronic condition as:

any anatomic or physiologic impairment that interferes with the individual’s ability to function fully in the environment. Chronic conditions are characterized by relatively stable periods that may be interrupted by acute episodes requiring hospitalization or medical attention. The individual’s prognosis varies between a normal life span and unpredictable early death. Chronic conditions are rarely cured, but they are managed through individual and family effort and diligence. (p. 165)

Yost and Hochstadt (1987) examined a project that involved providing a comprehensive foster care program to seriously medically ill children. These authors defined a medically complex child as one “requiring prolonged dependence upon medical care and high levels of technologic and/or nursing support” (p. 142). The authors identified five groups of seriously chronically ill children. The first group was seriously

chronically ill and required 24 hour nursing care (e.g., long-term tracheostomies, feeding gastrostomies, or ventilator support). The second group included “chronically ill children who need a change in medical management or counseling for adaptation” (p. 144). The third group included chronically ill children recovering from a “complicated surgery or accidents whose illness involves a prolonged recovery during which skilled nursing and medical care is required” (p.144). The fourth group consisted of children who were medically stable, but in transition from care centers to home. Their caretakers were in need of training regarding their child’s care. The final group was composed of children who were medically stable, but lacked an appropriate home setting. Children receiving care through this program were likely to have one of the following disorders:

bronchopulmonary dysplasia, ventilator dependence, cystic fibrosis, cardiopulmonary diseases, neuromuscular diseases, severe brain injuries, nutrition problems that required feeding through machines, and colostomies.

Walker, Epstein, Taylor, Crocker, and Tuttle (1989) asked parents of children with chronic health conditions to complete a questionnaire about their perceived needs. Children with chronic health conditions included in this study were identified with the following disorders: mental retardation, seizure disorder, cerebral palsy, congenital heart disease, spina bifida, scoliosis, Down syndrome, severe visual or hearing impairments, cleft lip and/or palate, asthma, autism, neurofibromatosis, hemophilia, cystic fibrosis, and juvenile rheumatoid arthritis. Findings determined that the perceived needs of parents were similar. Differences existed according to the child’s health condition. Education on entitlements, assistance on securing services, physical therapy, financial help, speech therapy, information on community resources, early intervention services, social and

recreational opportunities, and occupational therapy were the needs identified as “very important” by at least half of the participants.

Horner et al. (1987) also asked parents of chronically ill children and handicapped children to complete a survey on their perceived needs. The authors of this study did not identify the differences between a chronically ill child and handicapped child. Children with the following conditions were included in the study: apnea premature, arthritis, autism, cardiac problems, cerebral palsy, cleft lip or palate, cystic fibrosis, diabetes, Down syndrome, hypertension, immune problems, learning disabilities, muscular dystrophy, PKU, speech and hearing disorders, seizures, sickle cell, and spina bifida. Parents of chronically ill children identified service needs, socioeconomic needs, and health care related needs. The most important needs were planning for their child’s future, identifying community resources, understanding how the disability affects physical and emotional growth, improving communication with their child’s health care providers, and meeting the child’s emotional, social, and intellectual needs.

Youngblut, Brennan, and Swegart (1994) interviewed caretakers of medically fragile children to provide a description of the problems and decisions experienced and the coping strategies and family resources utilized on a daily basis. The children included in this study had neurological disorders (e.g., cerebral palsy, head injuries, paralysis, or seizure disorders), respiratory disorders (e.g., bronchopulmonary dysplasia or asthma) or chronic renal failure. Toileting, transportation, sleeping, nutrition, and discipline problems were identified. Many caretakers identified the need for additional financial support and alternative child care arrangements.

Newachek and Halfon (1998) performed a cross-sectional descriptive analysis on the results of a National Health Interview Survey (NHIS) to determine the degree of disability in children with chronic conditions. NHIS defines a condition as chronic if it is three months in duration or has always been considered chronic regardless of the length of duration (e.g., diabetes or asthma). Chronic conditions were identified under 14 disease and injury categories: (a) infectious or parasitic diseases; (b) neoplasms; (c) endocrine, nutritional, metabolic, or blood disorders; (d) mental or nervous system disorders; (e) diseases of the eyes or ears; (f) diseases of the circulatory system; (g) diseases of the respiratory system; (h) diseases of the digestive system; (i) genitourinary disorders, pregnancy, or childbirth; (j) diseases of the skin; (k) diseases of musculoskeletal system; (l) congenital anomalies; (m) certain symptoms or ill-defined conditions; and (n) injuries. Injuries were only included if they were at least 3 months in duration.

NHIS further defines a chronic condition as an impairment when the condition is a permanent defect that is static in nature (Newachek & Halfon, 1998). Impairments were identified under the following eight categories: (a) blindness; (b) deafness; (c) impairment of speech, special sense, or intelligence; (d) absence or loss of extremities; (e) paralysis; (f) deformity of limbs, trunk, or back; (g) nonparalytic orthopedic impairment; or (h) defect, abnormality, or special impairment.

Newachek and Halfon (1998) determined that 6.5% of all children in the United States have some degree of disability. Of the 6.5%, 4% were limited in the kind or amount of their major activity, 0.7% were unable to perform a major activity each year, and 1.8% were limited in other activities. Prevalence increases with age, especially with

children after the age of 5. Disabilities were more prevalent among African-Americans, males, and low-income and single parent homes. Chronic impairments accounted for 39% of all childhood activity limitations while those identified as chronic diseases and injuries accounted for 61%. Respiratory diseases, speech impairments, special sense, and intelligence accounted for 25% of disabilities. Mental and nervous systems accounted for one sixth of all disabilities.

According to the Institute of Medicine (IOM) (Harris-Wehling et al., 1995), “over 200 chronic conditions and disabilities affect youth, including asthma, diabetes, sickle cell anemia, spina bifida, epilepsy, and autism. With the exception of asthma, most of these conditions are uncommon” (p. 64). These children with special health care needs can be divided into:

three broad, overlapping subgroups: (a) children with developmental delays or disabilities, such as mental retardation, learning disabilities, and sensory impairments; (b) children with ongoing medical disorders and chronic illnesses, such as diabetes, asthma, sickle cell anemia, or AIDS; and (c) children with emotional or behavioral problems, including attention deficit disorder, conduct disorder, or other psychiatric diagnoses. (pp. 64-65)

Some children might fit into all three categories.

At a workshop held by the IOM, participants had difficulty developing a definition of children with special health care needs. Benefits of a non-categorical approach were discussed.

For such a non-categorical definition, a serious ongoing physical health condition is understood to be one that: (a) has a biological basis; (b) has lasted or is virtually certain to last for a least a year; and (c) produces limitations in function, activity, or social role; need for more than the usual amount of medical care; need for care at home or school; or dependency on medications, special diets, or assistive technologies. (Harris-Wehling et al., 1995, p. 65)

Historically, chronic health conditions have been identified as health conditions that have long-term duration. Many believe that this classification system is too limiting and suggest that social and psychological components of a chronic health condition should be taken into consideration. Moving from a categorical to a collective approach allows all dimensions of a child's ability to function to be taken into consideration. Perrin et al. (1993) suggest an alternative approach to classifying chronic health conditions that utilizes a physical-mental health continuum. The authors argue that few conditions can be identified as only physical or mental. It is suggested that the following dimensions should be addressed when identifying chronic health conditions: (a) duration; (b) age of onset; (c) limitation of age-appropriate activities; (d) visibility; (e) longevity; (f) mobility; (g) physiological functioning; (h) cognitive ability; (i) emotional/social; (j) sensory functioning; (k) communication; (l) course of condition; and (m) uncertainty (Perrin et al., 1993). It is also recommended that a definition of a chronic condition "should be comprehensive, generic, and flexible" (Perrin et al., 1993, p. 792).

Children with health care needs typically qualify for Supplemental Security Income (SSI). If it is determined that a child qualifies for SSI, there is an expectation that their medical needs will be met. The United States Supreme Court identified the importance of a generic definition of childhood disabilities. Prior to the Supreme Court's 1990 decision, the Social Security Administration only considered children eligible for benefits if they had a specific medical condition. In *Sullivan vs. Zebley*, the Supreme Court ruled that the Social Security Administration was required to determine a child's level of functioning in the following areas: "cognition, communication, motor abilities, social abilities, and patterns of interaction, regardless of the specific condition" (Perrin et

al., 1993, p.788). The SSI program “defines a child as disabled if the child has (a) a qualifying diagnosis or (b) a condition that produces or is likely to produce significant interference with age-appropriate major daily or personal care activities for at least one year” (IOM, 1996, p. 65).

The Child Welfare League of America (CWLA) develops and updates standards that are considered best practice in the delivery of child welfare services (CWLA, 1988). According to the health care standards written by the CWLA, children identified as chronically ill or with special needs include, but are not limited to, the following disorders: (a) prenatal drug exposure; (b) developmental disabilities; (c) technology dependent; (d) terminally ill; (e) AIDS; (f) multiple handicaps; and (g) severe emotional disturbance (CWLA).

Hill et al. (1990) conducted a national survey of child welfare agencies to determine the number of handicapped children in foster care in the United States. The authors experienced difficulty in determining the definition of a handicapped child because of different classifications used by each state. Some states used the term “special needs” while other states used “functional descriptors such as physical, emotional, or mental handicap; others used standard diagnostic descriptors that included a standard definition (e.g., mental retardation, visual impairment), and others use broad indicators (e.g., learning problem or psychological handicap)” (p. 450). For the purpose of their study, Hill et al. used a set of diagnostic descriptors that included “mental retardation; serious emotional disturbance/mental illness; specific learning disability; hearing, speech, or sight impairment; physical or health handicaps; and other – unclassified or multiple handicaps” (p. 450).

The State of Utah's DCFS utilizes a 6-point level system to determine the health status of children in foster care. A foster care child classified at level one is healthy. A child classified at level two is healthy and in counseling. This child has no medical or mental health conditions that require medication. A child with a chronic condition that requires preventive medications is identified on level three. This would include a child receiving oral contraceptives, medication for hay fever, or a topical ointment for eczema. A child classified on level four has an acute illness or chronic condition that requires regular ongoing follow-up treatment. Medically needy children are identified on level four and would include a teenager who is pregnant, has multiple sclerosis, or requires follow-up on a medication such as a psychotropic drug or Accutane. Level four also includes children in a residential placement, acute care facility, or the Utah State Hospital. A child on level five is identified as medically fragile. This child has "multiple and/or debilitating conditions(s) that require assistance with activities of daily living" (DCFS, 2009). This child is at risk of developing an acute condition and requires daily monitoring. A child who has just entered custody, is on the run, or whose foster provider cannot be contacted is classified on level six. In addition to a numeric score, the following alpha scores identify a child's health needs: (a) current on all requirements; (b) overdue for exam and/or follow-up only; (b/c) overdue for exam and/or follow-up and immunizations; and (c) overdue for immunizations only. For example, a medically fragile child who is overdue for an examination and immunizations would be identified as 5bc. A child with multiple sclerosis who is current on all health requirements would be identified as 4a.

Medically Fragile Children in Foster Care

There are over 500,000 children in foster care in the United States (Leslie, Kelleher, Burns, Landsverk, & Rolls, 2003). It is unknown how many children in out-of-home care are medically fragile. Research continues to show that children entering foster care are in poor health. Foster children experience higher rates of serious emotional and behavioral problems, chronic physical disabilities, birth defects, and developmental delays when compared to children from similar socioeconomic backgrounds and the general population (AAP, 1994; AAP, 1987; Blatt, Saletsky, Meguid, Church, O'Hara, Haller-Peck, & Anderson, 1997; Hansen, Mawjee, Barton, Metcalf, & Joye, 2004; Klee & Halfon, 1987; Klee, Soman, & Halfon, 1992; Leslie et al., 2003; Silver et al., 1999). They have higher rates of both acute and chronic medical conditions, developmental delays, and mental health disorders. Many of these issues have never been addressed in a proper setting and are exacerbated when the child is removed from a primary caretaker (Klee et al., 1992).

In a study completed by Hill et al. (1990), it was determined that the national average for the prevalence of handicaps for children in foster care was 20.5%. Due to the different classification systems, differences in the number of children with physical and emotional issues existed between states. The prevalence varied from 3% in Florida to 58% in Nevada. Utah reported that 22.2% of children in foster care were handicapped. In general, children in foster care were twice as likely to be handicapped when compared to the school-age population.

Purpose of the Study

The primary purpose of this qualitative, exploratory study was to increase the understanding of medically fragile children served by DCFS in the State of Utah and propose a definition for DCFS to consider adopting for medically fragile children. Adopting a definition for these children may result in more consistent and appropriate service provisions. Defining a medically fragile child is not a simple task. The literature shows that the definitions of a medically fragile child vary from restrictive to broad in nature. This is problematic because imprecise criteria may lead to a lack of uniformity in DCFS decision-making concerning which children are identified as medically fragile and therefore qualify for special DCFS services and caretaker payments. Findings from this study may provide DCFS with valuable information about the medically fragile children it serves. It may assist the agency in developing criteria that accurately describe a medically fragile child, ensuring these children are appropriately identified, determining if their needs are being met, and identifying how this population can be better served. This research may also benefit community partners who assist DCFS in meeting the needs of medically fragile children in foster care. Foster families, proctor families, residential providers, therapists, nurses, and doctors must have accurate and timely information to meet the needs of this vulnerable population.

The primary objective of this study was to increase the knowledge about medically fragile children in the child welfare system in order to assist DCFS in identifying and determining the level of care and services required to meet these children's needs. In order to meet this objective; the following research questions were explored:

1. What are the characteristics of a medically fragile child in foster care?
2. What is an appropriate definition of a medically fragile child in foster care?
3. Using the definition, have the children in foster care been properly identified as medically fragile?

Organization of the Dissertation

This chapter outlined the difficulty in appropriately identifying medically fragile children in foster care. Chapter 2 outlines various issues related to children in foster care. Children in foster care are in poorer health and have a higher rate of mental health and developmental issues than children in the general population. Chapter 2 also outlines standards and recommendations for health care services and provides exemplars in foster care health care programs. Chapter 3 outlines the methodology of this study. Telephone interviews were conducted with 26 participants who had experience working with medically fragile children in foster care. Analysis of the data led to a proposed methodology and definition for identifying medically fragile children. Chapter 4 discusses the results of the interviews. Participants stressed the importance of including the following in a definition of medically fragile children: a) medical and/or mental health diagnosis, b) level of oversight, c) level of health care needs, d) level of assistance with daily living, e) cognitive delays, f) developmental delays, and g) impact of psychosocial stressors. Chapter 5 explains the new measure and outlines recommendations for DCFS.

CHAPTER 2

LITERATURE REVIEW

Even though information is extensive on medically fragile children overall, there is a limited amount of literature on medically fragile children in foster care. Research has primarily focused on overall health and mental health issues of children in foster care. A related and relevant source of information is the health care standards for children in foster care established by the CWLA and their recommendations as to how these standards should be implemented by child welfare agencies throughout the United States. There is an abundance of research on policy recommendations for the delivery of health care services to children in foster care. Of the research that does exist on medically fragile children in foster care, the focus is on appropriate placements for this population.

Physical Health Care Issues of Children in Foster Care

Altshuler and Gleeson (1999) reviewed previous research completed on the well-being of children in foster care. They determined that children in foster care have significant deficits in their physical health when compared to the general population. Forty-five to 80% of children in foster care have a chronic or significant physical problem requiring medical follow through.

Silver et al. (1999) reviewed the initial evaluations of 267 children, 30 months and younger, between November 1992 and September 1997 who were referred to the

Starting Young Program, a multidisciplinary diagnostic and referral service for children receiving services through the Philadelphia Department of Human Services. They found that 22.1% of the children were under immunized, 43.1% had an acute medical condition, and 60.3% had a chronic condition. When reviewing chronic conditions, 22.9% of the children had a neuromuscular disorder, 7.9% had a skeletal disorder, and 6% had asthma. The weight or height ratio of 20.2% of the children was at or below the tenth percentile; this rate is twice as high as the general population. Referrals to a specialist for further evaluation were made for 41.2% of the children.

Takayama, Wolfe, and Coulter (1998) examined the medical records of 749 children entering foster care during a 15 month period in San Francisco. These children received a health clearance examination within 72 hours and a comprehensive health examination if they remained in foster care over three weeks. Health problems were identified in 60% of the children. Examinations revealed upper respiratory diseases in 19% of the children, skin conditions in 15%, marks of abuse in 6%, and asthma in 6%. Of the children who received comprehensive examinations, 20% had myopia and 12% were developmentally delayed. When comparing various age groups,

among 0 to 6-year olds, 27% had upper respiratory illnesses, 23% had developmental delay, and 21% had skin conditions; for children 7 to 12 years of age, 32% failed vision screening, 12% had dental caries, and 11% had upper respiratory illnesses; and among 13- to 18-year-olds, 31% failed vision screening and 12% had positive tuberculin skin tests. (p. 201)

Health problems were identified in 62% of children between the ages of 0 and 6, 53% of school age (7 to 12 years) children, and 63% of adolescents (13 to 18 years).

Halfon, Mendonca, and Berkowitz (1995) completed a systematic review of charts of all children in the Foster Care Program (FCP), a comprehensive health care

model created for foster care children at the Center for the Vulnerable Child in Oakland, California, for a period of 3 years. The purpose of the FCP was to identify health needs across multiple domains using a comprehensive assessment process. Results of this study determined that children in foster care have higher rates of chronic health problems than had originally been anticipated. Eighty-two percent of the children had at least one chronic condition, 22.5% had two or more chronic conditions and 28.8% had over three. 16% of children had asthma, which is three times the national average (Halfon & Newacheck, 1993). Maternal drug use was documented in 95% of infants. Of the infants who had a toxicological screening, 89% tested positive for drugs. Growth abnormalities (weight, height, head circumference, failure to thrive) were identified in one in five children. Even though the foster parents or social workers initially reported that 32.9% of these children had a history of problems, upon more thorough examination, 80% were identified with emotional, developmental, or behavioral problems.

Chernoff, Combs-Orme, Risley-Curtiss, and Heisler (1994) reported on the health status of children receiving services through the Foster Care Health Program (FCHP), a collaborative effort between the State of Maryland Department of Human Resources, the Baltimore City Department of Social Services, and the University of Maryland's Department of Pediatrics, for a period of 2 years. The FCHP provided two levels of health care service. The first level included a health assessment for all children entering foster care within 5 days of removal. Level two included a comprehensive multidisciplinary assessment of children remaining in care for at least 30 days. Results determined that 92% of children had an abnormality in at least one body system. Most abnormalities were found in the skin system (61%) while the fewest abnormalities were

found in the neurological system (2%). Eighty percent of the children who were 3 years and older had a vision and hearing screening completed. Twenty-five percent of these children failed the vision screening and 16% failed the hearing test. When examining children younger than 3 years of age, “three times the expected number were at or below the fifth percentile for weight and head circumference, and more than five times the expected number of children were equal to or less than the fifth percentile for height” (p.596). When the entire sample was examined, three times the expected number of children were shorter than children in the general population. Over one third of all children required at least one urgent referral (1 week) and more than two thirds required at least one nonurgent referral (2 to 4 weeks). Some children received both types of referrals. Of the children needing urgent or nonurgent referrals, almost 25% received referrals to three or more services. Of the 1,407 children in the study, almost 35% had a chronic illness.

Flaherty and Weiss (1990) reviewed initial evaluations of 5,181 children entering state custody in Illinois for 22 months. Forty-four percent of the children required medical treatment for at least one condition. The most prevalent conditions were anemia, ear and urinary tract infections, bruises and fractures from abuse, sexually transmitted diseases, pregnancy, and lead poisoning. Many of the children required referrals to specialists and 8% were hospitalized for further treatment.

Simms (1989) reviewed the health care information obtained on 113 children between the ages of 1 month and 6 years who received physical examinations and evaluations from a multidisciplinary team in Waterbury, Connecticut, for a period of 2 years. Chronic medical problems were found in 35% of the population. Cerebral palsy,

congenital heart disease, asthma, epilepsy, deafness, microcephaly, fetal alcohol syndrome, bronchopulmonary dysplasia, and AIDS were the most common conditions identified. The prevalence of children below the 5th percentile in height for his/her age was three times higher than the expected rate for children in the United States. Behavioral problems were identified in 39% of the children.

Hochstadt, Jaudes, Zimo, and Schachter (1987) reviewed medical screenings of 149 children taken into state's custody in Cook County, Illinois, during September 1984 to gain a better understanding of the medical and psychosocial needs of children in foster care. It was determined that these children have a higher incidence of chronic medical conditions; weigh less; are shorter; require medical sub-specialty care; and have higher rates of developmental delays, deficits in adaptive behavior, and behavioral problems related to psychiatric disorders. While 50% of the children had multiple physical abnormalities, only 13% of the children were normal. The most common abnormalities were growth deficiencies (height, weight, and head circumference), developmental delays, behavior problems, and skin disorders. Cardiovascular and dental problems were the next most frequently identified abnormalities. Forty percent of the children had at least one chronic condition. Thirty-four percent of the children had a serious medical problem that required a referral to a specialist. Most of these referrals were made to cardiologists, ophthalmologists, neurologists, or dentists.

Kavaler and Swire (1983) evaluated the health care information of 668 children in the New York City foster care program. Forty-five percent of the children had at least one chronic condition. Of these children, 20% had multiple conditions. Eight percent of the children were below the 5th percentile for height and weight. Thirty-three percent were

below the 25th percentile. Poor visual acuity was found in 22% of the children and 15% were referred for further audio testing. Dental information was reviewed for 473 of the participants. More than half of the children had one or more decayed teeth. The children between the ages of 1 and 6 completed a developmental screening. Nineteen percent of these children had questionable development and 10% were abnormal in physical, motor, perceptual, and cognitive abilities. School age children received intelligence testing. Their average was 87 on the verbal portion (mean = 100) and 90 on the nonverbal portion (mean = 100).

Schor (1982) determined that many children with disabilities in foster care do not have their health care needs adequately met. He reviewed the medical records of a random sample of 387 foster children enrolled in the Chesapeake Health Plan. This plan centralized the medical care of foster children in Baltimore, Maryland. Particular attention was paid to the prevalence of chronic health problems. Twelve percent of these children had not received any medical care. Seven hundred eighty-seven chronic problems were identified, which averaged 2.3 problems per child. Chronic problems were three to seven times more prevalent in foster children than children in the general population. Twenty-four percent of the children did not have chronic problems. Besides behavioral and psychological issues (37%), the most prevalent chronic conditions were ophthalmologic (35%), educational (31%), dermatological (22%), allergies (17%), dental (16%), otologic (12%), physical growth and development (12%), and musculoskeletal (9%). Forty-three percent of the children received a referral for psychiatric services. Schor also obtained additional information through a four month sample of health

encounter data. There were 1,184 health encounters during the 4-month study period. Of the 1,184 encounters, 45.4% of the diagnoses were identified as chronic health issues.

Mental Health Care Issues of Children in Foster Care

Children in foster care have higher rates of mental health issues than the general population. “Children who suffer maltreatment demonstrate a wide range of behavioral and emotional problems that include poor self-esteem, aggression, depression, cognitive impairments, communication difficulties, conduct disorders, and delinquency” (Halfon, Berkowitz, & Klee, 1992, p. 1238). In a review of literature on mental health issues of children in foster care, Altshuler and Gleeson (1999) determined that the prevalence of emotional disturbances (e.g., withdrawal, anxiety, depression, somatic complaints, and attachment issues) for children in foster care ranges between 25% and 96%. Depending on the study, Halfon et al. (1992) determined the prevalence of emotional disturbance among foster children ranges between 35% and 85%. Comparatively, mental health and developmental issues for children in the general population range between 12% and 15% (Halfon et al., 1992).

The health care data for 668 New York City foster care children was evaluated by Kavalier and Swire (1983). A subsample of 179 children participated in a psychiatric interview. The psychiatrists divided psychiatric impairment into the following categories: (a) well, (b) mild, (c) moderate, (d) marked, and (e) severe. Only 4% of the children did not exhibit any symptoms. Twenty-six percent were identified with mild, 35% were moderate, 25% were marked, and 10% were identified as severely impaired.

Chernoff et al. (1994) assessed the mental health status of children entering foster care in Baltimore, Maryland, during a 2-year period. Seventy-five percent of the children

were considered at risk for mental health problems because of a family history of mental illness and/or drug or alcohol problems. Eighteen percent of the children were considered at risk because of sexual abuse. Of the children 3 years and older, 15% admitted or were suspect for suicidal ideation and 7% admitted or were suspect for homicidal ideation. Mental health referrals increased with a child's age. Twenty-two percent of children between the ages of 3 and 6, 63% of children between the ages of 7 and 12, and 77% of teenagers were referred to mental health services.

Trupin, Forsyth-Stephens, and Low (1991) asked caseworkers of 3,398 children who were receiving services from the State of Washington to complete a survey of children's past mental health treatment, exposure to mental health risk conditions, handicapping conditions, current behavioral adjustment, and mental health and service needs. Of the 3,398 children, 2,455 (72%) were identified as having severe emotional disturbance (SED). Additional analysis of data for 1,617 children ages 6 and older revealed that over half of these children were in need of outpatient mental health treatment (individual, family, and group therapy). Of all the residential services reported, foster homes and group homes were the most needed. School children between the ages of 6 and 11 were in higher need of respite and therapeutic camp services, whereas children ages 12 through 16 were in need of foster home and group home placements. Older adolescents (ages 17 and 18) demonstrated a higher need for outpatient and inpatient alcohol or drug treatment and independent living skills. Females were in greater need for outpatient therapy, foster home placements, respite care, independent living plans, and child protective service referrals. Males were in greater need of outpatient or

inpatient alcohol or drug treatment, group home placements, independent living training, and afterschool activities.

A systematic review of charts of all foster children seen at the Foster Care Program in Oakland, California, was conducted over a 3 year period to determine their mental health status (Halfon et al., 1995). Sixteen percent of the children had developmental problems (gross motor, fine motor, language, cognition, and self-help), 12% had emotional problems (emotional function, relationship, coping, and behavior issues) and 51% had developmental and emotional problems. When looking specifically at emotional problems, 60% of the children had emotional function problems, 54% had coping problems, 51% had relationship problems and 29% had behavioral problems. Emotional, relational, and behavioral problems were more common in children placed in foster care after 2 years of age. When the children were divided into age groups, almost all (96%) of the school-age children had some type of emotional and developmental problem.

Psychosocial assessments were completed on 149 children entering foster care in Cook County, Illinois (Hochstadt et al., 1987). Results determined that foster care children presented with significantly more behavioral problems than the general population. Behavioral problems were more frequent and severe as the children aged. Thirty-eight percent of the children were referred to a psychologist for academic or behavior problems and 3.4% were referred to a psychiatrist because of severe emotional disturbance. When the population was narrowed to children over 3 years, 57% were in need of psychological services.

Frank (1980) rated a sample of 50 children when they entered foster care to determine their level of psychosocial problems. These children were rated again after 5 years in custody. The rating system utilized a 7-point scale. A child who received a rating of one had no psychosocial problems while a child exhibiting psychoses was rated as a seven. None of the children was rated as a one, two, or three, but was given ratings at the severe end of the scale. This was true for the initial evaluation and follow-up at 5 years. Twelve percent of the children were not seen by a mental health professional for the duration of the study. This is concerning since all of the children were rated as a 4, 5, 6, or 7. The raters determined that 50% of children received inadequate treatment. They also determined that the children's level of functioning deteriorated during the 5 years of the study.

Halfon, Berkowitz, and Klee (1992) reviewed Medi-Cal claims to determine mental health service utilization by children in California's foster care system. Medi-Cal is the Medicaid program for foster care children and other eligible children in California. Even though foster care children only represent 4% of children eligible for Medi-Cal, they utilized 41% of all mental health services. Children in California foster care are overrepresented in psychologist visits, psychiatry visits, inpatient hospitalization, inpatient psychiatric hospitalizations, and community-based interventions. These estimates might be conservative because some children in foster care might receive additional mental health services through different funding sources. Adjustment disorders, conduct disorders, anxiety disorders, and emotional disorders accounted for 75% of the diagnoses. The frequency of adjustment disorders was similar across all age

groups, while the prevalence of conduct disorders and anxiety disorders increased with age.

The Child Behavior Checklist (CBCL) was given to 158 foster care children in Eastern Tennessee between the ages of 4 and 18 (McIntyre & Keesler, 1986). There was evidence of psychological disorders in 48.7% of these children. Children in foster care were almost nine times more likely than children raised in their home to display psychopathology. Sixty-one percent of the children with psychological disorders exhibited multiple syndromes. Of the syndromes identified by the CBCL, 85.3% were represented in the foster care children.

Developmental Issues of Children in Foster Care

The number of children under the age of 6 entering foster care is significantly increasing (Franck, 1996; Ruff, Blank, & Barnett, 1990; Silver et al., 1999). This is particularly concerning because children under the age of 3 are more vulnerable to the effects of child abuse and neglect. Their nervous systems are more sensitive to stress than during any other stage of life. Child abuse can restrict brain growth and physical development (Silver et al., 1999). Children exposed to drugs are at greater risk of developmental delays and their prognosis is poor (Franck, 1996). As infants they exhibit behaviors that interfere with the bonding that occurs with their caregiver. This bonding is critical to their cognitive and emotional development.

Franck (1996) reviewed the results of an early intervention program for children under 5 years of age in New York City's foster care system. These children received developmental screenings if deemed necessary by their caseworker, medical personnel, or foster parents. Children under the age of 3 were screened every 6 months. Sixty percent

of children in New York City's foster care system are from drug abusing families. "Developmental delays were identified in slightly more than 40% of children with a known or suspected prenatal drug exposure, but a similar percentage of delays was found in children of parents with no drug history" (Franck, 1996, p.20).

In a review of literature on foster care children's "well-being," Altshuler and Gleeson (1999) identified two trends from the cognitive functioning studies. First, children in foster care scored approximately 10 points lower than the general population of children on intelligent quotient tests when they entered foster care. Minority children and children from lower socioeconomic backgrounds scored significantly lower. Second, changes in a child's I.Q. score over a period of 5 years were related to ethnicity. After 2 years in foster care, a significant increase was seen in African-American and Puerto Rican children's I.Q. scores, while Caucasian children's I.Q. scores declined.

Halfon et al. (1995) determined that 84% of the foster care children in their study had developmental and emotional problems; 16.2% of the children in their study had developmental problems (gross motor, fine motor, language, cognition, or self-help problems) and 51.4% displayed developmental and emotional problems. Cognitive problems were identified in 33% of children under the age of 5 and 52% of school age children. Language disorders were more prevalent in children between 1 and 5 years of age. There was a higher rate of gross and fine motor problems in children placed in foster care before the age of 1.

Hochstadt et al. (1987) determined that children in foster care have a higher incidence of developmental delays. Developmental delays were determined by physicians who completed physical examinations and reviewed each child's history and a

psychologist who administered the Denver Developmental Screening Test (DDST). The physicians determined there were developmental delays in 38% of the children 5 years and younger. Results of the DDST administered to children 4 years and younger indicated abnormal results on the composite (12.9%), gross motor (25.4%), fine motor (12.7%), and personal-social areas (15.5%). Borderline abnormalities are not identified from the DDST, which may explain the difference in the physicians' findings and the DDST results.

Children up to 30 months old who were receiving services through Philadelphia's Department of Human Services (DHS) were evaluated by a developmental team (Silver et al., 1999). Forty-nine percent the children qualified for early intervention services. This rate is significantly higher than the rate of 10% to 12% among the general population. Language delays were identified in 57.1% of the children, cognitive delays were identified in 33.4% of the population, and gross-motor problems were identified in 31.2% of the population.

Simms (1989) reviewed the developmental evaluations of 113 preschool foster care children between the ages of 1 month and 6 years completed by the multidisciplinary team in Waterbury, Connecticut, over a period of 2 years. Sixty-one percent of the children had a developmental delay in one or more areas. Fifty-two percent of the children exhibited language delays, 29.2% exhibited fine motor delays, 23.9% showed gross motor delays, and 18.6% showed cognitive delays. Only 40.6% of the children with developmental delays were already participating in a program to address the developmental issue. The children who were not yet involved in developmental programs

had an average age of 30.4 months and had been in foster care for approximately 5.95 months.

Child Welfare League of America (CWLA) Standards for Health

Care Services

The CWLA (1988) has developed standards in a variety of areas that have been recognized as best practice in the field of child welfare. The health care standards for children in out-of-home care were developed in collaboration with the American Academy of Pediatrics (AAP). The CWLA health standards serve as guidelines to assist child welfare agencies in meeting a variety of children's health care needs. The current standards recognize the term health as physical, mental, and emotional.

The CWLA health standards encompass eight aspects of care: (a) initial health screening; (b) establishment of health care records; (c) comprehensive health assessment; (d) developmental, educational, and mental health assessment; (e) ongoing primary health care services; (f) health information management; (g) centralized agency structures to organize and administer health care services; (h) coordination of other state and local agencies; and (i) education and training of foster parents, caseworkers, and health care professionals (Simms & Halfon, 1994, pp. 510-511).

The physical, mental, and emotional health care needs of children who are chronically ill or have special needs must be met (CWLA, 1988). The severity of these health problems requires an organized health care delivery system that includes primary health providers and a network of specialists. The CWLA suggests that the following services should be considered when working with chronically ill or special needs children in foster care: (a) detailed instructions to caretakers; (b) respite care for caretakers; (c)

necessary home modifications; (d) special utility funds for costs of electricity, phone, or water; (e) visiting nurses; (f) physical therapy; (g) occupational therapy; (h) transportation assistance; (i) speech therapy; (j) grief counseling; (k) supportive counseling; (l) parent-infant stimulation programs; and (m) parent support groups (CWLA, 1988). Children who are chronically ill or have special needs can be difficult to maintain in the home. These children and their caretakers require supportive services to ensure a successful placement can be maintained.

Additional Recommendations for Health Care Delivery

Before entering foster care, many foster children received sporadic health care. This contributes to the higher rate of chronic health care issues. Additionally, child welfare agencies typically use health care facilities that were designed to provide crisis care and not thorough assessments. The Medicaid program is the primary funding source for foster children's health and mental health issues (Risley-Curtiss & Kronenfeld, 2001). Many professionals do not accept children covered by Medicaid because of the low reimbursement rate. Other professionals limit the number of Medicaid children seen at their practice. This exacerbates the problem of providing quality medical care to foster children. It is critical to note that medically fragile children in foster care are more vulnerable and therefore require more comprehensive and consistent care in order for them to become responsible and well-adjusted adults.

In addition to the standards set by the CWLA, the AAP recommends that medical professionals involved with foster children need to communicate with each other in order to deliver services effectively (AAP, 1994). Because foster children are at risk for higher physical, emotional, and developmental problems and chronic illnesses, it is preferable

that they are seen by pediatricians who are familiar with the child welfare system. It is also preferable for the same pediatrician to provide services to a child during his or her stay in foster care. Continuity of care is critical to providing effective health care. This is especially true for children with chronic problems. AAP (1994) also recommends the following health care services to children in foster care: (a) child welfare agencies should adopt the standards developed by the Child Welfare League of America; (b) foster children should receive an initial physical examination before or immediately after placement; (c) foster children should receive a comprehensive physical and mental health evaluation within 1 month of placement; (d) the physical and mental health status of foster children should be evaluated twice in the first year of placement and annually thereafter; and (e) a system should be in place to ensure that medical and mental health information is transferred to the appropriate professionals. A medical passport is critical to the effectiveness of health care delivery because children are often in multiple placements. Ensuring the passport is given to each caretaker will increase the likelihood of comprehensive health care.

Halfon and Klee (1987) reviewed the health care services delivered to children in out-of-home care in 14 California counties. They identified a considerable amount of variability between the counties. Even though initial medical evaluations were available in all the counties studied, only children who were abused, neglected, ill, or injured received an initial medical evaluation in seven counties. Eight counties completed these evaluations at designated locations, three counties used an onsite nurse at the shelter, and three used various locations. Only one of the counties performed initial mental health evaluations on all children entering foster care. This is concerning since numerous studies

have determined that children in out-of-home care have high rates of mental health issues. The remaining counties assessed children based on their behavior. Most of the foster parents in this study reported that they did not receive medical or mental health information, immunization records, or names of the children's providers. Social workers in all counties identified low reimbursement and lack of providers as common barriers to securing health care services for these children.

Halfon and Klee (1987) recommend that policies should be developed to assess medical and mental health issues during initial evaluations of children in out-of-home care. These evaluations should include assessing physical, developmental, educational, and emotional problems. Initial health assessments should be completed within 72 hours of placement in out-of-home care by professionals trained to work with this specific population. Comprehensive examinations should be completed within 30 days of placement. Continuity of care should be addressed by having the same professional provide care for children during their stay in out-of-home care. It was also recommended that reimbursement rates for services be raised and that children in out-of-home care should be exempt from limitations on the number of visits allowed under the Medicaid program. Centralizing services would potentially decrease barriers and improve the quality of medical and mental health care.

Klee and Halfon (1987) also suggest that health reporting formats should be simplified so that they can be included in the child's case file and updated and given to the foster parents as necessary, especially when the child changes placements. A medical passport system should be developed to increase communication between physicians, foster parents, and social workers and decrease the likelihood of duplication of services.

Health and development information should be shared with school officials so that children receive appropriate specialized services. The authors also suggest training foster parents and social workers on the importance of collecting and sharing health information as a means of increasing the success of a medical passport system. A centralized information system was also recommended to track children's health care and follow up on unresolved health care issues.

Hochstadt et al. (1987) reviewed the medical and psychosocial needs of children entering out-of-home care and proposed a model to address the health care needs of this population. They recommended physical and mental health screenings for all children in out-of-home care. Screenings should be completed by professionals who are experienced in working with children who are victims of abuse and neglect. Children should receive physical and mental health treatment for areas of concern and have access to comprehensive, ongoing, and specialized services. Case management services should be utilized to coordinate health care services for high risk foster children. This can be accomplished by assigning a caseworker or identified center to assume responsibility for coordinating and securing health care services. These services are specifically needed for high risk children who are defined as children with chronic health issues; physical handicaps; or behavioral, cognitive, or emotional issues. Medical and mental health records should also be centralized. This will allow caseworkers, foster parents, and health care professionals to access comprehensive and current health information. The authors also suggest support for foster parents. Foster parents should receive assistance as necessary in accessing health care services for children in foster care. It is recommended

that this model can be accomplished by developing regional sites that have the ability to utilize a comprehensive approach to health care delivery.

Chernoff et al. (1994) assessed the health status of children entering foster care. They offered the following recommendations to improve the quality of health care to foster care children: a health assessment should be completed as soon as possible after a child is removed from the primary caretaker's home, the initial health assessment should be as comprehensive as possible, a system for documenting medical information should be developed and utilized, foster care children should receive a mental health evaluation and offered mental health services as needed, and a system should be developed to address follow-up referrals as necessary. The authors also believe that it is the responsibility of child welfare agencies to ensure that primary caretakers follow through on identified health problems after a child returns home. To ensure continuity of care, referrals for health and mental health services should be made when a child is released from foster care. Ideally a computer system would enable the child welfare agency to monitor compliance with health and mental health appointments while the child is in foster care and for a period of time upon his return home.

Simms, Freundlich, Battistelli, and Kaufman (1999) reviewed the effect of welfare and health care reform on health care delivery to children in foster children. These authors recommend that a health care system for foster care children should include comprehensive services that follow CWLA and/or AAP standards. All children should be eligible for Medicaid once they are removed from their caretakers' homes. Children should maintain Medicaid eligibility for 12 months after they return home to ensure follow up services continue. Health care providers should receive incentives to

encourage participation in the delivery of health care services to foster children. The local and state government should establish who is responsible for implementing health care delivery. This health care system should be established in urban and rural communities. A statewide database should also be developed.

Schneiderman, Connors, Fribourg, Gries, and Gonzales (1998) reviewed the mental health status of children in foster care. It is suggested that mental health services for children in foster care should be coordinated with the child welfare caseworker to ensure that family needs are addressed and appropriate service plans and interventions are implemented. Mental health services should also focus on prevention and dysfunction. Early screenings of children in foster care will increase the likelihood that accurate services are provided and prevent placement disruptions. It is also recommended that a child's mental health services address the reason for placement in foster care and consequences of the placement. Therapeutic services should also be available at critical points during a child's stay in foster care. Interventions should begin as soon as possible and be available during various transitions such as placement disruption, return to primary caretaker, termination of parental rights, placement in an adoptive home, and various crises (e.g., disclosure of abuse, pregnancy, or running away from placement).

Exemplars in Foster Care Health Care Programs

Some child welfare agencies have developed comprehensive health care programs for children in out-of-home care. These programs appear to be exemplar health care programs in child welfare. Onondaga County Department of Social Services developed excellence in health care for abused and neglected children (ENHANCE), a comprehensive health care program for children in out-of-home care (Blatt et al., 1997).

Before children are seen, their child welfare and medical histories are reviewed by staff. A child's initial visit with ENHANCE occurs within 1 week of placement in out-of-home care. A comprehensive visit is completed 1 month after the initial visit. At this time, the child receives a physical examination, mental health assessment, and developmental assessment (if the child is between the ages of birth to 18 months). Well-child visits are scheduled according to the recommendations of the AAP. Follow-up and acute visits are scheduled as needed. It is also recommended that the children in this program receive a discharge evaluation before being released from out-of-home care. At this appointment, medical information is provided to the child's guardian. ENHANCE also used a computer program to maintain an accurate medical history of each child. This program proved to be effective in providing comprehensive health care to children in out-of-home care. A critical component of this program was the Department of Social Services liaison, who addressed concerns of the caseworkers and medical staff.

The Center for the Vulnerable Child program at Children's Hospital in Oakland, California, developed a case management program that combined health care, social work, and child welfare services for children in out-of-home care, drug-exposed infants, and teenage mothers and their infants (Halfon & Berkowitz, 1993). The goal of this program was to provide comprehensive, ongoing, and coordinated health care to at-risk children. This program was staffed with a physician, clinical director, case manager, psychologist, infant specialist, clinical nurse, midwife, and substance abuse counselor. Comprehensive services that included prevention, identification, diagnosis, treatment, and rehabilitation were available at one location. Case management was a critical piece of this program. Caseworkers participated in the client assessment, service brokering,

monitoring of client's progress, and advocating for community services. Children in out-of-home care were in need of medical services, psychological treatment, and developmental assessments. The authors discussed the importance of utilizing a caseworker on site to secure medical services, therapeutic services, and developmental assessments.

The Department of Child and Family Services (DCFS) in Illinois developed HealthWorks, a comprehensive health care program for foster care children (Jaudes et al., 2004). In this program, children are required to receive an initial health screening within 24 hours of entering custody. There is a 24-hour hotline that provides information on hospital and clinics with the shortest wait time. Children are required to be seen within 1 hour upon arrival at a site. Children are required to receive a comprehensive health evaluation within 21 days of removal. This evaluation includes health, mental health, developmental, and substance abuse screenings (if appropriate). Foster parents select a primary care physician for the child. These providers receive higher Medicaid rates, \$5 per month per child for completion of required child welfare paperwork, and \$15 per child for initiating the health passport, the traveling medical summary for each child. Specialists are available as needed for specific care issues (e.g., optometry, pediatric issues, and dental issues). Medical case management is provided to children in custody. Children under 6 years of age receive case management by a community based agency. Children 6 and older receive case management services from child welfare workers. The Health Passport contains all necessary background medical information and is used by foster parents and physicians.

To improve access and quality of health care, the Department of Social Services (DSS) in Baltimore, Maryland, developed the Chesapeake Health Plan (CHP), the first prepaid health plan for foster care children (Schor, Neff, & LaAsmar, 1984). Children were seen at Baltimore City Hospitals (BCH) by medical (pediatricians, internist, gynecologist, and physician assistants) and mental health (psychiatrist, counselor, psychologist, and social workers) staff with expertise in adolescent medicine, adolescent gynecology and family planning, developmental pediatrics, and health education. Children with complex medical conditions were seen by contracted providers. CHP offered additional services that were beyond contract requirements. Children received eyeglasses when deemed necessary (as opposed to annually), orthodontic care, and plastic surgery. DSS hired a social worker to serve as a liaison between the two agencies. BCH was responsible for maintaining the official medical records for these children.

Early Intervention Programs for Foster Care Children

Ruff et al. (1990) argue that early childhood development has not been a major concern in child welfare. With the increasing numbers of young children entering foster care, this issue cannot be ignored. Child welfare workers and foster parents should be knowledgeable about the developmental process and how it is altered by abuse and neglect issues. The knowledge gained about the developmental process should be used in the treatment of vulnerable infants. This involves educating the foster parents about medical conditions (e.g., drug exposure, HIV, and abuse or neglect issues) and their interventions. The authors suggest using foster care as an early intervention to facilitate healthy development. If the foster and biological parents can work together, this will increase the likelihood of healthy attachments, which is critical for children to develop.

Franck (1996) studied an early intervention project in New York City and recommended that foster and biological parents should be involved with early interventions. These parents need training and access to community resources. Children need to receive developmental screenings to determine their needs. If they qualify, they should receive the entitlements available to children between the ages of zero and five. A system needs to be developed to follow children who have been identified with developmental delays to ensure that they are regularly rescreened. It is also recommended that the child welfare agency have a contact person who specializes in child development issues with this specific population. Medical professionals working with this population should be familiar with developmental issues. They often focus on abuse and neglect issues and do not address other risk factors.

The Starting Young Program is a diagnostic and referral service for children up to the age of 30 months who are receiving services through the Philadelphia Department of Human Services (DHS) (Silver et al., 1999). The multidisciplinary team includes a pediatrician, child psychologist, speech-language pathologist, physical therapist, pediatric social worker, and a social worker from ChildLink, an early intervention agency. Children are referred by their foster care or in-home worker. Children are evaluated by members of the multidisciplinary team. If necessary, recommendations for additional services are given. If the child is eligible for early intervention services, the ChildLink social worker coordinates the services. Children are evaluated every 6 months until they reach 30 months of age.

Programs for Medically Fragile Foster Children

Tucker and Roberts (1990) surveyed a panel of experts to identify psychosocial issues in children's health care. The most pressing issue identified by the panel was chronic illnesses of children and their complex health care needs. Due to technological advances in medicine, the number of children surviving complex and chronic health care problems is increasing. These children are often able to live and be cared for in their home. It is often difficult to coordinate the health care of these children because they are involved with multiple health professionals. They also have special needs in their home, school, and the community. The child and his or her family often have emotional needs related to the chronic illness that should be addressed. The financial strain that a chronic illness can produce should be addressed. It is also critical to educate the patient and his or her family on the illness and empower them to become actively involved in coordinating the child's health care treatment. Coordinating and educating children and parents are difficult and are exacerbated by the issue of having a child in foster care. Because foster care systems are often unable to meet the needs of children with chronic or complex medical problems, there is an increased likelihood that treatment may become fragmented and inconsistent.

The La Rabida-Children's Home and Aid Society Project was a collaborative project between a pediatric medical center and social service agency in Illinois (Yost & Hochstadt, 1987). Children being served in this program were seriously chronically ill children who required 24-hour care, chronically ill children who were in need of a change in medical management, children recovering from a serious surgery or accident, children transitioning home from tertiary centers, and medically stable children in need of an

appropriate home placement. Many parents of the children receiving treatment at this medical center were unable or unwilling to have their children return home. In this situation, foster care was viewed as the best alternative. Foster parents were trained to care for seriously chronically ill children in their homes. The goal of this program was to provide a comprehensive medical foster care program to children requiring intensive nursing and technological assistance. The medical center was responsible for providing training to all parties involved in the care of the children. The child welfare agency was responsible for identifying foster families who were willing to work with medically fragile children. Counseling was provided to biological parents, foster parents, and children.

Summary

A review of the literature reveals there is an extensive amount of information on the health care of children in foster care. These children have significant deficits in their physical health when compared to the general population. They also experience higher rates of mental health issues. Children in foster care are at higher risk for developmental delays. CWLA provides models for best practice when working with children involved with child welfare agencies. CWLA maintains that children who are chronically ill or have special needs require more specialized services to ensure their physical, emotional, and mental health care needs are being met. The literature demonstrates there are ongoing concerns regarding the delivery of health care services to children in foster care and how health care information is shared. Across the United States there are exemplars in foster care health care programs. Only a few of these programs address the special needs of medically fragile children. Overall, there is a limited amount of literature on medically

fragile children in foster care. It is difficult if not impossible to determine if these children are appropriately identified and if their needs are being met.

CHAPTER 3

METHODOLOGY

Research Design

A review of the literature reveals that a standardized set of criteria for identifying medically fragile children does not exist. Children in the foster care system are typically in poorer health than the general population. It is critical that standardized criteria be developed to ensure this population's health care needs can be met. This exploratory study consisted of interviews with a variety of professionals who work with medically fragile foster care children in the State of Utah with the intent of formulating criteria for identifying medically fragile children in the child welfare system. The interview questions asked participants to (a) describe the characteristics of a medically fragile child, (b) rank the identified characteristics, (c) identify appropriate terminology to describe this population, (d) describe their experience working with medically fragile children, and (e) identify the needs of medically fragile children. After this information was gathered, criteria were developed to assist DCFS in appropriately identifying medically fragile children. These criteria were compared to data provided by DCFS to determine discrepancies in the identification of medically fragile children. Findings related to the discrepancies will be presented to DCFS to assist the agency in improving identification of medically fragile children in the child welfare system and health care delivery to this population.

Theoretical Framework

Phenomenological

The theoretical framework guiding this study is primarily phenomenological. The investigator wanted to describe medically fragile children in foster care from the participants' perspectives. The investigator believes the participants' reality is what they perceive it to be. The phenomenological approach does not require an absence of presuppositions but critical analysis of one's own presuppositions (Kvale, 1996). The presuppositions contained in the literature were not addressed with the participants until they had the opportunity to explore their beliefs about medically fragile children. Knowledge is gained from our individual points of view. Even though two people may share the same experience, their knowledge gained from this experience may be completely different. Each of their experiences should be viewed as equally valued and true.

Ecological Perspective

“From the 1920s to the 1960s, most social work programs used a medical-model approach to assess and change human behavior” (Zastrow, 2008, p. 50). Social workers diagnosed a patient's problem and provided treatment. A patient's problem was considered to be internal and a result of “genetic endowment, metabolic disorders, infectious diseases, internal conflicts, chemical imbalances, unconscious use of defense mechanisms, or traumatic early experiences that cause emotional fixations and prevent future psychological growth” (Zastrow, 2008, p.50).

In the 1960s, social workers realized the environment was equally as responsible for a client's problems as internal factors and needed to be considered for treatment (Zastrow, 2008). The ecological perspective emphasizes the person-in-environment approach. This perspective is useful in child welfare practice because it moves "away from an illness orientation to a health/growth orientation" (Pecora, Whittaker, Maluccio, Barth, & Plotnick, 1992, p.37). Using this perspective, a child welfare worker draws upon the strengths of individuals, families, and groups while making the client's environment more receptive to his/her needs. When looking at an individual in his/her environment, a child welfare worker identifies potential sources of stress and support before developing appropriate treatment options.

When using an ecological perspective to identify medically fragile children, an individual would take environmental issues into consideration in addition to the medical disorder when identifying a medically fragile child. Emotional and social factors have an effect on a disorder and a disorder has an effect on emotional and social functioning (Perrin et al., 1993). The degree of severity the disorder has on a child's ability to interact in various settings (e.g., school, home, and community) would be considered in the identification of the disorder.

Recruitment and Sample

The sampling method for this study was purposive. In purposive sampling, participants are "chosen because they have particular features or characteristics which will enable detailed exploration and understanding of central themes and puzzles which the researcher wishes to study" (Ritchie & Lewis, 2003, p. 78). Dr. Navina Forsythe, DCFS Information Analyst, identified DCFS nurses, caseworkers, and foster parents

throughout the State of Utah for this exploratory study. Four of the participants (3 community nurses and 1 physician) were obtained as a result of recommendations from other participants. A DCFS nurse, foster parent, 2 community nurses, and physician suggested other community nurses, physicians, and physician assistants to interview.

The original plan for this study was to complete four focus groups. The intent was to conduct focus groups with key professionals who serve this population including:

1. Caseworkers
2. Foster parents
3. Nurses
4. Physicians/Physician Assistants

An email was sent by Dr. Forsythe to caseworkers who had at least one child on their caseload between February 2008 and February 2009 who were assigned the medically fragile payment code (MFC). Since the caseworkers who were interested in participating in this study were located throughout the State of Utah, setting up a time and place for a focus group was not feasible. At this point, it was determined that telephone interviews would be the most feasible option.

After the investigator received approval to change her method of data collection from the University of Utah's Institutional Review Board (IRB) and Department of Human Services' IRB, Dr. Forsythe contacted all of the DCFS nurses throughout the State of Utah via email. She also contacted caseworkers via email who had at least one child on their caseload between August 2008 and August 2009 who were assigned the MFC payment code. The emails included a letter from the investigator explaining the purpose of the study, the interview questions (see Appendix A), and consent form (see

Appendix B). If a DCFS nurse or caseworker was interested in participating in this study, he or she was asked to call or email the investigator. DCFS nurses and caseworkers faxed their consent form to the investigator before participating in a telephone interview.

Foster parents who had a child living with them between August 2008 and August 2009 who were assigned the MFC payment code received a packet sent via mail by Dr. Forsythe that contained a letter written by the investigator explaining the purpose of the study and included the interview questions, a consent form, and a self-addressed stamped envelope. If the foster parent wanted to participate in the study, he/she completed the consent form and mailed it to the investigator.

Because caseworkers could not be contacted for 6 months after they agreed to participate in a focus group in February 2009, five workers who had initially expressed interest in participating in the study did not respond to the second email sent by Dr. Forsythe in August 2009. Caseworkers were not contacted during this timeframe because the investigator was waiting for approval by DHS and the University of Utah's IRBs to modify the data collection process. The caseworker's lack of response could have been due to a number of reasons: caseworkers may have not had a medically fragile child on their caseload during the new timeframe requirements; caseworkers were no longer interested in participating; or caseworkers may have no longer been employed by DCFS. Because foster parents were under the impression that the investigator already had their contact information, many of them did not provide this information when they returned their consent form. Since contact information was missing, DHS requested approval by their IRB and the University of Utah's IRB for a second letter to be sent to foster parents.

Because of this misunderstanding, five foster parents who initially returned their consent form but did not provide contact information were unable to be interviewed.

Community nurses and physicians were contacted directly by the investigator via email. The email included a letter from the investigator explaining the purpose of the study and a copy of the interview questions. If a community nurse or physician was interested in participating in the study, they were asked to call or email the investigator. Once a community nurse or physician expressed interest in participating, a consent form was emailed to this individual. Community nurses and a physician faxed their consent forms to the investigator before participating in an interview.

All potential participants received a follow-up email or letter to encourage participation. Dr. Forsythe followed up with DCFS nurses, caseworkers and foster parents and the investigator followed up with community nurses and physicians. Participants were interviewed between September 2009 and June 2010. There were 26 participants in this study: a) 1 physician; b) 7 DCFS nurses; c) 3 community nurses; c) 8 caseworkers; and d) 7 foster parents (see Table 1). In order to better serve clients, DCFS has divided the State of Utah into five regions. Of the 22 participants (DCFS nurses, caseworkers, and foster care providers) recruited by DCFS, 9 were from Salt Lake Valley Region, 7 were from Northern Region, 4 were from Western Region, and 2 were from Eastern Region. The 3 community nurses and physician worked in the Salt Lake Valley Region (see Table 2). There were no participants from the Southwest Region. Because of concerns related to confidentiality, the specific regions that the DCFS nurses, caseworkers, and foster parents were from could not be identified in this report.

Table 1

Number of Participants in Each Group

Group	Number of Participants
Physicians	1
Nurses	10
Caseworkers	8
Foster Care Providers	7

Table 2

Number of Participants in DCFS Regions

Region	Number of Participants
Salt Lake Valley Region	13
Northern Region	7
Western Region	4
Eastern Region	2
Southwest Region	0

Data Collection

The investigator completed audio taped telephone interviews with each participant that lasted approximately 30 minutes. All participants received information regarding the study, the interview questions, and a consent form before their interview. Participants were encouraged to review the interview questions prior to their scheduled interview and contact the investigator with any questions. The interview was structured and participants were asked the following questions:

1. Describe the characteristics of a medically fragile child.
2. Rank the characteristics identified under Question #1 in order of severity/fragility. Which characteristics alone would qualify a child as medically fragile?

3. Is there terminology that may more appropriately identify/describe this population?
4. Describe your experience related to working with medically fragile children.
5. What are the needs of medically fragile children?

If the primary investigator had a question regarding a participant's answer, she asked for clarification. For example, if a participant identified a medical condition that was unfamiliar to the primary investigator, she asked if the participant could explain the medical condition. Some of the participants were initially concerned about providing the "right answer" but were informed that the primary investigator was not looking for the "right answer" and that their answer was just as valid as the answers provided by other study participants. At the end of the interview, participants were asked if there was anything else they thought would be important for the investigator to know about this population. Many of the participants asked questions at the end of the interview about the study and what would be done with the results.

Data Analysis

The tapes were transcribed by the primary investigator. After the tapes were transcribed, the investigator listened to them again while reading the text to verify the accuracy of the transcription. The transcripts were read numerous times to allow the investigator to become immersed with the data. After this process, the investigator created five spreadsheets for each of the interview questions. Participants were given an initial and number (e.g., N1 = nurse 1, C1 = caseworker 1, FP1 = foster parent 1) so that answers could be tracked to the appropriate individual and group. Their answers were

recorded under each question. Sometimes a participant answered one question while discussing another question. For example, 1 participant identified needs of medically fragile children (question 5) when discussing her experience with medically fragile children (question 4). This answer was recorded under questions 4 and 5 and a note was made under question 5 that the answer was actually identified in question 4. Themes were identified when many participants stated similar answers. As themes emerged, they were reviewed to determine if they were identified by participants in all four groups or a specific group.

In order to ensure that additional information and/or themes were not missed, the investigator read the transcripts again and wrote down key words and phrases that emerged from the data. Participants were identified in the same manner (e.g., N1 = nurse 1, C1 = caseworker 1, FP1 = foster parent 1) as in the previous analysis. Their answers were recorded next to key words and/or phrases. The question number was also identified next to the participant in order to help determine if the key words, phrases, and eventually themes related to a specific question. Themes were identified when similar key words and/or phrases appeared repeatedly during this process. These themes were then reviewed to determine if they related to one or more of the research questions. Themes were also reviewed to determine if they had been identified by participants in all four groups or by a specific group. For example, fair compensation was a concept identified only by the majority of the foster parents but was not related to a specific question. When looking at this issue, foster parents discussed fair compensation under questions 1, 3, 4, and 5. Completing this analysis allowed the investigator to identify additional themes that may have not been identified if only the initial analysis had been completed.

Validity

Validity was addressed throughout the study. The validity of the knowledge produced depends on the adequacy of the design and method (Kvale, 1996). The method that was used for this study was designed to produce knowledge that would be beneficial to the population being studied. When this information is disseminated, it is intended to benefit medically fragile children in the Utah child welfare system. Since all participants were guaranteed confidentiality, there should be no fear of possible consequences of being honest about their thoughts and feelings about medically fragile children involved with DCFS. If there was a question about a response obtained during an interview, the investigator asked for clarification. To increase validity during the transcribing process, the investigator read through the transcripts while listening to the audio tapes to ensure they were transcribed correctly.

Researcher Bias

Lincoln and Guba (1985) view a reflexive journal as a means to record information related to method and self-reflection. Throughout the course of this study, the investigator maintained an electronic reflexive journal to identify and reflect on issues that could affect objectivity. Journal entries were made after each interview and included the following information: a) date, b) summary of interview, c) personal notes, and d) actions taken. Additional information related to theory and method was included as necessary. Entries were also made in the journal in between interviews when the investigator reflected on the study.

Ethical Considerations

Agency and IRB Approval

The proposal for this exploratory study was submitted for review by University of Utah's IRB. It was also submitted to the State of Utah Department of Human Services' IRB. The proposal was reviewed and approved by the University of Utah and the Department of Human Services.

Human Subject Issues

Participation in this study was voluntary. The investigator received permission to audio tape the interviews. Participants did not receive remuneration for their participation. The risks for participating in this study were minimal. There were no direct benefits to participating in this study, but findings from this study may enhance the participants' capacity as a professional for competent practice with medically fragile children.

Confidentiality

Identifying information of the participants is protected. Participants' names are not included in the final report. Confidential information (audio tapes, transcripts, signed informed consent forms, etc.) is maintained in a locked filing cabinet in the investigator's office. All data related to this project will be destroyed one year after the project is completed. Although potential participants were contacted by a DCFS representative, its staff never knew who participated in the interviews.

Informed Consent

Each participant was given an informed consent form via email or mail before their scheduled interview. Participants were asked to read, sign, and submit the consent form before their interview. The investigator's contact information was included in the emails, letters, and consent form. Participants were encouraged to contact the investigator if they had any questions or concerns before or after the interview.

Limitations

The caseworkers and foster care providers identified by DCFS for this study were chosen based on their work with children assigned the MFC payment code. As the investigator became more familiar with DCFS protocol, she realized that the MFC payment code was used for children who were not necessarily medically fragile according to the DCFS practice guidelines. Because caseworkers and foster care parents were identified based on this payment code, it was possible that some participants had a child in their care or on their caseload who was not medically fragile according to DCFS guidelines. Because DCFS also takes placement into account when identifying a child's health status, some caseworkers and foster care providers may have been excluded from participating in this study.

CHAPTER 4

PRESENTATION OF FINDINGS

There are numerous definitions used to define medically fragile children. Because of this, it is difficult to determine the number of medically fragile children. Some definitions are restrictive in nature and result in fewer children being identified as medically fragile while other definitions are broad and result in more children being classified as medically fragile. This issue becomes more complex when trying to identify the medically fragile children involved in the child welfare system. Abused and neglected children are already a vulnerable population. These children are even more vulnerable when they have medical issues that qualify them as medically fragile. Therefore, it is critical to properly identify medically fragile children in the child welfare system in order to ensure that their needs are being met.

In order to more fully understand the number and needs of medically fragile children served by DCFS in the State of Utah, key informants of this study were asked the following interview questions:

1. What are the characteristics of a medically fragile child?
2. Rank the characteristics identified under question #1 in order of severity/fragility. Which characteristics alone would qualify a child as medically fragile?

3. Is there terminology that may more appropriately identify/describe this population?
4. Describe your experience related to working with medically fragile children.
5. What are the needs of medically fragile children?

The intent of asking these questions was to explore DCFS' current definition of medically fragile children and determine if this population has been accurately identified. The interview questions also identified characteristics of medically fragile children and explored if it was possible to prioritize these characteristics. Study participants' experiences with medically fragile children and the needs of medically fragile children were also identified.

The data received from the participants are organized under each interview question. When themes emerged from a particular group (e.g., nurses, caseworkers, or foster parents), they have been identified first. If themes were identified by multiple groups, they were subsequently identified. After themes from the interview questions have been discussed, additional themes that were not necessarily related to specific questions have been identified.

Interview Questions

Question #1: What Are the Characteristics of a Medically Fragile Child?

Interview Question #1 asked participants to identify the characteristics of medically fragile children. A wide range of characteristics was provided by a physician,

nurses, caseworkers, and foster parents. Some of the participants identified specific illnesses (e.g., diabetes) while others identified characteristics (e.g., level of oversight) that were associated with various illnesses. Many of the participants answered this question based on their personal experiences with medically fragile children with specific illnesses such as spina bifida or cerebral palsy. They had a difficult time identifying potential characteristics of medically fragile children with illnesses other than those with which they had experience.

Physician's Response

This key informant reported that “respiratory insufficiency, inability to protect the airway, inadequate swallow, inability to resist infection, [and] challenges related to fluid or electrolyte balance” were characteristics of medically fragile children. She also stated that another characteristic of medically fragile children was that their status is likely to change with minimal provocation. Something can “tip them over from doing well to being in the intensive care unit in a matter of an hour.” For example, most children can recover from a cold but a medically fragile child might have a cold that progresses to pneumonia.

Nurses' Response

The nurses provided a wide range of responses when asked to identify characteristics of a medically fragile child. Besides the common characteristics the nurses identified with the caseworkers and/or foster parents, the characteristic of a medically fragile child that was identified most often by nurses was being technology dependent.

For example, a child who required a feeding tube, tracheostomy or ventilator would be considered medically fragile.

Another characteristic identified by nurses includes a child who requires care by a trained professional in order to remain at home. In addition to a child's primary care physician and specialists, trained professionals also included home health care professionals and foster parents. For example, a community nurse reported that a foster parent of a medically fragile child might be trained to perform tasks that one might "traditionally think that nurses would provide."

Each nurse's response was unique. Additional characteristics of medically fragile children identified by the nurses included: chronic conditions, medications, oxygen needs, feeding issues, brain injuries, failure to thrive, drug exposure, prematurity, genetic issues, abuse and trauma, mental health issues, physical disabilities, pregnancy, or being a Transition to Adult Living (TAL) client.

Caseworkers' Response

The caseworkers also provided a wide range of responses when asked to identify characteristics of a medically fragile child. Besides the common characteristics the caseworkers identified with the nurses and/or foster parents, the characteristic of a medically fragile child most often identified by caseworkers was having a feeding tube.

Caseworkers also reported that the frequency of receiving medical care was another characteristic of medically fragile children. Medical issues are more prevalent with this population and these issues can be life-threatening. Because of these medical issues, medically fragile children require more appointments and procedures than other

children. They also receive more care in a hospital than other children on a caseworker's caseload.

Each caseworker's response was also unique. The characteristics of medically fragile children identified by the caseworkers included: medications, oxygen needs, brain trauma, drug exposure, abuse and neglect, cerebral palsy, cortical blindness, low IQ, spina bifida, allergies, mobility issues, and developmental issues.

Foster Parents' Response

The foster parents also provided a wide range of responses when asked to identify characteristics of a medically fragile child. Besides the common characteristics the foster parents identified with the nurses and/or caseworkers, the characteristics of a medically fragile child identified most often were mental health and behavioral issues. Participants reported that children with depression, schizophrenia, bipolar disorder, ADHD, oppositional defiant disorder, and conduct disorder should also qualify as medically fragile. Some of the foster parents felt that if a child required mental health therapy multiple times per week, they should be identified as medically fragile. One foster parent stated, "And then the next one that I put is if somebody has to receive mental health multiple times a week. That's medically fragile to me. Because if they can't even go two or three days without help, to me that's medically fragile." Another foster parent reported,

Now my schizophrenic, you have to understand mental illness in order to understand how they work and what you need to do to work with them... And I was able to, I know her pretty well that I could tell when her voices were coming full blast and strong and did what we needed to do in order for her to take care of herself. A lot of our structured homes, she would have never made it because they would want her to follow all the rules and you can't be in your bedroom and you can't do this and you can't do that.

As was the case with the nurses and caseworkers, each foster parent's response was unique. The characteristics of medically fragile children identified by the foster parents included: medication, oxygen needs, brain trauma, drug exposure, prematurity, abuse and neglect, trauma, use of technology, developmental delays, infections, seizures, bulimia, anorexia, pregnancy, heart issues, diabetes, Celiac's disease, cerebral palsy, cortical blindness, neurological disorders or being paralyzed.

Characteristic: Level of Oversight

In addition to the characteristics already identified, one characteristic of a medically fragile child identified by most of the study participants was the intense level of oversight required in order to provide appropriate care for this population. As stated by one DCFS nurse, "So I think to sum all that up, how much line of site they need from a caretaker, [an] adult, is how I would prioritize this level of severity. How much they need to sustain life, line of site." Participants reported that foster parents provided the majority of this oversight but other health care professionals also provided additional levels of oversight. When DCFS nurses have a medically fragile child on their caseload, they are required to provide a higher level of oversight to ensure that the child is attending all required medical appointments and procedures and following his or her medical regimen. As explained by one DCFS nurse, "What I've said for us, the medically fragile child is somebody that needs oversight on an ongoing basis...to make sure that things don't fall through the cracks, that they don't miss follow-up stuff like that."

Participants expressed that providing this level of oversight was challenging for a variety of reasons. Medically fragile children need to be continually assessed to determine if there are any threats to their health. These children often require daily

monitoring and caretakers who are hyper vigilant to ensure they are as healthy as possible. This level of oversight can be overwhelming given a caretaker's additional responsibilities such as employment or caring for other children in the home.

Medically fragile children are often required to be supervised at a higher level than other children their age. Even if a child is old enough to stay at home alone based on his/her chronological age, he/she may not be able to be left alone because of his/her medical condition. Once again, this makes it potentially difficult for a caretaker to run simple errands or complete tasks that most parents can complete with little or no coordination. This was summarized by one caseworker,

You can't leave her home and run to the grocery store...So a child might be able to, might have a lot of medical needs but cognitively they can manage on their own. They could kind of protect themselves, where the two that I have really would be at the mercy of anyone. So their protective capacity would be very low.

Characteristic: Extraordinary Health Care Needs

My child has been inpatient half of his life and so it's a thing that we have to deal with constantly. And it's not just as easy as go[ing] to the hospital for a couple of hours. You're there all the time. It's challenging to get all their needs scheduled as far as therapies and doctor visits. I mean, sometimes we have 15 or 20 appointments a week. And it's hard to fit them all in. (foster parent)

An additional characteristic of medically fragile children identified by the participants was having health issues that are "above and beyond" regular health care. The participants reported that these health issues were usually serious and often overwhelming. For example, one DCFS caseworker reported that most of the children on her caseload see their primary care physician for their annual physical and this is usually the only time they see a physician unless they become ill. On the other hand, medically fragile children see their primary care physician multiple times per year in addition to a

variety of specialists. Besides the frequency of doctor's appointments, participants reported there are often emergency room visits and hospital stays. Some medically fragile children have professionals that provide services in their homes. These services include physical therapy, occupational therapy, early intervention services and various medical procedures provided by a home health care nurse.

Some of the participants discussed the seriousness of these health issues by expressing the possibility of a child dying due to his/her poor health. One foster parent discussed experiencing the death of a medically fragile child in her care and how her family continues to deal with their grief. A DCFS caseworker expressed great admiration for foster parents who have willingly taken a medically fragile child into their care when they know the child's prognosis is poor.

Characteristic: Assistance with Daily Living

So he's a medically fragile child because he can't feed himself. He has to have that feeding by another person. And there's more than that but that would be, so he has to have that feeding by another person as well as all of his basic needs have to be, come from another person. So he's [a] dependent person. (DCFS nurse)

The third characteristic of medically fragile children that many of the participants identified was the child's need for assistance with daily living. This assistance would not be required from the caretaker of a child who was not medically fragile. For example, medically fragile children might need assistance with various self-care tasks such as toileting or bathing. They might also need assistance with feeding. If the child has medical equipment, the caretaker must be able to utilize and monitor it. As explained by one foster parent,

She has a G-tube. So every night they kind of clean it out. They flush it with water and then they hook her up to a machine that feeds her Pediasure through the

night. Just kind of the steps that you take to give them the care that they need for that time of day.

Characteristic: Temporarily Fragile

Some of the participants expressed that children can be medically fragile on a temporary basis. Many who held this belief reported that children are often medically fragile when they enter foster care because of abuse and neglect issues. Once these issues have been identified, treated, and resolved, the child may no longer be medically fragile. A healthy child could sustain a life threatening injury and his/her health status would change to medically fragile while in the process of recovery. A suicidal youth would be identified as medically fragile until it was determined that he/she was no longer at risk of attempting suicide. As summarized by a caseworker, “Sometimes it’s only temporary, medically fragile, like if they are before they have their surgery or while they’re recovering from a surgery, but after that, they’re no longer. It can be used temporarily that way as well.”

One foster parent reported that she frequently cares for medically fragile infants in DCFS custody. She stated that she contacted DCFS when she felt a medically fragile infant in her care was doing well and suggested that the child’s health status be modified. Based on her feedback to DCFS, the child was no longer considered medically fragile.

Question #2: Rank the Characteristics Identified Under Question #1
in Order of Severity/Fragility. Which Characteristics Alone
Would Qualify a Child as Medically Fragile?

Because of the wide range of responses to Interview Question #1, it was extremely difficult to identify themes from the participants’ responses to Interview

Question #2. Many of the participants reported that the characteristics they identified were independent and could not be ranked in order of severity/fragility. These participants questioned how one could give priority to one characteristic or disease over another one. As reported by one foster parent, “So I don’t know how you would rank those kinds of things because I don’t think they rank them by life expectancy or any such thing.” This point was further illustrated by a DCFS nurse who stated, “They’re all medically fragile Trudi. They really are. You can’t really rank them as who’s more serious than the other because each are [sic] at risk.”

Physician’s Response

This key informant reported that the characteristics she provided in response to Interview Question #1 (respiratory insufficiency, inability to protect the airway, inadequate swallow, inability to resist infection, and challenges related to fluid or electrolyte) were independent and any of them would qualify a child as medically fragile. She also clarified that a medically complex child could have many characteristics from her list. She explained that medical complexity involves multiple systems but does not necessarily make one medically fragile. Using a child with quadriplegic cerebral palsy as an example, she provided the following explanation for medically complex,

So each one of those organ systems is involved, the nervous system, the musculoskeletal system, the GI system, pulmonary mechanics and so forth. So that to me is medically complex. Lots of organ systems [are] involved but there are many kids in that situation who are not necessarily fragile that somehow, they don’t wind up in the emergency room every month or 2 months with another pneumonia, another issue. They do okay.

Level of Oversight

One of my children, he was in a shelter home before we could find him a more permanent proctor home, a permanent foster home and it really was very intimidating to the shelter mom and I know she was really nervous and so I think it's just kind of that level of monitoring and how much information they should keep track of and that extra responsibility that really makes the difference.
(caseworker)

Nurses, caseworkers, and foster parents reported that one of the most important characteristics when determining if a child is medically fragile was the intense level of oversight. It was reported that this level of oversight was essential for a variety of reasons. If these children are not being monitored or constantly assessed, their health could decompensate. Depending on the health of the child, a community nurse reported this level of monitoring may be hourly, daily, or weekly.

One DCFS nurse reported, "Those are the ones that we have to stay on top of." As previously mentioned under Interview Question #1, DCFS nurses monitor all children in foster care, but medically fragile children are monitored on a more frequent basis than healthy children on their caseload. DCFS has practice guidelines in place to determine if a child is medically fragile. The DCFS nurse assigned to a child's case has 30 days to gather information to determine the child's health status based on the DCFS Health Status Outcome Measure. After reviewing all available information, the DCFS nurse ranks the child's health on a scale between 1 (healthy) and 5 (medically fragile). The child is ranked as a 6 if he or she is on the run, new in custody, or attempts to contact his/her foster parents are unsuccessful. Children are monitored at the same frequency for the first 6 months they are in DCFS custody. Their numeric score on the Health Status Outcome Measure at 6 months determines how frequently they are monitored by a DCFS nurse after this point. If children are ranked as medically fragile, they are monitored

every 2 months. If they are ranked as a four, they are monitored every 4 months. If they are ranked as a one, two, or three, they are monitored every 6 months.

Assistance with Daily Living

Nurses and caseworkers also reported that the need for assistance with life activities was another important characteristic when determining if a child is medically fragile. As previously stated, medically fragile children need assistance with various activities that other children their age were capable of doing on their own. This includes assistance with self-care activities such as bathing, dressing, and toileting and other activities such as feeding.

Question #3: Is There Terminology That May More Appropriately Identify/Describe This Population?

Physician's Response

This key informant reported that medically fragile is too broad to describe this population. She also discussed the importance of using people first language. People first language is a respectful way to communicate that does not label a person with his or her disease or diagnosis. This type of communication reinforces that the individual is a person first. For example, she explained that one should not refer to a child as a medically fragile child but a child with medical fragility. A child with diabetes should not be called a diabetic and a child with asthma should not be called an asthmatic. Using people first language should be considered when determining appropriate terminology for this population.

This key informant also reported it is critical to look at the level in which psychosocial complexity plays a role in the outcome of the child. Two children with the same disease may have different outcomes because of psychosocial issues. She pointed out the differences in outcome related to a child's family who is under extreme stress and dissatisfied with the care of their child vs. a family who is resilient and adaptable. Some families have resources and coping skills and others do not. These differences could have a profound impact on the child's outcome. She reported that psychosocial issues are often identified in a category such as "other" and it is too important to just be identified as "other." This key informant also stated a child may have a disease that typically has a positive outcome if one follows the treatment regimen, but this child may have a poor outcome because of psychosocial and environmental barriers.

Nurses' Response

The majority of the nurses interviewed believed that "medically fragile" was appropriate terminology to describe this population. It is interesting to note that they had various reasons why they thought medically fragile was appropriate. One community nurse stated that it was "pretty descriptive" while another community nurse reported that it was "just common terminology." Some of the nurses liked this term because it was "all encompassing." One DCFS nurse stated,

I mean, it's a broad, it's a broad term. So I think that it's good that it's broad because you can be medically fragile for so many reasons from everything from neurological problems to cardiovascular problems. So this way, it encompasses all of those things.

One of the community nurses stressed the importance of using a holistic approach when diagnosing a medically fragile child. She explained the importance of also looking

at cognitive, emotional, and developmental factors when diagnosing a child as medically fragile. She believed that these factors, and not the medical diagnosis, should determine if a child is medically fragile. While discussing the use of the term, medically fragile, she stated,

So it doesn't say anything about what the child is, how they are going to function cognitively or developmentally. It kind of leaves the developmental piece out because you can have a medically fragile child that's normally developing and obtaining all their self-sufficiency needs and then you can have a medically fragile [child] that has no capability of moving forward with their development and functioning, interacting with their peers, obtaining skills of self-care.

Caseworkers' Response

Everybody's obviously got their own take on it as with anything but I think it's pretty similar. People know what you mean when you say you've got a medically fragile child. You've got a difficult child that's going to require a lot of attention, a lot of care. (caseworker)

The majority of the DCFS caseworkers interviewed also believed that "medically fragile" was appropriate terminology to describe this population. Caseworkers also had various reasons for identifying this terminology as appropriate. They reported that there is a common understanding when this phrase is used to describe a child. In contrast, 1 caseworker stated that this terminology is not well defined, but she saw this as a positive because it gave individuals flexibility when classifying a child as medically fragile. One caseworker reported that although the term was appropriate, developmental needs should also be assessed. Her explanation for this was that medically fragile children are often developmentally delayed because of their medical needs.

Foster Parents' Response

I can't think of one but I would like one to use because a lot of people, when they hear medically fragile, they kind of assume wheelchair bound, little movement,

maybe a trach. There's kind of a bad connotation to it but I can't think of a better word to describe it. (foster parent)

The foster parents reported mixed responses when asked Interview Question #3.

Some of the foster parents reported that they could not think of a better term. Some of them thought it had a negative connotation, but they did not offer alternative terminology. Some of the foster parents thought it would be better to use terminology that related to their diagnosis or specific issues. For example, 1 foster parent proposed using, "...this is a victim of physical abuse, this is a victim of drug exposure, this is a child with a history of prematurity." Only 1 foster parent really liked "medically fragile" and stated it was "an excellent word for the children."

Case by Case

Participants stated that regardless of a child's diagnosis, every child's health and health care needs should be addressed on a case by case basis. As explained by a DCFS nurse, "One kid can have three diseases and another kid can have one and the kid with one can be way more sensitive than the other so it's got to be case by case. You can't just lump them in a nutshell." This was also reiterated by a foster parent, "And to say one is more severe than the other, it depends on the incident. It depends on the child."

Participants who were unsure if "medically fragile" was the best term to define this population often stated that medically fragile children cannot be grouped together. It was explained that even though two children have the same diagnosis, they may have completely different outcomes. In addition to looking at the disease trajectory, it is critical to consider other variables that may affect a child's prognosis. These variables include psychosocial issues, developmental issues, and/or cognitive issues.

Question #4: Describe Your Experience Related to Working With Medically Fragile Children.

Physician's Response

This key informant reported that she is amazed by resilient families and how adaptable they are. She also reported that she is humbled by her privileged position where families share their “stuff” with her, whether it is good or bad and when they are at their best or worst. She explained how some families have “horrific circumstances and stress.” Other families are demanding and dissatisfied with their children’s care. Overall, she enjoys her relationships with her patients and their families. She shared, “And the chronicity of it, I think is what drove me to the field on the first place, which is the long term standing relationship, with the family over the bumpy times, over the good times and back and forth.”

When describing her experience, this key informant reiterated the importance of psychosocial complexity and its role in a child’s outcome. She stressed, “So no two kids are the same. No two families are the same.” She reported that when psychosocial complexity is taken into consideration, this will greatly impact whether a medically fragile child will “do great or really poorly.”

Nurses' Response

When asked to describe their experiences with medically fragile children, most of the nurses shared their current and previous work experience as it related to working with medically fragile children. Participants had worked in a variety of locations including Primary Children’s Medical Center, the University of Utah, Shriner’s Hospital,

emergency rooms, intensive care units, surgical centers, and various clinics. Other than discussing their work experience, there were not any themes that emerged from the nurses' responses.

Based on their experiences, 2 DCFS nurses who worked with teenagers reported that they considered most, if not all, the youth on their caseload medically fragile because of past trauma and neglect or mental health and behavioral issues. One of these nurses stated, "...I would say they're all medically fragile in one way or another because most of them have suffered a great deal of abuse and neglect." The other nurse stated, "But I'd say the majority of the kids that I work with are medically fragile because again I look at medically fragile as issues relating to behavioral problems." She reported that this population participates in many behaviors that make them medically fragile. These behaviors include having unprotected sex, abusing alcohol and/or drugs, refusing to participate in mental health therapy, refusing to take psychotropic medications, or running from their placement.

Caseworkers' Response

I think working with medically fragile children is hard. I mean working with abused and neglected children period is hard but when you have medically fragile children, at a moment's notice, you know that that child may or may not make it. So I've had a couple of my kids have close calls. So, that right there is stressful, not only for me but for the foster parents. (caseworker)

Caseworkers discussed how stressful and overwhelming it could be to have a medically fragile child on their caseload. These feelings were heightened when a medically fragile child was hospitalized because of his or her serious condition, the potential involvement of the child's biological family, and information sharing with

appropriate parties. One caseworker stated that when her medically fragile client was in the hospital “it’s like just kind of flying by the seat of your pants.”

Some caseworkers expressed how difficult it was to navigate the system and secure services for this population. Some caseworkers felt there were services available but they were unsure how to access them. One caseworker expressed frustration with budget cuts and how it had impacted her ability to access services for her medically fragile client. Another caseworker disclosed that she felt she had probably made mistakes when it came to funding and procedures related to medical care because the system is “bureaucratically intense.”

Only 2 caseworkers reported they had a positive experience when working with medically fragile children. One of these caseworkers attributed her positive experience to the work of DCFS staff and especially their nurses. She expressed that DCFS did a good job in working with medically fragile children and that “the nurses that we have on staff are on top of what the kids’ needs are.” The other caseworker was neutral about her experience but later reported it was positive because the foster parents “did an amazing job and took care of everything.”

Foster Parents’ Response

At first, when we first found out he was going to have all these problems, we were really scared, really scared. It was overwhelming at first and we were frightened about it. We just loved him and we still do as our own and we just take 1 day at a time. (foster parent)

Similar to the caseworkers, foster parents reported how stressful and challenging it was to care for a medically fragile child in foster care. As reported by 1 foster parent, “I think it’s emotionally tiring too. It’s emotionally tiring. It’s physically tiring. When I

have a suicidal kid on board and they take off, man I just stress to death. It's emotional, stressful, and tiring." Foster parents shared how they were overwhelmed and didn't realize how difficult it was to care for a medically fragile child. They stressed that it was impossible for anyone to understand how difficult it was unless they actually experienced it. Some of the foster parents expressed that they were originally fearful of working with this population because of their vast medical needs. This fear decreased after becoming familiar with the children. The amount of time required to care for a medically fragile child was also reported as stressful. Because of the time involved, parents faced various challenges in scheduling and made many sacrifices and changes to their lifestyle in order to care for the medically fragile children in their home.

Even though the foster parents interviewed expressed a great amount of stress and challenges when working with medically fragile children, the majority of them reported it was a positive experience. One foster parent expressed how uncomfortable she was being around medically fragile children until she started taking care of a medically fragile foster child. She explained how the experience changed her attitude and she understood why parents would advocate for their child and his/her needs. As explained by 1 foster parent, "We have loved doing what we do. We feel like we are very good at what we do. We have felt very, very privileged to have the babies that we've had in our care." Because of their experiences and love for the children in their home, some of the foster parents interviewed had adopted, were in the process of adopting, or had agreed to provide long-term care for a medically fragile child.

Question #5: What Are the Needs of Medically Fragile Children?

Physician's Response

This key informant stated, “My gut reaction is they need to be heard. They need to have a voice. Parents need to be recognized as the expert in their child’s care. Once we get there, then the rest of it kind of falls into place.” She reported that medically fragile children need a medical home, a primary care provider, health insurance, and a place to access services. She also reported that the parents need financial support and respite services. She stressed the importance of providing medically fragile children and their parents with choices. They need options for various issues related to their diagnosis and should be able to make choices based on these options.

This key informant shared that she is unsure if overall the healthcare system is meeting the needs of this population and proposed that the medically fragile children in foster care may actually be better served than medically fragile children in the general population. Children in DCFS custody are required to complete annual physical examinations and attend follow up appointments as required. There is a system in place to track such things as a child’s annual examination and follow up appointments. Caseworkers and DCFS nurses are in contact with foster parents to ensure that children in foster care are attending these appointments. If a child is not in DCFS custody, a parent has the option of not following through with various appointments and services required for medically fragile children.

Nurses' Response

The nurses interviewed expressed how it was critical for medically fragile children to have access to health care and specialists. They discussed the need for medically fragile children to have the equipment, devices, and supplies necessary for their care. Nurses stressed the need for physical, occupational, and speech therapies. Other medical services identified included medication management and mental health therapy.

Because it is critical for medically fragile children to have access to health care and specialists, nurses also stressed the importance of health insurance and funding for this population. Some of the DCFS nurses expressed frustration with Medicaid, the insurance for which the majority of children in foster care qualify. They reported that private insurance companies will approve various services that are denied by Medicaid. One DCFS nurse stated, "It takes a lot of time to try to get some of these needs for these kids who are medically fragile met because of funding." This could potentially become an issue because of the time it takes to receive approval for a specific treatment, for example, or needed medical equipment.

Foster Parents' Response

Foster parents expressed the need for medically fragile children to live in a home that provided stability and consistency. Medically fragile children should have a routine. There need to be rules established in the foster home that medically fragile children are required to follow. Even though these children have medical issues, foster parents reported that they needed to be held accountable for their actions and receive appropriate discipline.

Love and Emotional Support

They need a loving base because if you can do that for them, you can do anything. If you can give them that first need of love, support, and encouragement, then I think you can accomplish anything with them...And I want to make sure that he is happy. That's the most important thing to me is to make sure he is happy and loved. Because everything else can kind of falls in under that. (foster parent)

The majority of participants stated that medically fragile children need love and emotional support. They stressed the importance of nurturing and interacting with medically fragile children in a healthy manner. This was reiterated by a foster parent who stated, "They (foster parent's children) play in very healthy ways with these babies and teach them and expose them to normalcy, and everything from rough and tumble to sit on my lap and play patty-cake." These children need emotional support like any other child but also need this support when they are ill and/or dealing with their medical issues.

Caretakers as Experts

It goes back to assessment in my mind because families very often become expert caregivers. And so to get there, they've received layers and layers of subtle education so that they can detect changes. They can assess their child and say I just know their blood sugar's not right or I know these antibiotics aren't working or I know that this tumor is affecting the way they walk. The families become the sensitive assessment people and they know something's not right. (community nurse)

Participants expressed the need for caretakers to be recognized as experts in their medically fragile child's care. As reported by one foster parent,

And so you have to work your way through all of these problems until you solve them one at a time. And then, the only people who really know, who really can see what's happening to these kids is the foster family that has them because they have them every day. There is no way for anybody else to be able to tell you.

Participants identified how foster parents frequently understand the needs of medically fragile children more than professionals involved in their care because of the

parents' day to day interactions with them. Because of these interactions, they are better able to assess if their children are receiving appropriate medical services. It is critical for health care professionals and DCFS staff to listen to the issues and concerns identified by foster parents. A health care professional who has never worked with a specific medically fragile child may overlook a symptom or condition that the caretaker recognizes as a significant change in the child. A health care professional may also minimize these symptoms or overreact if he/she is not familiar with the child's medical history.

Qualified Caretaker

Caseworkers and nurses reported the critical need for medically fragile children to have a qualified caretaker. At the same time, caseworkers and nurses expressed how difficult it was to find foster parents who had the ability to care for a medically fragile child. As reported by 1 DCFS caseworker, "And it's really, really hard to find foster parents who are either willing or capable of taking care of these children's needs. I would say that's one of the biggest challenges." These children need a caretaker who is reliable, knowledgeable, strong, and nurturing. Caseworkers and nurses also addressed the additional stress that foster parents experience when caring for a medically fragile child. Foster parents are presented with situations that they may not have previously experienced when working with a child who is not medically fragile and are learning as they go. This was explained by another DCFS caseworker who stated,

What I've seen is every single one of my medically fragile children has needed a stay at home parent which is hard to find in today's economy...I mean we have the ones that they know they take the child that the child won't live and they're going to have to bury the child, but yet they take them in their home anyway. So I think they really need some dedicated strong trained people to care for them.

It is also important for foster parents of medically fragile children to be advocates. As mentioned earlier, they are also the experts in their child's care and are often the voices of the children in their care. They need to be assertive and feel comfortable expressing concerns to various professionals involved in their child's care.

Respite

Caseworkers and foster parents identified respite as an overlooked need. Caseworkers reported that it is really difficult to find respite for a medically fragile child. They expressed concern about foster parents becoming burned out because of the constant supervision and oversight. It can be difficult to find someone within a foster family's support system to provide respite. One foster parent expressed that her extended family is apprehensive to help care for her medically fragile child for fear that they will not be able to assist the child if there is a crisis situation. Foster parents reported concerns with utilizing the respite services offered by DCFS because they felt the respite parents were not qualified to assist their child in case of a medical emergency. A few of the participants reported that they would like access to a professional company to utilize for respite. As explained by 2 foster parents,

The foster care system does offer respite care but I don't feel comfortable using it because I don't feel like another parent, with her (client) condition, I don't feel comfortable dropping her off at another foster parent's house basically. So I think if we had in home respite care with a professional company like RISE or something like that then I would take advantage of respite. At this point, I'm not taking advantage of the State respite care.

And see, DCFS, they do respite and they arrange respite for some of their clients, but with medically fragile, it's almost impossible to get that. And I would think if they could hire a nurse for that purpose and kind of help her rotate among those medically fragile kids to help those families because I'll tell you, I felt like I couldn't even go on a date with my husband.

Coordination

Participants discussed the importance of coordinating medical care when working with medically fragile children because of concerns that they may “fall through the cracks.” These children have numerous medical appointments and are followed by multiple providers. Some participants expressed concerns with coordinating care between providers. Foster parents are also trying to coordinate appointments with family members’ schedules and this can be a difficult task. Some parents reported how it would be helpful to have someone help them coordinate the medical care of the medically fragile children in their care. One foster parent identified how overwhelming it was to reschedule appointments when her child was hospitalized and she had to cancel existing appointments. Another foster parent reported that she lives 25 miles from Primary Children’s Medical Center and sometimes she is required to travel there three times in one day.

One community nurse expressed concern about not having care coordinators in the health care system. A care coordinator is a professional who has the experience and knowledge to help caretakers manage their children’s care. They “uniquely know” a child and his/her family because of the frequency of their interactions. This key informant reported that the largest disconnect in the medical system is the lack of funding for health care coordinators. She stated that institutions cannot pay for this service or they do not recognize the importance of it. These thoughts were also shared by a foster parents who expressed,

They need a case manager. They need somebody to manage their medical care within the medical system and that needs to be, some nurses within DCFS do a great job of organizing the paperwork and keeping the records but true case

management takes place in the doctor's office and that's what needs to happen. Not all parents are capable of that.

Transfer of Information

Some of the participants stressed the importance of providing the foster parents with as much medical information as necessary about the medically fragile child before the child moved into their home in order to ensure they were able to meet the child's needs. Participants reported that information should be shared by the current foster parents, DCFS nurse, caseworker, and medical professionals. A delay in information sharing may have serious consequences when working with the medically fragile population. For example, a foster parent explained how she obtained critical information from previous foster placements after the child in her care had been hospitalized twice. If the foster parent had received this information before the child moved in, these hospitalizations may have been prevented. Some participants expressed concern about not receiving firsthand information from medical professionals. As reported by another foster parent,

So we thought we knew what we were doing because we had secondhand information. So if I could go back and do it again, I would have liked it to be a requirement that we had to meet with the doctors before she went into our care. Not that we would have changed our minds but it would have been better to have information firsthand.

One caseworker expressed concern about trying to coordinate information sharing between medical professionals and a medically fragile child's new foster parents. The medical professionals were hesitant to share information because of concerns regarding confidentiality. This created stress for the new foster parents because they felt they did not have enough information.

Additional Themes

The following themes were the result of answers to multiple interview questions. These themes were not necessarily related to a specific interview question but were important issues addressed by many participants. The additional themes identified were a) proper identification of medically fragile children in foster care and b) fair compensation.

Proper Identification of Medically Fragile Children in Foster Care

As stated earlier, DCFS nurses assigned to a case have 30 days to rank a child's health status based on the information they receive and obtain on a child in DCFS custody. Some of the participants did not know how the child's health status was determined. One caseworker reported that a child did not have to meet all the criteria to be classified as medically fragile and the child's team ultimately determined the classification. One foster parent reported that she contacted the DCFS nurse and discussed changing a child's health status. Another foster parent stated that the criteria used to rank a child as medically fragile were not shared.

One issue discussed throughout the course of the interviews questioned the accuracy of identifying medically fragile children in DCFS foster care. Even though DCFS has established a 6-point level system to determine if a child is medically fragile, there were concerns about whether or not it is being accurately used to determine a child's level of fragility. Some of the DCFS nurses reported that some medically fragile children were not being identified as medically fragile because of his/her placement. For example, medically fragile children (level = 5) who resided at the State Hospital, residential placement, or acute care facility would only be identified as medically needy

(level = 4) because of their placement. If these children lived in a foster home, they would have been identified as medically fragile instead. One DCFS nurse expressed concern with medically fragile children not being accurately identified because of their placement. Another DCFS nurse stated that when these children are at the State Hospital, residential facility, or acute facility, it reduces the oversight that DCFS nurses are required to provide because they do not have to worry about whether or not children's needs are being met.

On the other hand, some foster parents of children who do not meet the qualifications of medically fragile or medically needy as defined by DCFS are receiving additional money under the MFC payment code. One caseworker explained that her region identifies juvenile sex offenders and other children participating in multiple mental health appointments per week as medically fragile. This caseworker stated, "It's not like they have to meet all these criteria. It's just, if the team can kind of come to agreement that that's what they need and there's oversight." If one ranked these children using the DCFS Health Status Outcome Measure, they probably would not be identified as medically fragile.

Additionally, some children are being classified as medically fragile in order to assist DCFS nurses in tracking more difficult children. As reported by 1 DCFS nurse, "Why is it medically fragile? Well because the nurse wanted to pay more attention and make sure she called more frequently. Well there's another way to do it." This nurse suggested that coworkers utilize an alternative system to monitor children rather than classify a child as medically fragile.

Fair Compensation

I have had to battle for every single child to get the compensation where it should be. They're real eager to pay their top compensation and it's a laughable amount but they're real eager to pay that for a truant teenager but my 18 month old that is a micro-preemie and is the most severely medically needy child I've ever met or heard about, requires 24-hour monitoring and they're hesitant to pay the most that they can pay for that. And I find that appalling. (foster parent)

One issue that was brought up by most of the foster parents was appropriate reimbursement for caring for a medically fragile child. Most of the foster parents believed the reimbursement they were receiving was inadequate. They expressed a variety of feelings about having to ask for fair compensation instead of it being offered. Some foster parents felt that DCFS caseworkers believed they were trying to take advantage of the system. As reported by 1 foster parent, "It was just hard working with her (caseworker) because she, I got the impression that she felt like we were trying to take the system for all it was worth when she did not understand what was involved." Another foster parent expressed,

But when you make me beg and plead and ask over and over again for the measly few dollars that you can give me; it's ridiculous. It's devaluing. Because how can you truly show gratitude and appreciation for a foster family? How can you do that? You give them every penny that you can give them. You tell them thank you.

Some of the foster parents were asked to purchase expensive items to help them care for the medically fragile child in their home. They felt these requests were excessive and the items should have been purchased by DCFS. One parent expressed frustration with DCFS because she purchased items that could have been paid for by Medicaid. She was never informed that Medicaid would pay for these items until she was in the adoption process.

It is interesting to note that only 1 foster parent reported that the reimbursement was more than adequate. This foster parent usually cared for medically fragile infants and stated that if a foster parent had an older child, they would probably spend all the money that DCFS provided but that this amount would still be sufficient.

CHAPTER 5

SUMMARY, IMPLICATIONS, AND RECOMMENDATIONS

In this chapter, findings from the previous chapter are summarized and their implications are discussed. Recommendations for additional research are also discussed.

Summary of Findings

The purpose of this study was to answer the following research questions:

1. What are the characteristics of a medically fragile child in foster care?
2. What is an appropriate definition of a medically fragile child in foster care?
3. Using the definition, have the children in foster care been properly identified as medically fragile?

Participants in this study included foster parents, caseworkers, DCFS nurses, community nurses, and a physician. Participants were asked five interview questions about medically fragile children and their experiences with this population. There were many similarities and differences identified through the analysis of the participants' responses to the interview questions. When answering these questions, additional themes emerged as participants discussed their experiences with medically fragile children.

What Are the Characteristics of a Medically Fragile Child in
Foster Care?

Participants identified numerous characteristics of medically fragile children. Characteristics varied from an actual medical diagnosis (e.g., diabetes, cerebral palsy, spina bifida), to tasks required by the caretakers (e.g., monitoring, supervision). It was difficult to determine specific medical diagnoses that would qualify a child as medically fragile because of the disparate opinions. For example, some participants reported that a child with a mental health diagnosis was medically fragile while others disagreed.

There were also differences in the characteristics identified among the groups. The physician reported that respiratory and swallowing issues, difficulty with fluid and electrolyte balance, and increased risk for infection were characteristics of a medically fragile child. The nurses reported that being technology dependent and requiring care by a trained professional were characteristics of a medically fragile child. The DCFS caseworkers reported that needing a feeding tube and receiving frequent medical care were characteristics of a medically fragile child while the DCFS foster parents reported that mental health needs and behavioral issues would qualify a child as medically fragile.

A higher level of oversight was the first characteristic of a medically fragile child that was identified by the majority of the participants. This oversight was primarily the responsibility of the foster parents and included monitoring a child's condition and providing increased supervision. The second characteristic most commonly identified by the majority of the participants was having *extraordinary health care needs*.

Extraordinary health needs included additional medical appointments, medical care provided in the home, emergency room visits, surgeries, and hospital stays. The third

characteristic of a medically fragile child identified by the majority of the participants was *assistance with daily living*. Participants reported that these activities may include assistance with bathing, dressing, toileting, or feeding. The current DCFS definition of a medically fragile child includes two of these three characteristics (oversight and assistance with daily activities).

What Is an Appropriate Definition of a Medically Fragile Child in Foster Care?

There was not consensus from the participants' answers to the interview questions. As previously stated, some participants focused on medical diagnoses to classify a child as medically fragile while other participants identified other factors. The level of oversight, extraordinary health care needs, and assistance with daily activities were characteristics identified by most of the participants. When asked to rank the characteristics in order of severity and identify which characteristics alone would identify a child as medically fragile, there was little to no consensus on which characteristics were the most critical. Participants once again stressed that the level of oversight was one of the most important characteristics. Nurses and caseworkers also reported that assistance with daily activities was another important characteristic.

The current DCFS definition of a medically fragile child is one that "has multiple and/or debilitating condition(s) that require assistance with activities of daily living. Any child that is at risk for developing acute condition. Requires daily monitoring." (DCFS, 2009) While this is a good foundation for a definition, the term should be clarified so that it is understood and used consistently throughout DCFS. Clarification of the definition would decrease confusion among DCFS nurses when determining a child's health status

and increase uniformity of service provision to this population within the agency. For example, some of the participants identified a child with a specific medical or mental health diagnosis as medically fragile while other participants disagreed. Additionally, some foster parents of children who are not considered medically fragile according to the DCFS definition are receiving additional money under a payment code that was established to assist foster parents caring for medically fragile or medically needy children.

Participants stressed the importance of looking at each child on a case by case basis and using additional criteria to determine a child's health status. Two children with the same diagnosis could be functioning at completely different levels. Implementing new criteria would assist DCFS in more accurately identifying this population. Additional characteristics such as cognitive and developmental delays and psychosocial stressors were identified as important factors to be included when determining a child's health status.

In order to create a definition of medically fragile children in foster care that includes the major themes identified by the participants, it is recommended that the following criteria be included in a definition:

- a) physical health diagnosis,
- b) mental health diagnosis,
- c) level of oversight,
- d) level of health care needs,
- e) level of assistance with daily living,
- f) cognitive delays,

- g) developmental delays, and
- h) psychosocial stressors.

In addition to identifying a medical and/or mental health diagnosis, the severity of a child's level of oversight, level of health care needs, level of assistance with daily living, cognitive delays, developmental delays and psychosocial stressors will also be reviewed and identified as *healthy, low, medium, or high*.

It is critical to assess cognitive delays when determining a child's health status. For example, if a teenager with a medical or mental health diagnosis has subaverage intellectual functioning, this might increase the likelihood of this youth being identified as medically fragile. This youth may not have the intellectual capacity to take prescribed medications at specific times of the day or utilize public transportation to get to medical appointments. This youth may also not understand the importance of following a medical regimen or understand the limitations the illness has on his or her health.

It is also critical to assess developmental delays when determining a child's health status. A child who is not reaching developmental milestones within age appropriate timeframes may be at higher risk for medical fragility. For example, if a child with a medical or mental health diagnosis is nonverbal or has limited communication skills, this might increase the likelihood of this child being identified as medically fragile.

The psychosocial stressors of a child in foster care should also be assessed. These stressors may include such things as recent removal from home, abuse and/or neglect, inadequate support system, inadequate health care services, academic problems, divorce and death. It should be determined how the child is able to cope with various stressors and if they have a negative impact on a child's health status. When reviewing the

psychosocial stressors of a child, his/her foster parents' psychosocial stressors should be included. Hopefully, DCFS has thoroughly reviewed foster parents' applications, interviewed the applicants, and has only licensed families with capacity to handle a variety of stressors in an appropriate manner. It is critical that a foster family's stressors have as little impact as possible on a medically fragile child's well-being.

Using the proposed measure (see Table 3 and Appendix C) to assess a child's health status, his/her medical and/or mental health diagnosis would first be identified. Second, the child's level of oversight, level of health care needs, level of assistance with daily living, cognitive delays, developmental delays, and impact of psychosocial stressors would be identified as healthy, low, medium, or high (see Table 4). Depending on how these characteristics are classified, a child would then be identified as healthy (1), low risk (2), moderate risk (3), or medically fragile (4). The new measure would include DCFS' current alpha system to track overdue examinations, follow-up appointments, and immunizations.

Table 3

Updated Health Status Outcome Measure

UPDATED HEALTH STATUS OUTCOME MEASURE				
Client: _____				
Identifying Information (DOB, Medicaid #, foster parent, etc):				
Medical Diagnosis:				

Mental Health Diagnosis:				

Characteristics (See Table 4):	Healthy:	Low:	Medium:	High:
Level of Oversight:				
Level of Health Care Needs:				
Level of Assistance with Daily Living:				
Cognitive Delays				
Developmental Delays				
Impact of Psychosocial Stressors:				
Circle one:				
1. Healthy				
2. Low Risk				
3. Moderate Risk				
4. Medically Fragile				
Circle one:				
a. Current on all requirements/follow-up appointments				
b. Overdue for examination and/or follow-up appointment only				
c. Overdue for examination and/or follow-up appointment and immunizations				
d. Overdue for immunizations only				

Table 4

Definitions of Characteristics

Level of Oversight	
Healthy	Child requires normal oversight for his/her age.
Low	Caretaker's normal daily activities are negatively impacted or eliminated up to 25% of the time.
Medium	At least 26% - 50% of caretaker's normal daily activities are negatively impacted or eliminated.
High	Over 50% of the caretaker's normal daily activities are negatively impacted or eliminated.
Level of Health Care Needs	
Healthy	Child has normal health care needs for his/her age.
Low	Child's health care needs negatively impact or eliminate his/her daily activities up to 25% of the time.
Medium	Child's health care needs negatively impact or eliminate between 26% - 50% of his/her daily activities
High	Child's health care needs negatively impact or eliminate over 50% of his/her daily activities.
Level of Assistance with Daily Activities	
Healthy	Child requires normal assistance with daily activities for his/her age.
Low	Child is unable to complete up to 25% of his/her daily activities independently.
Medium	Child is unable to complete between 26% and 50% of daily activities independently.
High	Child is unable to complete over 50% of daily activities independently.
Cognitive Delays	
Healthy	Child's cognitive abilities are at age appropriate levels.

Table 4 continued

Definitions of Characteristics

Low	Up to 25% of child's cognitive abilities are below age appropriate levels.
Medium	Between 26% and 50% of child's cognitive abilities are below age appropriate levels.
High	Over 50% of child's cognitive abilities are below age appropriate levels.
Developmental Delays	
Healthy	Child's developmental abilities are at age appropriate levels.
Low	Up to 25% of child's developmental abilities are below age appropriate levels.
Medium	Between 26% and 50% of child's developmental abilities are below age appropriate levels.
High	Over 50% of child's developmental abilities are below age appropriate levels.
Impact of Psychosocial Stressors	
Healthy	Child utilizes appropriate coping skills on most occasions.
Low	Child is unable to utilize appropriate coping skills up to 25% of the time.
Medium	Child is unable to utilize appropriate coping skills between 26% and 50% of the time.
High	Child is unable to utilize appropriate coping skills over 50% of the time.

For example, if the majority of characteristics were identified as high, this child would be identified as medically fragile. If the majority of characteristics were identified as medium, this child would be moderate risk. If the majority of characteristics were identified as low, this child would be low risk. A healthy child would not have a medical or mental health diagnosis and would require only age appropriate levels of oversight and assistance with daily activities. His or her level of health care needs would be normal when compared to other children his/her age. He or she would not have cognitive and developmental delays. Psychosocial stressors would not negatively impact the child.

For the purpose of this study, the investigator has included suggested percentage levels for each characteristic. When assessing a child's level of oversight, this characteristic would be identified as high if over 50% of the caretaker's normal daily activities were negatively impacted or eliminated as a result of the oversight required for this child. When assessing a child's level of health care needs, this characteristic would be identified as high if over 50% of a child's daily activities were negatively impacted or eliminated as a result of his or her health care needs. When assessing level of assistance with daily activities, this characteristic would be identified as high if a child was unable to complete over 50% of his/her daily activities independently. When assessing the impact of cognitive delays, this characteristic would be identified as high if over 50% of a child's cognitive abilities were below age appropriate levels. When assessing the impact of developmental delays, this characteristic would be identified as high if over 50% of a child's developmental abilities were below age appropriate levels. When assessing the impact of psychosocial stressors, this characteristic would be identified as high if a child was unable to appropriately cope with various stressors more than 50% of the time. These

characteristics would be identified as medium if a child was between the 26% and 50% range. These characteristics would be identified as low if a child was below 25%.

Looking at each of these variables should increase the accuracy of children being identified as medically fragile. For example, participants disagreed about whether or not a child with diabetes was medically fragile. If the new characteristics are taken into account when determining a child's health status, one child with diabetes may be identified as medically fragile while another child with diabetes may not. If a child with diabetes required a high level of oversight and assistance with daily activities, had serious health care needs and cognitive and developmental delays, and was greatly impacted by psychosocial stressors, he or she would be considered medically fragile.

Utilizing this measure should resolve the current issue of a medically fragile child being improperly identified as medically needy because he/she is in a residential placement, acute care facility, or Utah State Hospital. Children at these facilities typically require a higher level of oversight, have more health care needs, and require assistance with daily living. A medically fragile child should not be classified as medically needy because he/she is residing in a highly structured placement with professionals who are responsible for providing the child's care and assisting in meeting his/her needs. The proposed measure would exclude placement site as a factor in determining a child's health status.

Implementing this measure should also create a standardized format for determining if a client qualifies for the MFC payment code. Since these characteristics are likely the ones already discussed by a child's team to determine if the foster parents should be reimbursed at a higher rate, the treatment team could review this form and if

the child is medically fragile, the foster parents should qualify for the MFC payment code.

A small panel of experts could be convened to determine if the suggested percentage levels of oversight, health care needs, assistance with daily living, cognitive delays, developmental delays, and impact of psychosocial stressors are appropriate when classifying these characteristics as healthy, low, moderate, or high. This panel should include DCFS nurses, DCFS clinical consultants, and community partners with experience working with medically fragile children. A pilot study could then be implemented to assess if children are more accurately identified as medically fragile. Based on the findings of the pilot study, the expert panel could make final recommendations for a definitive definition.

Once a final definition of a medically fragile child has been established, all DCFS nurses should be trained on the use of the new measure. DCFS should ensure that the measure is being used consistently among the five regions. In order to increase understanding on what qualifies a child as medically fragile, it would also be beneficial for caseworkers and foster parents to understand how this determination is made.

Implementation of the new measure utilizes the ecological perspective which will result in a more holistic approach in identifying medically fragile children. Instead of only identifying a medical diagnosis when classifying a child's health status, a variety of characteristics will be assessed. A child who has the ability to cope with psychosocial stressors in an appropriate manner and has the ability to communicate and interact with peers in an appropriate manner will probably be at lower risk of being identified as medically fragile. A child with a resilient family is also more likely to be at lower risk of

being identified as medically fragile. On the other hand, a child is at higher risk to be identified a medically fragile if he or she has cognitive and/or developmental delays and does not cope with psychosocial stressors in an appropriate manner.

Using the Definition, Have the Children in Foster Care Been
Properly Identified as Medically Fragile?

At this point in time, this question cannot be answered. If DCFS conducts the recommended pilot study using the new measure to identify medically fragile children, it should be determined if children are being properly identified as medically fragile. DCFS can compare the new measure to the Health Status Outcome Measure and identify similarities and/or differences in the classification of children's health.

This population is not always accurately identified by using the current DCFS definition of medically fragile children. As stated earlier, if a medically fragile child is at a hospital for a medical or mental health issue, he or she is considered a level four (medically needy) instead of a level five (medically fragile) on the DCFS Health Status Outcome Measure. Based on this information, the child's placement is the determining factor in deciding if he/she will be identified as medically fragile. If a child is in a hospital setting, it is highly probable that he/she requires high levels of oversight and assistance with activities of daily living and has a high level of health care needs. Having this level of care provided by professionals does not justify identifying a child as medically needy instead of medically fragile. Utilizing the proposed definition may alleviate this discrepancy.

Recommendations for DCFS

Data from the participants suggest there are issues affecting the quality of care received by medically fragile children in foster care. Meeting the needs of children in foster care can be challenging and this challenge is exacerbated when a child is medically fragile. Medically fragile children in foster care require additional services and have more needs when compared to other children in foster care.

Respite Services

Caseworkers and foster parents identified how respite services are insufficient. They also reported that working with medically fragile children is extremely stressful. It is recommended that DCFS recruit and train individuals who are qualified to provide respite services for medically fragile children in foster care. Respite services are critical for foster parents providing care to medically fragile children to decrease the likelihood that they will become burned out and request that the child be removed from their care. Foster parents need to be able to run errands, maintain a household, and care for other children in their home. They also need time to engage in self-care. If foster parents are able to utilize respite services, it will increase the likelihood that they will provide higher quality care in a healthier environment.

DCFS should ascertain why foster parents of medically fragile children do not feel comfortable utilizing DCFS respite services and respond accordingly. Current DCFS respite policy does not include guidelines specific to medically fragile children. Foster parents should be included in the process of choosing a respite care provider for their foster child because they are the experts in regard to their child's care. This will likely increase their level of comfort when they leave their child in another's care. If it is a good

match, the foster parents are also likely to use the same provider in the future. This process is also beneficial for the foster child, who will be in the care of someone with whom he/she is familiar.

Another recommendation is to provide training for individuals in the foster parents' support system (e.g., extended family members, neighbors, or members of church). Foster parents may have a strong support system but individuals within this system may be hesitant to assist in the care of a medically fragile child because of the potential for a medical emergency. Training individuals in a foster family's support system may be beneficial for a variety of reasons. Foster parents are probably more comfortable leaving their medically fragile child in the care of someone with whom they have an established relationship. Individuals in the foster parents' support system are also likely to have a relationship with the child and the child would probably feel more comfortable with them. Training should include proper use of medical equipment, CPR training, and emergency protocol.

DCFS can also assist foster parents caring for medically fragile children by creating a support group or blog specifically for these parents. Since it may be difficult for a foster parent to find someone to care for a medically fragile child while he/she participates in a group, a blog might be a better option. Foster parents of medically fragile children are dealing with unique issues. They could receive support and suggestions from other foster parents and professionals working with medically fragile children. This additional support may benefit the foster parents, medically fragile children, and DCFS.

Standardizing Practice Guidelines

DCFS should examine why allowances are made for some foster parents to receive additional reimbursement when others are denied. For example, according to DCFS practice guidelines, a juvenile sex offender would probably not be classified as medically fragile. If juvenile sex offenders are in fact being classified as medically fragile in one region, this discrepancy should be reviewed and corrected as it is unfair to foster parents for reimbursement to be inconsistent among the regions.

As previously stated, DCFS has practice guidelines in place to determine if a child is medically fragile. The DCFS nurse assigned to a child's case has 30 days to gather and review information to determine the child's medical status using the DCFS Health Status Outcome Measure. Even though the DCFS nurse is responsible for determining if a child is medically fragile, the child's treatment team determines if he/she will be considered for the medically fragile payment code which will provide the foster parents with additional money. The treatment team is made up of key players involved with the child. Teams may include the caseworker, child (when appropriate), biological parents, foster parents/foster care provider, the DCFS nurse, and mental health therapist. Even though the DCFS nurse is also a member of the team, it is not mandatory that she/he attend all child and family team meetings. It is recommended that nurses are present at all child and family team meetings. Because of his/her medical background, it is crucial for the DCFS nurse to provide his/her input on a child's case, especially when determining if a child qualifies for additional funding.

If the investigator's new definition is utilized by DCFS, this may resolve the current issue of providing additional payment to foster parents who are not caring for a

medically fragile child. The DCFS nurse could incorporate the feedback she receives from team members about the child's required level of oversight and assistance with daily activities, level of health care needs, and ability to cope with psychosocial stressors in order to determine the child's health status. If it is determined that the child is medically fragile, the foster parents should receive additional payment through the MFC code.

Using the new measure will help DCFS staff explain to a foster parent why a child qualifies or does not qualify for additional payment under the MFC code. All foster parents should understand what qualifies a child as medically fragile by practice guidelines in order for them to understand their compensation level. Understanding this process will also help them when a medically fragile child in their care is reclassified and no longer qualifies for the medically fragile payment or if a child in their care becomes medically fragile because of an unforeseen situation.

Fair Compensation

DCFS administration should review the amount of money they are reimbursing foster parents providing care for medically fragile children and determine if this is an appropriate amount. Many of the foster parents shared experiences that resulted in their feeling that DCFS staff thought they were trying to take advantage of the system by asking for assistance. These types of interactions are undesirable and could result in losing foster parents. Foster parents of medically fragile children are providing a higher level of oversight and assistance with day to day activities. They are often dealing with stressful situations such as a medical emergency, multiple medical appointments, or juggling daily activities and caring for other children.

If there is special equipment needed to meet the needs of a medically fragile child, DCFS should financially assist the foster parents or purchase the equipment for them. It is unrealistic to expect a foster parent to make a major purchase in order to be able to provide appropriate care for a medically fragile child.

Coordination

Medically fragile children are in need of coordinated care. Ideally, this coordinated care would take place in a medical setting. Because this is not always feasible, it is recommended that DCFS identify and utilize a point person within their organization to perform these tasks. Since the DCFS nurses are the only staff with a medical background, it seems logical that they would be the assigned point person for coordination. Ultimately, any assistance the DCFS nurse can give foster parents in coordinating services benefits the medically fragile child.

Transfer of Information

Foster parents need to have as much information as possible about a medically fragile child's health. Ideally, it would be beneficial for the foster parents to receive firsthand information from a child's primary care provider. Since this is often not feasible, DCFS should ensure that the foster parents are receiving thorough information that will allow them to care for a medically fragile child in the most effective manner. Children in custody have a Home-To-Home book that travels with them to each placement. This book includes medical information about the child that is reviewed by the caseworker with the foster parents. It is critical that the medical information in this book be reviewed prior to a child's placement or at the time of the child's placement.

If it is feasible, foster parents should receive information from previous caretakers or have that information relayed to them by DCFS. Previous caretakers often have insight into a child's situation that the caseworker or DCFS nurse does not have. For example, a previous caretaker can share ideas to help with feeding, difficulty at bedtime, and other care issues.

Convene Panel of Experts and Implement Pilot Study

It is recommended that DCFS collaborate with research assistants from the College of Social Work (CSW) and convene a panel of experts to determine if the suggested percentage levels of oversight, health care needs, assistance with daily living, cognitive delays, developmental delays, and impact of psychosocial variables are appropriate when classifying these characteristics as healthy, low, moderate, or high. As previously stated, this panel should include DCFS nurses, DCFS clinical consultants, and community partners with experience working with medically fragile children. Once consensus has been reached, DCFS representatives and CSW research assistants should implement a pilot study to determine if children are being more accurately identified as medically fragile. After the pilot study is completed, the expert panel should reconvene and make final recommendations for a definitive definition.

DCFS Policy Recommendations

If the pilot study is successful, it is recommended that DCFS replace its Health Status Outcome Measure with the measure created by the investigator. Utilizing this new measure could address many of the issues identified by the participants. Children will not be identified as medically fragile just because of a specific diagnosis. Each child's case

will be looked at individually and include examination of levels of oversight, health care needs, and assistance with daily activities. Cognitive and developmental delays and the impact of psychosocial stressors will also be reviewed. Incorporating these characteristics will allow DCFS to view the child in a more holistic manner than just categorizing him or her based on an illness.

It is also recommended that DCFS create a standard guideline for utilizing the MFC payment code. If a child is medically fragile, the foster parents of this child should qualify for additional money. DCFS should determine if it is appropriate to offer the MFC code to parents who do not have medically fragile children in their care. Implementing the new measure should resolve this issue because various characteristics that are likely being addressed by the treatment team when determining if the parents qualify for additional reimbursement are included on the new form.

In addition to standardizing use of the MFC code, current rates of reimbursement should be reviewed. Most foster parents expressed dissatisfaction with the amount of money they were being reimbursed for providing care to a medically fragile child. Some of these children are coming from high cost care centers. If they are unable to live in with a foster family, they are likely to return to a high cost center. DCFS should assess if they are willing to reimburse foster parents at a higher rate in order for children to live in a family setting.

According to current DCFS policy regarding respite services, foster parents qualify for 12 days of respite per year. Based on the concerns with respite, foster parents of medically fragile children are not utilizing this service. DCFS policy indicates that it is the responsibility of the foster parents to find a respite provider and that if they cannot,

DCFS will assist. Because of the many needs of medically fragile children, DCFS should consider modifying its existing policy and be proactive in assisting foster parents to find qualified respite providers. It is critical for foster parents of medically fragile children to be able to utilize respite services to decrease the likelihood of a placement disruption or burnout.

Summary of Recommendations

1. DCFS should implement the new measure to identify a medically fragile child.
2. Qualified respite providers for medically fragile children should be provided.
3. DCFS should play a key role in assisting foster parents in finding a respite provider.
4. DCFS should offer individuals in the foster parents' support system training to assist them in caring for a medically fragile child.
5. DCFS should offer an alternative support service (e.g., support group or blog) for foster parents.
6. Foster parents should receive additional reimbursement under the MFC payment code when their child has been identified as medically fragile.
7. DCFS nurses should be required to attend all child and family team meetings.
8. Foster parents and caseworkers should be trained and understand how DCFS identifies a child as medically fragile.

9. DCFS should periodically review the amount of money that foster parents of medically fragile children receive and consider a higher reimbursement rate as the child's needs change.
10. DCFS should provide foster parents with assistance in coordinating health care services for medically fragile children.
11. Foster parents should receive all necessary information about a medically fragile child's health care prior to the child being placed in their home. If feasible, they should also have contact with previous caregivers.

Recommendations for Further Research

It is recommended that additional research be conducted on the new measure to determine its effectiveness in identifying medically fragile children in foster care. This research could also compare the new measure to DCFS' Health Status Outcome Measure. It is anticipated that some physical and mental health diagnoses may result in a similar classification but others may vary because of the inclusion of the new characteristics (e.g., oversight, health care needs, assistance with daily living, cognitive delays, developmental delays, and impact of psychosocial stressors). This research could identify if there are medical and mental health diagnoses that typically contribute to a child's being identified as medically fragile and which diagnoses are more likely to be identified as low risk or moderate risk. This would assist DCFS in looking at specific physical and mental health diagnoses and determining the effect they have on a child's health and well-being. This research could also identify services and other factors that are correlated with positive and negative health and child welfare outcomes. Other factors may include

a child's level of care, residing in an urban vs. rural community, and characteristics of the child's family.

This study focused on medically fragile children in foster care. It would also be beneficial to conduct research on medically fragile children receiving DCFS in-home services. Research could address whether or not medically fragile children living with their parents are properly identified, receive appropriate care and have their needs met. Medically fragile children living with their parents and receiving DCFS services may present with different needs than medically fragile children in foster care.

As previously stated, this study focused on medically fragile children who reside in foster homes. A study looking at medically fragile children in foster care in various placements (e.g., kinship placements, group homes, and residential settings) could reveal how this population is served and if there are differences based on the level of care. If differences are noted, DCFS could identify how this population is best served and use this information to improve services and care in the various settings.

Research focusing on the caregivers of medically fragile children receiving child welfare services would benefit DCFS. Foster parents are a critical factor in determining a child's well-being. A parent with a high stress level is more likely to have a negative impact on a child whereas a parent who is able to appropriately cope with stress is more likely to have a positive impact on a child. Unmet needs and factors leading to an increase in stress levels could be discussed and solutions for reducing stress could be identified and implemented.

Interviewing medically fragile children in foster care would be extremely helpful in identifying various needs from the perspective of the child. Depending on the

children's well-being, they could be interviewed about their experiences in the child welfare system, feelings about the services they receive, and perceptions about their health and well-being. Unmet needs could also be identified. DCFS could utilize these findings to improve the quality of care and services to this population.

Value to Social Work

There is a limited amount of literature on medically fragile children in foster care. Findings of this study will ultimately add to the body of knowledge about medically fragile children in foster care. As previously stated, medically fragile children are a vulnerable population and they are even more vulnerable when they are in foster care. Utilizing the proposed measure explained in this study will improve the identification of medically fragile children in foster care. When these children are properly identified, this will ultimately improve the health care delivery and services provided to this vulnerable population.

APPENDIX A

INTERVIEW QUESTIONS

1. Describe the characteristics of a medically fragile child.
2. Rank the characteristics identified under Question #1 in order of severity/fragility. Which characteristics alone would qualify a child as medically fragile?
3. Is there terminology that may more appropriately identify/describe this population?
4. Describe your experience related to working with medically fragile children.
5. What are the needs of medically fragile children?

APPENDIX B

CONSENT FORM

Background

The purpose of this exploratory study is to increase understanding of medically fragile children served by the Division of Child and Family Services (DCFS). The purpose of this study is also to complete requirements for my doctoral dissertation. This study seeks to identify the characteristics of a medically fragile child and determine the impact these characteristics have on child well-being (physical and mental health, safety, etc.).

Study Procedure

If you agree to participate in this study, you will be asked to participate in a focus group. It is anticipated that the focus group will take approximately 90 minutes. The focus group will consist of individuals who work with medically fragile children in a similar capacity (caseworker, caregiver, medical, etc.). You will be asked a variety of questions about your experiences with medically fragile children in Utah's child welfare system. You will also be asked to identify as many characteristics of medically fragile children as you can and to weight their impact on child well-being. The groups will be audio-taped to facilitate accurate data collection.

If a focus group cannot be coordinated, you will be asked to participate in a telephone interview. You will be asked a variety of questions about your experiences with medically fragile children in Utah's child welfare system. You will also be asked to identify as many characteristics of medically fragile children as you can to weight their impact on child well-being.

Risks

The risks involved in participating in this study are minimal. They may involve being nervous about participating in a focus group, telephone interview, being audio-taped or re-experiencing feelings related to working with this population. Every effort will be made to make the focus group or telephone interview comfortable and enjoyable for you. Participation is voluntary. You may refuse to answer any of the questions or withdraw from participating at any time. If you participate in a focus group, confidentiality may be compromised because others in the focus group will hear all the responses. If issues arise, Trudi Moore can refer you to a professional who you can talk to about your feelings.

There may be risks that are not anticipated. However, every effort will be made to minimize any risks.

Benefits

You will not benefit directly by participating in this study. However, the findings from this study may enhance your capacity as a professional for competent practice with medically fragile children.

Alternative Procedures

You may choose not to take part in this study.

Confidentiality

Although every precaution will be taken to ensure that the information you provide will be protected, nobody can absolutely guarantee that there will be no breaches of confidential information. We will take the following steps to ensure your privacy:

- All of your responses will be kept in the researchers' locked files at their office.
- Your name, your identifying information will be removed from the database.
- You will be identified in the database by a identification number created by the researchers.
- All information pertaining to this project stored in the researchers' files will be destroyed one year after the project is completed.
- Focus group participants will be asked to keep the information shared in the group confidential.

Your information will be kept confidential except in cases where the researcher is legally obligated to report specific incidents. These include, but may not be limited to, incidents of abuse and suicide risk. All other information will be kept confidential by the researchers.

However, if you disclose actual or suspected abuse, neglect, or exploitation of a child, or disabled or elderly adult, the researcher or any member of the study staff must, and will, report this to Child Protective Services (CPS), Adult Protective Services (APS) or the nearest law enforcement agency.

Person to Contact

If you have any questions, concerns, or complaints, and/or if you would like a copy of the final report, you are encouraged to contact the primary investigator, Trudi Moore at 801-979-7528. You may also call if you feel you have been harmed by participating in this study.

Research Participant Advocate

You may also contact the Research Participant Advocate (RPA) by phone at (801) 581-3803 or by email at participant.advocate@hsc.utah.edu.

Institutional Review Board

Contact the Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also, contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Utah IRB may be reached by phone at (801) 581-3655 or by e-mail at irb@hsc.utah.edu. You may also contact the Department of Human Services IRB at (801) 538-4045.

Voluntary Participation

It is up to you to decide whether to take part in this study. If you decide to take part you will be asked to sign a consent form. Refusal to participate or the decision to withdraw from this research will involve no penalty or loss of benefits to which you are otherwise entitled. This will not affect your relationship with the investigator.

Costs and Compensation to Participants

You will not be compensated monetarily for participating in the study. The only cost you will have is your time to participate.

Consent

By signing this consent form, I confirm I have read and understand the information presented in it. I have had the opportunity to ask questions. I understand my participation is voluntary, and I am free to withdraw at any time without giving a reason and without cost. I understand that I will be given a signed copy of this consent form. I voluntarily agree to take part in this study.

Printed Name of Participant

Signature of Participant

Date

Printed Name of Researcher or Staff

Signature of Researcher or Staff

Date

APPENDIX C

UPDATED HEALTH STATUS OUTCOME MEASURE
INSTRUCTION GUIDE

UPDATED HEALTH STATUS OUTCOME MEASURE INSTRUCTION GUIDE

Client: *Insert client's name*

Identifying Information: (DOB, Medicaid #, foster parent, etc): *DCFS will determine the appropriate identifying information to be included on this form.*

Medical Diagnosis: *(e.g. diabetes, cerebral palsy, asthma, or cancer)*

Mental Health Diagnosis: *(e.g. oppositional defiant disorder, post traumatic stress disorder, dysthymic disorder, or generalized anxiety disorder)*

Characteristics:

Level of Oversight: *Because of child's medical and/or mental health diagnosis, caretaker's daily activities are negatively impacted. Daily activities include, but are not limited to, employment, sleep, hygiene, stress management, and exercise.*

Level of Health Care Needs: *Because of child's medical and/or mental health diagnosis, health care needs negatively impact or eliminate daily activities. Daily activities include, but are not limited to, attending school, participating in family gatherings, spending time with peers, and participating in extracurricular activities.*

Level of Assistance with Daily Activities: *Because of medical and/or mental health diagnosis, child is unable to complete daily activities independently. Daily activities include, but are not limited to, feeding, showering, toileting, brushing teeth, and brushing hair.*

Cognitive Delays: *Child's cognitive abilities are below age appropriate levels. Cognitive delays are determined by a child's intellectual functioning (e.g. intelligence quotient).*

Developmental Delays: *Child's developmental abilities are below age appropriate levels. Developmental delays include, but are not limited to, fine and gross motor skills, social skills, communication skills, and learning disabilities.*

Impact of Psychosocial Stressors: *Child has a difficult time coping with psychosocial stressors. Psychosocial stressors include, but are not limited to, removal from home, academic problems, abuse/neglect, death of a family member, discord with family, etc.*

Ranking of Characteristics:

Healthy: Normal

Low: Up to 25%

Medium: Between 26% and 50%

High: Over 50%

***Examples:**

1. If the majority of characteristics are identified as healthy, the child is identified as healthy (1).
2. If the majority of characteristics are identified as low, the child is identified as low risk (2).
3. If the majority of characteristics are identified as medium, the child is identified as moderate risk (3).
4. If majority of characteristics are identified as high, the child is medically fragile (4).

***Additional Examples:**

1. If the child has three characteristics identified as low and three characteristics identified as medium, the child is identified as moderate risk (3).
2. If the child has four characteristics identified as low and two characteristics identified as high, the child is identified as moderate risk (3).
3. If the child has three characteristics identified as healthy, one characteristic as low, and two characteristics as medium, the child is identified as low risk (2).
4. If the child has one characteristic identified as healthy, two characteristics as low and three characteristics as medium, the child is identified as moderate risk.

***Circle one:**

1. Healthy
2. Low Risk
3. Moderate Risk
4. Medically Fragile

Circle one:

- a. Current on all requirements/follow-up appointments
- b. Overdue for examination and/or follow-up appointments only
- c. Overdue for examination and/or follow-up appointment and immunizations
- d. Overdue for immunizations only

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