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Children with Special Health Care Needs: Comparison of the Effects of Home Care Setting, Prescribed Pediatric Extended Care Setting, and Long-Term Care Setting on Child and Family Health Outcomes and Health Care Service Use

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FLORIDA INTERNATIONAL UNIVERSITY

Miami, Florida

CHILDREN WITH SPECIAL HEALTH CARE NEEDS: COMPARISON OF THE EFFECTS OF HOME CARE SETTING, PRESCRIBED PEDIATRIC EXTENDED CARE SETTING, AND LONG-TERM CARE SETTING ON CHILD AND FAMILY HEALTH OUTCOMES AND HEALTH CARE SERVICE USE

A dissertation submitted in partial fulfillment of

the requirements for the degree of

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by

Carmen Caicedo

2013

To: Dean Ora Strickland
College of Nursing and Health Sciences

This dissertation, written by Carmen Caicedo, and entitled Children with Special Health Care Needs: Comparison of the Effects of Home Care Setting, Prescribed Pediatric Extended Care Setting, and Long-Term Care Setting on Child and Family Health Outcomes and Health Care Service Use, having been approved in respect to style and intellectual content, is referred to you for judgment.

We have read this dissertation and recommend that it be approved.

JoAnne Youngblut

Sharon Pontious

Timothy Page

Jean Hannan

Dorothy Brooten, Major Professor

Date of Defense: March 27, 2013

The dissertation of Carmen Caicedo is approved.

Dean Ora Lea Strickland
College of Nursing and Health Sciences

Dean Lakshmi N. Reddi
University Graduate School

Florida International University, 2013

DEDICATION

I dedicate this dissertation to all the parents and guardians and their children with special needs who participated for without you I would be unable to complete this study.

I dedicate this dissertation to all the administrators and health care providers who allowed me access to contact the parents and guardians of the children with special needs who participated in this study. Without you I would be unable to complete this study.

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ABSTRACT OF THE DISSERTATION

CHILDREN WITH SPECIAL HEALTH CARE NEEDS: COMPARISON OF THE EFFECTS OF HOME CARE SETTING, PRESCRIBED PEDIATRIC EXTENDED CARE SETTING, AND LONG-TERM CARE SETTING ON CHILD AND FAMILY HEALTH OUTCOMES AND HEALTH CARE SERVICE USE

by

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Florida International University, 2013

Miami, Florida

Professor Dorothy Brooten, Major Professor

Technological advances during the past 30 years have dramatically improved survival rates for children with life-threatening conditions (preterm births, congenital anomalies, disease, or injury) resulting in children with special health care needs (CSHCN), children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who require health and related services beyond that required by children generally. There are approximately 10.2 million of these children in the United States or one in five households with a child with special health care needs. Care for these children is limited to home care, medical day care (Prescribed Pediatric Extended Care; P-PEC) or a long term care (LTC) facility. There is very limited research examining health outcomes of CSHCN and their families. The purpose of this research was to compare the effects of home care settings, P-PEC settings, and LTC settings on child health and functioning, family health and function, and health care service use of families with CSHCN. Eighty four CSHCN ages 2 to 21 years having a medically fragile or complex medical condition that required continual monitoring were enrolled with their parents/guardians. Interviews were conducted monthly for five months using the PedsQL ^{TM} Generic Core Module for child health and functioning, PedsQL ^{TM} Family Impact Module for family health and functioning, and Access to Care from the NS-CSHCN survey for health care services. Descriptive statistics, chi square, and ANCOVA were conducted to determine differences across care settings. Children in the P-PEC settings had a highest health care quality of life (HRQL) overall including physical and psychosocial functioning. Parents/guardians with CSHCN in LTC had the highest HRQL including having time and energy for a social life and employment. Parents/guardians with CSHCN in home care settings had the poorest HRQL including physical and psychosocial functioning with cognitive difficulties, difficulties with worry, communication, and daily activities. They had the fewest hours of employment and the most hours providing direct care for their children. Overall health care service use was the same across the care settings.

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Chapter 1

Introduction

An estimated 10.2 million children in the United States, or 1 in 5 households with children, are reported to have a child with a special health care need (Bethell, Read, Blumberg, & Newacheck, 2008; U.S. Department of Health & Human Services [HHS], 2008). Children with special health care needs (CSHCN) have been defined as “those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (McPherson, Arango, Fox, Lauver, McManus, Newacheck, Perrin, Shonkoff, & Strickland, 1998).

The magnitude of health care costs for these children is great. The US had health care expenditures of $67 billion for 60 million children in 2000. Only 16% of the overall population was CSHCN, yet they accounted for 41% of the total expenditures. This small group of CSHCN accounted for a disproportionately large share of the health care costs. The average medical expense per year for CSHCN was 3 times more compared to children without special needs ($2,498 vs. $803). CSHCN had more than twice the amount of physician service costs ($406 vs. $150) and 6 times the non-physician services costs ($144 vs. $24). Average cost for prescription medications was 10 times higher for CSHCN ($340 vs. $34) (Chevarley, 2006). On average, out-of-pocket expenses for families with children with special health care needs are about twice those of other children, generally exceeding 5% of the family income (Newacheck & Kim, 2005).

Currently most families care for their CSHCN at home. Ninety-one percent of CSHCN have one or more medical conditions and 25% of CSHCN have 3 or more medical conditions. Eighty-five percent of CSHCN experience one or more functional limitations in daily living and 28% of CSHCN have 4 or more functional limitations (HHS, 2007). Caring for special needs children increases family stress, including physical and psychological changes (Brehaut, Kohen, Garner, Miller, Lach, Klassen, & Rosenbaum, 2009), financial difficulties (Kuhlthau, Hill, Yucel, & Perrin, 2005), unmet needs (Inkelas, Raghawavan, Larson, Kuo, & Ortega 2007), and concerns for their child's future due to their child's medical needs.

Children with complex and disabling chronic conditions often require healthcare on a continuum that includes pediatric rehabilitative services, along with other preventative, primary, specialty, emergent and acute care services (Child Health, 2007; Newacheck & Kim, 2005). Access to these services is important for CSHCN and their families to reach their full health and functioning potential. However, access to services for these children continues to be limited.

Significance

Children with Special Health Care Needs

The exact number of CSHCN is unknown because the prevalence rates of CSHCN are reported as ranges, rather than point estimates. Methods to validly detect many of the less prevalent chronic conditions of childhood require numerous survey items making most applications cost prohibitive (van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004). Therefore, an estimated 5% to 30% of children nationwide have special health care needs depending on the definition used (Bethell et al., 2008; van der Lee, Mokkinik, Grootenhuis, & Heymans, 2007). Identifying children with special health care needs has been complicated because there has not been a standard definition for CSHCN. The earliest definition concerned the duration of the disease and the effect of the condition on the child's daily activities (Pless & Douglas, 1971). Later definitions emphasized the extent and type of their consequence the condition had on the child's ability to function and the type of health care needs (Stein, Bauman, Westbrook, Coupey, & Ireys, 1993). In the most recent Maternal and Child Health Bureau (MCHB) definition, CSHCN are identified based on the consequences of the disease or condition, the types of services or treatments that the child requires, or the effect of the condition on the child's functional abilities. This definition captures the highly heterogeneous group of children with a variety of conditions and severity (McPherson et al, 1998).

The first nationwide survey to use the MCHB definition was the National Survey of Children with Special Health Care Needs (NS-CSHCN), conducted in 2001. The proportion of CSHCN increased from 13% in 2001 to 14% in 2006. Some reasons for this apparent increase may be the result of changes in survey methodology, improvements in screening, diagnosing, or an increased awareness in behavioral, emotional, and developmental disorders. However, all methods to identify CSHCN share these characteristics: interdependence between the perceived need for and access to and use of health care services; and the identification and subsequent treatment of the condition (Bethel et al, 2008). Further increases in CSHCN are predicted as advances in medical technology and trauma services continue to enhance survival rates among children who are born preterm, have congenital impairments, or acquire serious impairments or infections in the course of their development (Perrine, Bloom & Gortmaker, 2007; Wise, 2004).

The term “children with special health care needs” covers children with chronic conditions as well as children with disabilities with a range of impairment from mild to severe. This latter includes medically fragile and technology dependent children. Children with chronic physical health conditions (such as asthma, type I diabetes, sickle cell anemia), development disabilities or delays (such as mental retardation or cerebral palsy), acquired disabilities (such as brain injury), behavioral and mental health conditions (such as attention deficit disorder, hyperactivity disorder or depression), or any combination of conditions are considered CSHCN (Peters, 2005). A medically complex child is defined as one who has chronic debilitating diseases or conditions of one or more physiological or organ systems that requires 24-hour medical, nursing or health supervision or interventions. A medically fragile child is defined as one who is medically complex and whose medical condition requires dependence on medical technology or a procedure to sustain life such as, total parenteral nutrition (TPN), ventilator dependent, or is dependent on intense medical supervision to sustain life, and without such services is likely to expire without warning (Special Needs Children in Florida, 2003).

Health Care Services

CSHCN have a higher need for health and rehabilitative services than typically developing children. These children often require services from specialty physicians, mental health providers, physical, occupational, speech/language therapists, and/or home health care agencies. Children with major birth defects or other serious health complications, including extreme prematurity who are now living past infancy may require health care interventions and related services of a type and amount that are beyond that required by children generally. Children with serious chronic disorders require intense medical management and care coordination both in the hospital and in the community settings (McPherson et al, 1998; Newacheck & Kim, 2005). Experts in the field have described in detail requirements needed for providing coordinated care for CSHCN (Perrine, Shayne, & Bloom, 1993; Stein, 1989).

Approaches to Care

In 1992, the American Academy of Pediatrics (AAP) adopted the concept of “medical home” for pediatric practice as a framework of care coordination. The medical home is the delivery of primary care under well-trained pediatricians that is accessible, continuous, comprehensive, coordinated, compassionate, family-centered, and culturally effective (AAP, 1998). The medical home is an attempt to capture the unique potential of pediatricians as the primary care physician, to ease the burden on families raising CSHCN while improving both quality and efficiency of care. Families still struggle to find the services their children need even when services are available. It is difficult to coordinate all the needed health care services when the health care system is fragmented. Evidence of this is captured in findings of the NS-CSHCN: over 54% of the families of CSHCN indicate that their children do not receive coordinated care in a medical home; and a quarter of families raising CSHCN reported that parents had to give up or cut back on work due to their children's needs (HHS, 2007). However, there are differences in the approach to care coordination.

Alternatives of care available for families with CSHCN continue to be limited to the following options: a) having one parent reduce or resign from employment in order to stay home to provide care, thereby losing income to pay for medical insurance; b) maintaining the child at home, using limited and costly private duty nursing services, thereby isolating the children from peers; c) enrolling the medically involved children in a medical day care program such as a prescribed pediatric extended care center; d) leaving the children in the hospital, transitional care unit, rehabilitation, or a long-term/residential nursing facility.

Care in the Home Setting

Today technology has allowed many of these children to be cared for in their own homes. Pediatric home care has become a significant and necessary component of the home health care industry (AAP, 2006). The impetus towards home care has been influenced by many factors including, increased hospital costs, reduced reimbursement by payers, increased numbers of seriously ill children, and the recognition that prolonged hospital stays are detrimental to both normal child development and on family functioning and health. The shift of the responsibility for care of the medically fragile/technology-dependent child at home has produced a diversity of issues. Some of these issues include the changes in family dynamics (Gallo & Knafl, 1998), such as physical and emotional burnout, changes in relationships, social isolation, or financial burdens. The use and success of the home care services are directly related to the available resources and effectiveness of support systems because home care requires tremendous financial, emotional, and time resources from the family (Parish 2005).

Medical Day Care Setting

In 2002, the AAP, the American Public Health Association, and the National Resource Center for Health and Safety in Child Care released *Caring for Our Children* with standards and recommendations on all aspects for child care settings. However, each state regulates their own agencies' policies concerning specific situations promoting the inclusion of CSHCN in child care settings.

Like many other families with young children, families with CSHCN face a variety of child care issues in addition to their medical needs. These issues include affordable, good quality care within a reasonable distance from home (Booth, 2002). Despite the federal mandates that all early childhood, early intervention programs must be accessible to all children, many programs are limited. The physical, emotional, cognitive, and social health of CSHCN are strongly influenced by how well their families function (AAP, 2003).

Prescribed pediatric extended care (P-PEC) center is a state regulated, community-based center, which provides comprehensive nursing care for CSHCN (Harrigan, Ratliffe, Patrinos, Tse, 2002; Pierce, Freedman, 1987). These are the medical day care settings for CSHCN in Florida. P-PECs complement home care by combining medical care along with the benefits of socialization, activities, and specialized therapies. They are staffed by registered nurses who provide the acute medical care needed by the children (Florida Medicaid Report, 2004). Little has been documented on the experience of children with special needs and P-PEC care. Despite an increasing number of children prescribed by physicians to P-PEC centers, there are few current data describing and analyzing the effects of P-PEC care on the lives of CSHCN, their families, and the health care system.

Hospital, Transitional Care Unit, Long-term Care Setting

Some CSHCN require access to the full spectrum of medical services, equipment, monitoring, intensive nursing care, medical backup with emergency services are essential for life. Transitional care can be provided in a special hospital unit or a rehabilitation sub acute care facility when the CSHCN is stable. It includes an emphasis on family education and training and gradually increasing the care the family provides (Storgion & Stutts, 2000). Long-term /residential care settings are for CSHCN who are comatose or have low mobility but a few constant nursing needs, such as medication administration, multiple daily tube feedings. There are two levels of nursing facility care: skilled and intermediate. The skilled nursing facilities provide 24-hour-a-day nursing and rehabilitation services and can include special care for medically complex children. The Intermediate Care Facilities (ICF) are for children with relatively few nursing needs but considerable custodial care, such as feeding, bathing, dressing, and frequent attention. Technology-dependent children who are alert but need a highly protective environment with enhanced services may benefit from the ICF as an appropriate setting (Florida Medicaid Report, 2004). If a child was in a vegetative state, parents may be offered a nursing home facility, if one was available in their community (Sullivan-Bolyai, Knafl, Sadler, & Gillis, 2003).

Families with Children with Special Health Care Needs

It has been increasingly necessary for families to care for their special needs children at home despite the extensive medical needs characteristic of this growing population. Although the magnitude of healthcare costs for these children is great, it is a motivating factor for health care providers and insurers to become more aggressive about placing these children in less costly settings. At the same time, the health care system has been altered by economic and workforce instability. As a result, children with chronic illness or disability are living at home with their families (Bethell et al., 2008).

The nature of the care parents provide to their CSHCN include the usual aspects of parenting as well as a wide range of clinical procedures. The tasks, such as administering medications or oxygen therapy, changing tracheostomy tubes, suctioning airways, passing nasogastric tubes or foley catheters, administering intravenous infusions, and giving injections were traditionally completed by nurses (Heaton, Noyes, Sloper, & Shah, 2005). Parents described performing these procedures as being the most distressing part of care giving. They wanted to see themselves as parents not as nurses (Kirk, Glendinning & Callery, 2005).

The medically fragile/technology dependent child's "special care needs" must be incorporated into the normal routines of work, school, housekeeping, child care, and transportation (Kirk et al., 2005; Youngblut, Brennan & Swegart, 1994). The long-term care of children with complex needs places a strain on their families. It is not uncommon to find high levels of stress in the caregivers and other family members which results in depression, poor physical health (Brehaut et al., 2009), social isolation, increased financial strain (Kuhlthau et al., 2005), uncertainty about the future, and fatigue (Sullivan-Bolyai, Knafl, Sadler, & Gillis, 2003).

According to Viner-Brown & Kim (2005) financial problems or employment problems were more likely to occur among low-income families with young children and whose CSHCN condition usually/always affected their activities. In families who spend 11 or more hours a week caring for their CSHCN, 19% live in poverty compared to 4% living in families with higher incomes (HHS, 2007). However, Loprest & Davidoff (2004) found that families whose CSHCN had activity limitations were significantly less likely to work and worked fewer hours. Families caring for children with more severe conditions at home were more likely to report financial and employment problems (Kuhlthau et al., 2005; Rupp & Ressler, 2009; Okumura, Van Cleave, Gnanasekaran & Houtrow, 2009). The greater the impact of a child's condition on his/ her functional ability, the more time the family spends on the child's care (Bumbalo, Ustinich, Ramcharran & Schwalberg, 2005; Nageswaran, Silver & Stein, 2008).

Cost of Care Burden

The economic value of the quality and quantity of care provided by families for their CSHCN is an important indicator of the hidden societal costs of care. The value of these costs associated with this care is a large resource to the community. A few studies have measured time taken to care for CSHCN. One such study demonstrated the high economic value of caregivers of healthy children and chronically ill children. Hiring caregivers for healthy children was approximately $10,000 and for ill children the range was $19,000 to $36,000 per year (Wilson, Moskowitz, Acee, Heyman, Harmatz, Fernando, & Folkman, 2005).

Families of CSHCN also have out of pocket costs in caring for their children. Families of over half of CSHCN reported spending $250 or more on health care in the previous year for their CSHCN (HHS, 2007). Families of 13% of CSHCN spent between $501 and $1,000, and families of 20% of children spent more than $1,000. The level of out-of-pocket costs experienced by families of CSHCN also varies by their children's insurance status. Thirty-two percent of uninsured children's families paid more than $1,000 annually, compared to 27% of those with only private coverage and 5% of those with only public insurance (HHS, 2007).

In summary, advances in medical technologies have increased the survival of younger, more medically complex infants. Families with special needs children are facing increased stress, including physical and psychological changes, financial concerns with or without insurance and limited community resources. Based on these challenges families face in caring for special needs children and the limited services available, there is a need for research to examine current models of care to determine the most effective and cost efficient health care service delivery system for the CSHCN and their families.

Thus the purpose of this study is to compare effects of home care settings, prescribed pediatric extended care settings and hospital, transitional care unit, long-term/residential care settings on child and family health and functioning, and health care service use of families with CSHCN. The hospital, transitional care unit, and long-term/residential care settings will be referred to in this proposal as long-term care settings for reasons of brevity.

Study Purpose

Research Questions

The study is designed to address the following research questions: Comparing three health care settings, home care settings, prescribed pediatric extended care settings, and long-term care settings and controlling for child's condition severity are there differences in:

1. Child health and functioning outcomes: Physical health, mental health, and functioning (social and school participation)?

2. Family health and functioning outcomes: Physical health, mental health, functioning (family relationships, employment, and social participation), and family cost

of care burden (out-of-pocket expenses, time spent traveling to and from doctor visits and other health care services, lost employment time, lost leisure time, time spent caring for the child at home)?

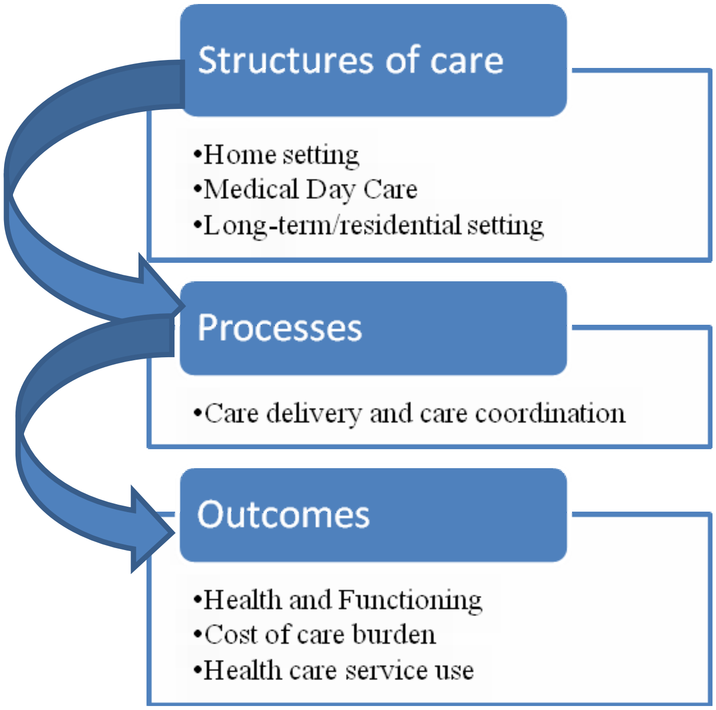
3. Health care service use: Routine doctor office visits (primary and specialty), acute care, urgent care, and emergency room visits, hospitalizations (frequency and length of stay), ancillary care including nursing services, physical and occupational therapy, speech pathology, and respiratory therapy?

Data on child health and functioning, family health and functioning, and health care service use in the three care settings will be collected monthly for six months. Study data will provide a comparison of the most effective and cost efficient service delivery system for these vulnerable children and their families. These data will be important for family health care providers and those who make public health policy decisions.

Conceptual Framework

The framework that guides this study is based on the Donabedian Structure/Process/Outcome (SPO) model which has been used for over three decades to evaluate and compare components of health care with health outcomes (Donabedian, 1966). This conceptual framework defines structure as characteristics of the healthcare delivery system, such as the individuals or organizations providing the services. The process components are all that is done to and for the population of consumers and patients, such as diagnosis, treatments, interventions, education, preventative services, and palliative end-of-life care. Outcomes are the end results of care, such as changes in health status and function, life expectancy, and perceived quality of life (Patrick, 1997).

The ultimate outcome of the health care delivery system is providing quality care delivered in the most efficient and humane manner at the lowest cost.



Donabedian's S/P/O

Study Variables for the Framework

In this study, structure is the setting where the CSHCN receives daytime care: home care settings; prescribed pediatric extended care settings; and hospital, transitional care setting or long-term care settings. Care provided in all settings was assumed to be of high quality following prescribed federal and state standards which maximize the likelihood of positive outcomes. Outcomes of care are child health and functioning outcomes: physical health, mental health, and functioning (social and school participation), family health and functioning outcomes: physical health, mental health, functioning (family relationships, employment, and social participation), family cost of care burden (out-of-pocket expenses, time spent traveling to and from doctor visits and other health care services, lost employment time, lost leisure time, time spent caring for the child at home), and health care services used (routine doctor office visits (primary and specialty), acute, urgent care, and emergency room visits, hospitalizations (frequency and length of stay), ancillary care including nursing services, physical and occupational therapy, speech pathology, and respiratory therapy. The study focuses on the structure and the related outcomes from the process of care in each structure.

Chapter 2

Review of the Literature

Introduction

An estimated 10.2 million children in the United States are reported to have a special health care need. This estimate translates into 1 in 5 households with children who have at least one child with special health care needs or over 8.8 million households nationally. By the MCHB definition, CSHCN require more than routine health and preventative care and the occasional treatment of an acute condition. Children with complex and disabling chronic conditions often require healthcare on a continuum that includes pediatric rehabilitative services, along with other preventative, primary, specialty, emergent and acute care services (Child Health, 2007; Newacheck & Kim, 2005).

Although the magnitude of health care costs for these children is great, it is a motivating factor for providers and insurers to become more aggressive about placing these children in less costly settings. Currently most families care for their CSHCN at home (Kirk et al., 2005; Newacheck, Rising, & Kim, 2006). However, caring for special needs children increases family stress, including physical and psychological changes (Brehaut et al., 2009), financial difficulties (Kuhlthau et al., 2005), unmet needs (Inkelas et al., 2007), and concerns for their child's future due to their child's medical needs. Access to needed services is important for CSHCN and their families to reach their full health and functioning potential. Yet, access services for these children remain limited.

This chapter reviews the literature on definition and prevalence of CSHCN, health care service use, approaches to care, and factors important in child and family health and functioning. Factors important in health care service use and approaches to care include available options for the family and the resulting use of health care services. Factors important in child health and functioning include; child health, including physical health, mental health; and functioning, social and school participation. Factors important in family health include physical health, mental health; functioning including family relationships, employment, and social participation; and family cost of care burden, including out-of-pocket expenses, time spent traveling to and from physician visits and other related health care services, lost employment time, lost leisure time, time spent caring for the child at home.

Children with Special Health Care Needs

Definition and Prevalence

No standardized or widely used definition of CSHSN existed until the 1998 MCHB published definition "children with special health care needs are those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson et al., 1998). This definition has 3 key attributes: 1) incorporates all types of conditions, whether physical, developmental, emotional, or behavioral; 2) consequence based or need based resulting in an increased service need; and 3) population at risk for developing a special health care need. The at risk population was included because it is better to prevent a child from developing a special health need than to treat the child after developing the special health need (McPherson et al., 1998; Newacheck et al., 2006).

This definition has been used by state Title V Maternal and Child Health Programs, Medicaid programs, private health plans, and health services researchers. Several measures using this definition have been developed to identify CSHCN and chronic health conditions, disabilities, and health care service use (Bethell, Read, Stein, Blumberg, Wells, & Newacheck, 2002; Stein & Silver, 1999). Researchers, policymakers, and program leaders use references of estimated prevalence rates, socio-demographic characteristics, health status, and health care service needs of CSHCN from different studies. However, the prevalence rates can vary when applying different definitions of chronic conditions and CSHCN to the same data set. Alternately, using the same definition to identify CSHCN when applied to different national data sets can produce a prevalence variation.

Bethell et al., (2008) conducted a study that compared the prevalence and characteristics of CSHCN using the CSHCN Screener across three different national surveys: 1) 2001 National Survey of Children with Special Health Care Needs (NS-CSHCN), 2) 2003 National Survey of Children's Health (NSCH), 3) the Medical Expenditure Panel Survey (MEPS) 2001- 2004. CSHCN were classified according to published scoring methodology. The estimated prevalence of CSHCN differed significantly: the NS-CSHCN estimate was 12.8%, the NSCH was 17.6%, and the MEPS range was 18.8% in 2004 to 19.3% in 2002. The CSHCN prevalence rates and the demographic characteristics that identified the CSHCN, such as age, gender, race/ethnicity, and household income were not significantly different across the surveys. The identifying characteristics and health care needs of CSHCN, such as the need or use of prescription medications' and ' above routine service need or use' screener items and was consistent across the surveys. Children were least likely to be identified as CSHCN based on ‘the need or use of specialty therapies’. However, when the survey methods varied, such as introduction of the survey purpose or questionnaire format, the prevalence rate differed across the surveys (Bethell et al., 2008).

Newacheck & Taylor (1992) used a categorical approach to define child health from a list of conditions that are known to be chronic from a population-based sample of children included in the 1988 National Health Interview Survey (NHIS). The purpose of this study was to estimate the prevalence of childhood conditions using a supplemental questionnaire with a checklist of 19 different recurrent or chronic conditions, five impairment groupings and 14 disease groupings, and health care service use. An estimated 31% of the children or almost 20 million children nationwide under 18 years old had a reported chronic condition, such as respiratory allergies 9.7%, repeated ear infections 8.3%, and asthma 4.3%. Among the children with chronic conditions, 70% were reported to have one condition from the checklist; 21% had two conditions; and 9% had three or more conditions. Conditions of low prevalence included diabetes, sickle cell disease, and cerebral palsy each accounting for less than two children with the condition out of every thousand children (Newacheck & Taylor 1992).

In 1999, Stein & Silver conducted a study using data from the 1994 National Health Interview Survey-Disability Supplement (NHIS-DS). The Questionnaire for Identifying Children with Chronic Conditions (QuICCC) was designed specifically for using consequence-based criteria to identify children with disabilities. The child must have at least one of three consequences: functional limitations; dependency on compensatory devices or assistance; and service use or need over and beyond routine care to be positively identified as having a chronic condition. An estimated 15% of the children or almost 10 million children nationwide were identified as having a chronic condition (Stein & Silver, 1999). However, these estimates do not include some children with prevalent chronic conditions who may not have disabilities.

In 2002, Bethell and colleagues conducted a study using a new tool, CSHCN Screener that builds on the MCHB definition and the concepts of the QuICCC for identifying CSHCN. The CSHCN Screener included five questions: does the child have a need or use prescribed medications; have a need or use medical care, need or use mental health or educational services that is more than is usual for most children of the same age; is the child limited or prevented in any way to do things most children of the same age do; does the child have a need or receives special therapy, such as physical, occupational, or speech therapy; does the child have an emotional, developmental, or behavioral problem in which they need treatment or counseling. The child needed to have one or more positive responses to be identified as having a special need. The CSHCN Screener was administered to three samples: a national sample of households with children (n = 17,985) from the National Survey of CSHCN; children enrolled in Medicaid managed care health plans (n = 3,894) from the Temporary Aid to Needy Families (TANF) program; and children receiving Supplemental Security Income (SSI) benefits in Washington State (n = 1550) (Bethell et al., 2002).

In the national sample, the screener positively identified 15% CSHCN; in the Medicaid managed care sample 21% CSHCN; and the SSI sample 95% CSHCN. The majority of positive response to the first two screener questions, the need for prescription medications and above routine service use, identified 80-90% of the children as having special health care needs across the study samples. The third most frequent item reported was functional limitations. Therefore, if the Screener was limited to the two most frequently positive items, many children (10%-20%) would be eliminated especially those not requiring medications or those with above routine service use. Such conditions may include mental retardation, learning disabilities, blindness, deafness, or autism (Bethell et al., 2002).

Davidoff (2004) conducted a study to identify CSHCN using existing questions from the National Survey of Children's Health (NHIS) modeled after the CSHCN Screener. The analysis used data from 1997, 1999, and 2000 NHIS. The author created additional indicators to identify chronic conditions. The first indicator included any chronic condition with a consequence of limitation of activity, any diagnosed condition by a physician, any active asthma symptoms in the past year, parent reported symptoms, such as seizures, respiratory allergies, eczema or skin allergies, digestive allergies, frequent diarrhea or colitis, anemia, or frequent headaches in the past year, a childhood depression indicator (has the child been unhappy or sad in the past six months), and children with very low birth weight (under 1,500 gm) under the age of two years. The second indicator excludes those symptoms or conditions only reported by the parent without an additional consequence response. The first indicator showed 40% of the children were identified with a chronic condition and the second indicator identified 18% of the children with a chronic condition. An emotional, developmental, or behavioral condition was reported for 11% of the children (Davidoff, 2004).

Overall, 24% of the children met at least one of the five Screener categories; 14% had an elevated or unusual service use; 11% had prescription medications; 7% had limitations in activity; 5% had mental health service use; 5% had special therapies use. Using the additional indicator sets, the estimates changed: 7% and 11% had an elevated or unusual service use; 6% and 9% had prescription use, respectively; and both sets had 7% limitations in activity; both sets had 3% mental health use; both sets had 3% special therapies use. Many children with less serious conditions, such as skin or respiratory allergies, may use different prescription medications and make regular physician office visits, thus exhibiting consequences of a chronic condition. Whereas, a child with a seizure disorder that has been controlled by prescription medications, requires only routine office visits and has been symptom free in the past 6 months is counted in the second condition set only. That is, not all children with a specific diagnosis will have limitations of activity or require elevated or unusual health services. The issue of the different levels of severity of the chronic condition or the degree of impact of the CSHCN on the family can generate varying prevalence estimates (Davidoff, 2004).

In summary, the exact number of children with special health care needs nationwide is unknown. Administrative data on diagnosis and health care service use is available from Medicaid to identify CSHCN. Others rely on surveys or family interviews for information about the CSHCN. There is no uniform definition for identifying CSHCN. Public agencies, private health plans, providers, and researchers use different definitions and strategies to identify CSHCN for various purposes. The most widely used definition has been the 1998 MCHB definition which is a broad, service based definition.

Prevalence of Children with Special Health Care Needs

Children with special needs can cover children with disabilities as well as children with chronic conditions that range from mild to severe. The number of children with a chronic condition has been increasing over the past four decades due to improvements in survival rates for relatively low prevalence childhood conditions that had high fatality rates, such as extremely premature births, cystic fibrosis, spina bifida, and congenital heart conditions (Perrine et al., 2007). Children with chronic physical health conditions, such as asthma, type I diabetes, sickle cell anemia; development disabilities or delays, such as mental retardation or cerebral palsy; acquired disabilities, such as paralysis or brain injury; behavioral and mental health conditions, such as attention deficit disorder, hyperactivity disorder, depression; or a combination of conditions can all be considered CSHCN (Viner-Brown & Kim, 2005).

Improvements in medical technology have allowed children, including those with major birth defects, extreme prematurity, or other serious health complications, who would have died in infancy to now survive into adulthood. There have been dramatic advances in neonatal care as younger and smaller infants survive. Preterm births, < 37 weeks gestation, have increased 36% since the early 1980s in the US (March of Dimes Foundation, 2009). Over 500,000 infants are born preterm each year and may have significant health consequences, such as neurodevelopmental sequelae and other health problems (Behrman & Sith Butler, 2007).

Hille and colleagues (2007) and the Dutch Project on Premature and Small for Gestational Age Infants (POPS), conducted a longitudinal survey to examine the survivors born premature (< 32 weeks gestation) and/or very low birth weight (< 1500 g) who were born in 1983. Of the 959 surviving 19 year olds, 596 (62%) responded. Results showed moderate or severe problems with cognition in 4.3% of the survivors, problems with hearing 1.8%, and problems with vision in 1.9%. A total of 12.6% had moderate or severe problems in cognitive or motor functioning. The most frequent problems (47%) were in neuromotor functioning, including minor neurologic dysfunction and abnormalities in coordination of movements. When compared to the general Dutch population, twice as many young adults who were born preterm and/or with a very low birth weight were poorly educated, and three times as many were neither employed nor in school at age 19 years (Hille, Weisglas-Kuperus, van Goudoever, Jacabusse, Ens-Dokkum, Groot, et al., 2007).

A study by Wilson-Costello and her colleagues conducted (2007) a retrospective chart review comparing neonatal therapies and neurodevelopment outcomes in the US among extremely low birth weight (500-999 g) infants born during three different periods: 1982-1989, 1990-1998, and 2000-2002. The study population included a total of 1,478 infants: 496 infants born during period one; 749 infants born during period two; and 233 infants born during period three. Major neurologic impairments included cerebral palsy, hypotonia, hypertonia, and shunt-dependent hydrocephalus. Their findings showed survival without impairment increased and survival with impairment decreased. Cerebral palsy decreased from 13% to 5%. Rate of chronic lung disease did not change; sepsis decreased, as well as severe intraventricular hemorrhage. On follow-up, the rate of neurodevelopment impairment decreased from 35% to 23% (Wilson-Costello, Friedman, Minich, Siner, Taylor, Schluchter, & Hack, 2007).

Children with congenital malformations, genetic disorders, cancer, major trauma, and typically adult disorders are receiving new treatments allowing them to survive into adulthood along with other morbidities.

Spina bifida is a neural tube defect and is the most common disabling congenital condition affecting the central nervous system. Spina bifida affects 3.1 of 10,000 pregnancies in the United States (Shin, Besser, Siffel, Kucik, Shaw, Lu, et al., 2010). Although infants with spina bifida survive with early interventions, this condition continues to influence physical, cognitive, and functional functioning. Less than 67% of adolescents and young adults treated with a shunt for hydrocephalus are employable, while 33% are limited if special accommodations are provided (Hetherington, Dennis, Barnes, Drake, & Gentili, 2006).

Cystic fibrosis (CF) is the most common fatal inherited disease in White Americans, occurring once in 1600 births (Sawicki, Sellars, & Robinson, 2009). More aggressive management of CF, along with the use of new therapies, has led to increasing survival rates. The daily recommended treatment regimes are complex and time consuming. Although the median age at death was 25 years, many are surviving into their fifties (Sawicki et al., 2009).

About 35,000 infants (one out of every 125) are born each year in the US with heart defects including atrioventricular septal defect; coarctation of the aorta; tetralogy of Fallot; transposition of the great arteries; ventricular septal defects; hypoplastic left heart syndrome. However, up to 79% of these children survive with surgery and remain event-free for many years (Sweet, Wong, Webber, Horslen, Guidinger, Fine, & Magee, 2006).

More than 12,000 newly diagnosed cases of cancer occur in the United States each year among children. A current 5-year survival rate is estimated at 80%. Children with cancer, including the adverse effects of therapies used to achieve a cure, are at risk for psychosocial problems into adulthood (Ness & Gurney, 2007).

In 2004, 1,816 pediatric organ transplantations were performed. According to Sweet and colleagues (2006), outcomes for kidney, liver, and heart transplantation in children often rank among the best. Unique considerations in caring for pediatric organ transplantation include: acute post-transplant complications, medication management and regime adherence, cardiac and renal complications, endocrine problems, growth and development, and psychosocial adjustments. For adolescents, it is a time of physical and psychological transitions to adulthood. Successful transplantation in adolescents may require more effective management of their transition as adult caregivers (Waite & Laraque, 2006).

The most recent reported NS-CSHCN was administered in 2005-2006 to provide national data on the prevalence and characteristics of CSHCN. The survey results showed 13.9% or approximately 10.2 million children under age 18 years identified as CSHCN and 21.8% of the households with children had at least one special needs child. The prevalence of CSHCN varied by race/ethnicity and gender, and increased with age of the child. Special health care needs (SHCN) were reported as highest among children with multiracial ethnicity (18%) and lowest among Asian children (6.3%); 16% of the CSHCN were males and 12% were females. The highest prevalence of disabilities was reported in the school-aged children: 16% in children aged 6 to 11 years and 16.8% in children aged 12 to 17 years. This may reflect that some special needs or disabilities are either not diagnosed in the youngest age group (birth to five years of age), the children do not develop the condition until later in their development, or perhaps the younger children had greater mortality. The prevalence of CSHCN identified did not vary significantly by family income. Each income group had approximately 14% CSHCN (HHS, 2007).

An estimated 91% of identified CSHCN had at least one condition on the list; 9% had no conditions from the list; 34% had one condition; 32% had two conditions; and 25% had three or more listed conditions. The most commonly reported health condition was allergies (53% of CSHCN). Other commonly reported conditions were asthma (39%), attention deficit disorder/attention deficit hyperactivity disorder (30%), and depression, anxiety, or other emotional problems (21%), and migraine or frequent headaches (15%). Other selected conditions were autism spectrum disorder, joint problems, seizure disorder, heart or blood problems, cerebral palsy, diabetes, Down syndrome, muscular dystrophy, and cystic fibrosis. The percentage of CSHCN identified from the survey with these conditions ranged from 0.3% to 5% (HHS, 2007).

Research indicates an estimated 14% or 10 million children in the US were identified by the federal MCHB definition as having a special health care need. Ninety-one percent of CSHCN have at least one of the listed conditions and 25% of CSHCN have three or more of these conditions. The proportion of CSHCN increased from 13% in 2001 to 14% in 2006. The reasons for this apparent increase may be the result of changes in survey methodology, improvements in screening, diagnosing, treatments, and/or an increased awareness in behavioral, emotional, and developmental disorders (Bethell et al., 2008; Perrine et al., 2007; Wise, 2004). However, all methods to identify CSHCN share the same characteristics: interdependence between the perceived need for and access to and use of health care services; and the identification and subsequent treatment of the condition (Bethel et al, 2008).

Health Care Service Use

Newacheck & Kim (2005) profiled CSHCN health care use from the 2000 MEPS data. Out of 6965 participants, the CSHCN Screener identified 949 children (16%) as having special health care needs. The analysis showed that CSHCN had four times the number of inpatient hospitalizations than other children; spent about seven times as many days in the hospital as other children (370 vs. 49 days per 1000). CSHCN had more than twice as many physician office visits than other children in a year; and have one and a half times as many emergency room visits in a year. CSHCN receive five times as many prescription medications as other children per year; and about 87% of home health care days were accounted for CSHCN (Newacheck & Kim, 2005).

According to the NS-CSHCN 2005-2006, among the identified CSHCN 86% had a need or use for prescription medications, 81% had preventive dental care, 78% had routine preventive care, 52% had specialty care, 33% had vision care, 23% had specialty therapies, 19% used disposable medical supplies, 11% used medical equipment, 5% had hearing care, 4% used mobility aide/devices, and 2% used communication aids/devices. Ten percent of CSHCN had one unmet health service need and 6% had more than one unmet needed health care service (HHS, 2007).

The proportion of CSHCN experiencing a special need varied across income levels. The need or use for prescription medications was the most common special need with 72% of CSHCN with family incomes below poverty the level to 83% of CSHCN with a family income of 400% of or above poverty level. (Federal Poverty Level in 2005 was defined as 100% of poverty as $19,350 for a family of four). Among CSHCN living in poverty, parents reported 38% of CSHCN had an emotional, developmental, or behavioral problem compared to 22% of CSHCN living in the highest income families. Parents in poverty reported 28% of CSHCN had limitations in activities compared to 16% of CSHCN living in the highest income families. Low-income and uninsured CSHCN (25%) were more likely not to receive the services they needed compared to higher-income CSHCN (8%) (HHS, 2008).

Nageswaran, Silver, & Stein (2007) conducted an analysis using the NS-CSHCN 2001 data to evaluate the association of functional limitation with health care service needs of CSHCN. Functional limitation was defined as any medical, behavioral, emotional, or developmental condition that affects the child's ability to do things other children the same age do. Out of the 38,866 respondents, 38,581 answered positively to the question on limitation with 40% of the CSHCN had no limitations, 37% had some limitations, and 23% had severe functional limitations.

The findings showed CSHCN with severe functional limitations were more likely to receive specialized therapies and educational services, and have more physician office visits compared to CSHCN without functional limitations. They had significantly greater odds of delayed care, unmet health care needs and care coordination needs compared to CSHCN without limitations. The need for prescription medications was lower in the group of CSHCN with severe limitations compared to CSHCN without limitations. With greater functional limitations, CSHCN were more likely to miss school, their family miss work, and have care provided at home (Nageswaran, Silver, & Stein, 2007).

Ngui & Flores (2007) examined racial/ethnic disparities in unmet needs including specialty, dental, and other health care needs using the NS-CSHCN 2000-2001 data. The two questions from the survey used in this study included: In the past 12 months, has you child needed care from a specialty doctor, dental care including check-ups, mental health care or counseling, or special therapy: physical, occupational, or speech? And did your child receive all the services needed? The analysis used only White, Black, and Hispanic CSHCN. The other categories had insufficient numbers. Among CSHCN with completed data (n = 30,948), 74% were White, 15% were Black, and 11% were Hispanic. Black and Hispanic CSHCN were more likely to be younger, had less educated mothers, to be insured or have public insurance, and had no usual source of health care ($p < .01$). Blacks and Hispanics CSHCN mean severity scores were significantly higher than White CSHCN. Compared with White CSHCN, Black CSHCN had significantly greater unmet specialty (10% versus 7%) and dental health care needs (16% versus 9%). This study indicated significant risk factors for unmet needs included having no insurance, having no usual source of health care, and poverty.

Research conducted by Benedict (2008) was to determine whether the quality of a medical home was associated with access to therapeutic and supportive services among CSHCN and their families. Data from the 2001 National Survey-CSHCN was used for the analysis. Only CSHCN who were under 17 years of age and were reported to need therapeutic (n = 15,793) or supportive (n = 23,376) services were included in this study.

Medical home for this study was defined as: 1) the child received all necessary preventative care, 2) the care was accessible without delay in care as a result of cost or insurance, transportation, office hours, or physician availability, 3) the care was family centered where the healthcare provider spends enough time with the family, listens to the family, provides information, and helps the family feel like a partner, 4) care was from a usual source, a personal physician or nurse, had care coordination through the physician's office, services were easy to use with easy referrals to other providers, and 5) care was culturally sensitive without language, communication, or cultural problems. The children whose medical home fully met the above indicators were considered to have a high-quality medical home (Benedict, 2008).

Among CSHCN who needed therapies, less than 24% reported meeting all the indicators for a high-quality medical home. Among CSHCN who needed supportive services, 33% of the families reported a high-quality medical home. Families were more likely to report a need for supportive than for therapeutic services. Families who needed therapeutic services (16%) and supportive services (10%) reported these as unmet needs. Families of CSHCN who needed these services were less likely to report having a medical home than families with other types of special health needs. The findings showed that better quality medical homes resulted in less unmet needs, with and without controls for severity of the condition and SES (Benedict, 2008).

This study suggests that having a quality medical home was associated with receiving the therapeutic and supportive services. Families rely on therapeutic and supportive services to help them care for their CSHCN in the home and community. However, if these services are not provided, the health and functioning outcomes of the CSHCN and their families will be at risk (Benedict, 2008).

In the study conducted by Lykens and colleagues (2009), other factors affecting CSHCN receiving specialty care were identified among different socioeconomic levels. Data were obtained from the NS-CSHCN 2000-2001 survey. The study factors included demographics, geographic location, insurance coverage, and severity of condition. Out of the 38,866 CSHCN, 53% were identified as having a specialty service need and were included in this analysis. Of those CSHCN reported a need, 93% received the needed care. As the family income increased, the more likely the CSHCN received the needed specialty care. As the severity of the condition increased, the likelihood of having received all care needed decreased. In the lower-income families, the mothers' educational status of having a high school education or less increased the likelihood of having received all the care needed as compared to mothers with a college degree or more. This may be due to the supports provided to the lower-income families that are not available to the higher-income families without costs. CSHCN who did not meet the components of health insurance (coverage, continuity, and adequacy) had a greater than three times odds of having one or more unmet health care need (Lykens, Fulda, Bae, & Singh, 2009).

Results showed the low-income children and those without insurance had more difficulty receiving the needed specialty care; the middle-income group with the more severe the condition had more difficulty receiving needed specialty care (Lykens et al., 2009)

Nageswaran (2009) conducted a cross-sectional study to determine the need for respite care for CSHCN using data from the NS-CSHCN 2000-2001. Out of 38,831 CSHCN identified, 8.8% (n = 3,178) reported needing respite care in the previous 12 months. The results showed a need for respite care was highest for families with younger CSHCN, less educated mothers, lower-income families, and minorities ($p < .01$). Caregivers who needed respite care, 24% reported their need was unmet. Of those who reported unmet respite needs, 767 described the reasons for the unmet need as 26% lack of transportation, 22% too much cost, 13% reported a health plan problem, 7% reported the time was not convenient, and 18% reported various other reasons.

Research has shown one consequence of the advances in medical technology is that there is a growing group of children with continuous medical and nursing needs that enable them to survive. It is expected that these children need and use more health care services by definition. Significant risk factors for unmet health care service use include having no insurance, having no usual source of health care, and poverty. Better quality of coordinated primary care resulted in less unmet health care service use, with and without controls for severity of the condition and SES.

Health Care Service Options

Approaches to Care

Today the choices available to families needing services for their medically dependent children continue to be limited. However, due to managed care systems and attempts to prevent institutionalization, the trend has been that families care for their children at home (Bethell et al., 2007). Access to these services is important for CSHCN and their families to reach their full health and functioning potential.

Experts in the field have described in detail requirements needed for providing coordinated care for CSHCN (Perrine, Shayne, & Bloom, 1993; Stein, 1989). In the past, services for medically fragile/technology dependent children have been fragmented with poor coordination. Many barriers to care have been identified, such as inadequate communication between professionals, inadequate coordination of services, varying eligibility requirements for services, lack of community-based resources, and insufficient financial assistance. Increased costs due to duplication and inadequate health care, decreased patient safety, and dissatisfaction of care by professionals, the characteristics of families and the patients contribute to the outcomes (Smaldone, Honig & Byne, 2005). Therefore, there has been a clear national agenda to address these needs by providing family-centered services that are community-based and accessible for CSHCN and their families through the medical home model of care (Hutchins & McPherson, 1991; HHS, 2002).

Medical Home

The medical home is a method to connect CSHCN and their families with the appropriate resources, such as financing, community-based support and educational services, through care coordination and communication. A family has a medical home when they experience a special relationship with their primary care pediatrician (PCP) that is based on mutual trust and respect. Specifically, this happens when the PCP knows the child's health history, listens to the concerns of parent and the child, treats the family and child with compassion and understanding, and involves the family in decision-making through a collaborative relationship. This type of family-professional partnerships has been found to improve parents' confidence, problem-solving, and the mental health of mothers of CSHCN. Parents who advocate for their child's needed services can benefit from the direct partnership they have with the PCP when all health records are centralized in the medical home. A collaborative relationship with the family can build stronger alliances and help the family make more fully-informed clinical decisions. The primary pediatrician’s office would function as the point of care coordination for the CSHCN’s health information. The medical home model has emerged as the standard of quality comprehensive health care for all children especially for those cared for at home (AAP, 2002; AAP, 2007; Strickland, Singh, Kogan, Mann, van Dyck, Newacheck, 2009).

Care in the Home Setting

Stein & Jessop (1984) conducted a randomized control trial of the Pediatric Home Care (PHC) program for chronically ill children and their families compared to the traditionally offered sources of standard care. The PHC program and the standard care (SC) resources were provided at the Albert Einstein College of Medicine-Bronx Municipal Hospital Center. The outcomes to be compared were: satisfaction of care; child's psychological adjustment; mother's psychological symptoms; impact of the illness on the family; and the child's functional status. Eligibility criteria included children with a chronic physical condition lasting longer than three months or required a continuous hospitalization lasting at least 1 month; age younger than 11 years old; reside with their parents in the Bronx; receive some portion of their care at the Bronx Municipal Hospital Center; and their parents had to speak English or Spanish. Exclusion criteria included the children were not moderately or severely retarded or not expected to live for the duration of the study. Additional criteria used were relevant to the study outcomes included the degree to which there was serious or burdensome medical condition requiring special care and the increase difficulty in the family's social situation using the traditional sources of care.

Standard care for all home care patients at the Bronx Municipal Hospital Center included at least an initial assessment, one home visit, and one monthly contact for at least 6 months. After the 6-month period, the patients were reevaluated to determine if more home care was needed. Those patients who needed continued home care were renewed for an additional 6-month period. Services were provided in the child's home as needed, in the clinics, inpatient units, and the program's offices. The services of the PCH group included an interdisciplinary team which provided a comprehensive primary care including care coordination, patient advocacy, and education for children with chronically ill children and their families. The team consisted of a generalist pediatrician, a pediatric nurse practitioner, a social worker, consulting psychiatrist, physical therapist, the referring physician and any subspecialist involved in the child's care, and the child's family (Stein & Jessop, 1984).

Out of 381 children, 219 were enrolled into the study. The sample demographic characteristics included: over half were Hispanic, 27% were Black, and 13% were other race/ethnicity; 40% of the mothers were married, 33% were divorced, separated, or widowed and 27% were single; mothers with less than a high school education was 56% and more than high school 44%. About half of the children were living with both parents, 39% were living with mother only, and 13% were living with mother and a partner. Sources of income included public assistance 55%, mothers' employment 17%, and anther household member's employment 55% (Stein & Jessop, 1984).

The design of the study was to focus on two criteria used in evaluating the need for home services at the Bronx Municipal Hospital Center. The criteria were the illness burden on the family and the coping resources available to the family to care for their child. To ensure the PHC group and the SC group were balanced on the family burden and the resources, two scales were used at enrollment: the Clinician's Overall Burden Index (COBI) (Cronbach's alpha for this sample = .70) and the Judged Ability to Cope (JAC) scale (Cronbach's alpha for this sample = .76). The COBI measured the burden of the illness that placed demands on the family from the clinician's perspective and was completed by the child's physician. The higher the COBI score represented more burdensome conditions. The measures included medical and nursing tasks the family needed to perform to care for their child; disruption in family routines, such as sleeping, frequent trips to the hospital due to the child needs; functional limitations of the child; dependency of the child on the family; psychological burden attributed to the child's condition. The JAC scale measured the capacity of the family to provide care including the resources available to them. The higher JAC score represented greater ability to cope with the illness. The measure included family resources such as social, financial, educational, and caregiver health status. The children were then stratified into high-burden and low-resource groups and then randomly assigned to PCH or SC groups (Stein & Jessop, 1984).

Data were collected at three time points from mothers of both PHC (experimental group) and the SC (control group). Time one (enrollment) took place at least two weeks of enrollment and randomization; time two was after six months of care; and time three was after an additional six months regardless whether or not the patient had home services renewed. The initial interview covered pretest dependent variables through several structured instruments. These measures included the Satisfaction with Care (Cronbach's alpha for this sample = .85), the Impact on Family Scale (Cronbach's alpha for this sample = .88), the Psychiatric Symptom Index (Cronbach's alpha for this sample = .93), the Personal Adjustment and Roll Skills Scale (Cronbach's alpha for this sample = .82) and the Functional Status Measure (Cronbach's alpha for this sample > .62). Time two and time three interviews included utilization data and the same variables as time one (Stein & Jessop, 1984).

Out of the 219 participants enrolled, 209 completed the Time one interview (104 in SC and 105 in PHC); 188 participants completed Time two interviews and 182 completed Time three. A total of 174 participants completed all three interviews. Both groups were compared with the Time one (pretest) data using chi square and two-tailed t tests as appropriate. All data for PHC and SC groups were compared at Time two and Time three using analysis of covariance with the Time one data. There were no significant differences between the groups on Time one data for characteristics of the child, family, or pretest scores. However, significant differences between the groups at Time two were found in satisfaction of care and the child's psychological adjustment. There were no differences in mother's psychiatric symptoms, impact on the family, or the functional status of the child. Although, there were changes over time with mothers in the PHC group showed improvement while mothers in the SC group were more symptomatic. Changes were noted as a decrease in the impact scores and an increase in the functional status scores in both groups over time. These changes may be related to the length of time the children and families were involved in the PHC as well as a change in the family situation over time. The support offered through the PHC services may have compensated the increased burden of caring for the child's medical and nursing tasks at home (Stein & Jessop, 1984).

This study demonstrated that a comprehensive service for children with chronic conditions and their families can have measurable benefits and improved outcomes on the children’s psychological adjustment. However, the intervention as a whole was measured without any identification of what parts were most effective.

A secondary analysis by Jessop & Stein (1991) using the data from the above PHC intervention was conducted to determine which subgroups benefited the most and which benefited the least. The PHC randomized trial stratified the children chronically ill (n = 219) into high-burden and low-resource groups using the COBI and JAC scales. Individual items characteristics generated from the COBI and JAC were used to differentiate the subgroups in the analysis. After the overall differences between the PHC and SC were conducted with the Time one data, a second analysis of covariance was conducted to determine any differences in the subgroups as high-low burden groups and high-low resources groups (Jessop & Stein, 1991).

The results showed at six months, the PHC did better than SC when the illness burden and coping resources were low ($p < .10$) and the SC did better than PHC for both functional status ($p < .004$) and impact on the family ($p < .10$). The SC did better than PHC when the illness burden was low and the resources were high. However, when the illness burden of the child’s condition was high and coping resources were high, SC did better than PHC in functional status and impact on family. The PHC did better than SC when the coping resources were low regardless of the illness burden (Jessop & Stein, 1991).

When the additional stratification matrix of the high-low groups of the illness burden and the coping resources groups was included in the analysis, there were significant interactions in the PHC and SC groups. Those with lower illness burdens and lower coping resources benefited the most from the PHC intervention. Those with higher coping resources did better in the SC intervention (Jessop & Stein, 1991).

This study demonstrated how health care professionals used clinical judgments about the children with a milder illness burden not needing the intensive services of the PHC and families could manage with the traditional resources. The families in this study were among some of the most disadvantaged in the study area. However, some of the families did well without the additional resources and some in the PHC did not do well with the additional resources. The combination of illness burden or the severity of the child's condition and the available coping resources each family exhibits should determine the type and amount of services provided for the child's care. This study suggests that families' coping resources should be assessed prior to allocating services so as not to provide additional resources when they have adequate resources (Jessop & Stein, 1991).

In 2004, a longitudinal study was conducted by Palfrey and colleagues to assess the feasibility of establishing a "medical home" practice for families caring for their children with special needs. A group of six community-based pediatric practices (four private, two neighborhood health centers) joined together and formed the Pediatric Alliance for Coordinated Care (PACC) to conduct this study.

The intervention included: 1) services of the PNP acting as a case manager, 2) consultation from a local parent with a CSHCN from each site, 3) modifications of the office routines, 4) implementation of an individualized healthcare plan for each child, 5) regularly scheduled continuing education for the PACC physicians and PNP, and 6) expedited referrals and communication with specialists and hospital-based personnel (Palfrey, Sofis, Davidson, Liu, Freeman, & Ganz, 2004).

The sample was recruited from each of the practices by the PACC physicians in the Boston, Massachusetts area. Of the 222 families invited to participate, only 150 met eligibility requirements. Clinical selection criteria included any one of the following: 1) biologically based health problem involving more than 1 body system, 2) had a severe single system disorder, 3) had simultaneous involvement with more than one medical specialist expected to last more than 12 months, 5) be dependent on medical technology, such as gastrostomy, tracheostomy, oxygen, ventilator, continuous positive airway pressure, or mechanical bed, 6) be dependent on a wheelchair, 7) had an ongoing need for home- or school-based health care services, 8) had early intervention involvement for a biological risks and/or developmental impairment (for children less than 3 years old), or 9) had great difficulty in coordinating treatment and rehabilitation due to the complexity of the child's needs (Palfrey et al., 2004).

Families completed a 96-item questionnaire developed by New England SERVE at enrollment and at a two year follow-up. Only 117 (78%) of the families complete the follow-up survey. Reasons for 33 families not providing information at the two year follow-up included moving, changing pediatric practices, lack of time, other overwhelming social circumstances, and death of the child. Data on the missing children did not differ from the follow-up group on age, gender, or number of conditions. Outcome measures included characteristics of the CSHCN and family, parental satisfaction of the PACC intervention, number of hospitalizations and emergency room visits, lost work for the parent and lost school days for the CSHCN before and after the intervention (Palfrey et al., 2004).

Over half of the CSHCN (56%) were younger than five years old; 67% were males; 59% were White. Sixty percent of the CSHCN had five or more conditions, and 41% were technology-dependent. During the intervention, families reported that with the involvement of the PNP ease of care access improved. Sixty eight percent of the families said it was easier to talk with a nurse, 67% easier receiving letters of medical necessity, 61% getting early medical care when the child sick and getting appointments. Sixty percent of the families reported it was easier communicating with the physician, 60% easier receiving referrals, 59% getting other resources for the child, 56% of the families understood the child's condition better, and 52% of the families were involved in setting goals for the child. Families whose children had more severe problems were more likely to report improvements in obtaining health and support services during the intervention. Satisfaction with the primary care physician was high at baseline and remained high during the study. There were no differences between baseline and follow-up in the number of emergency room visits and the percentage of lost school days (for those in schools). However, there were differences in the parents' lost workdays and for the number of hospitalizations. Twenty-six percent of the parents missed more than 20 workdays per year before the intervention compared to only 14% of the parents missing more than 20 workdays after the intervention. Hospitalization rates for children with conditions considered severe decreased from 67% to 53%. Hospitalization rates for children with less severe conditions decreased from 50% to 36% (Palfrey et al., 2004).

The families of CSHCN who were considered severe seemed to benefit the most from the interventions. Parental satisfaction with the primary care pediatrician increased with the interventions. The families were part of the consultation team writing the child's individual health care plan (IHP) which helped reduce unnecessary duplication of office visits and tests. It provided up-to-date information for all the health care provides (Palfrey et al., 2004).

A longitudinal study on comprehensive primary care for CSHCN by Farmer and colleagues (2005) examined care coordination using the medical home model developed by Palfrey et al. (2004) for CSHCN in a Midwest state. This study compared the outcomes of the participants who lived in rural and urban settings. A total of 149 families with CSHCN meeting eligibility criteria were referred, 37 declined and 29 didn't complete the survey. The remaining 51 parents responded to a pre-/post-intervention survey. The eligibility criteria were the same as described in Palfrey et al. (2004).

There were three University-affiliated primary care practices serving children in a nine county region. One practice was a general pediatrics clinic located 3 miles from the academic center with 8 attending physicians and 15 residents per week. The second was a family medicine clinic located 35 miles away with two attending physicians and five residents per week. The third practice was a family medicine clinic located 40 miles away with four attending physicians and seven residents per week. A single pediatric nurse practitioner (NP) had contact with the majority of the families. However, fvei of the 51 families received services from a social worker because a NP was not available in the rural areas. However, the social worker was able to communicate with the NP. Use of a social worker for care coordination differed from the Palfrey et al. (2004) study. The intervention was based on care coordination, provision of information about resources and services, emotional support and encouragement for families to advocate for their children (Farmer, Clark, Sherman, Marien, & Selva, 2005).

Each family received a home visit by a nurse practitioner who conducted a comprehensive assessment of medical and nonmedical needs of the CSHCN and family. A personalized letter was written providing health, educational, and community resources, and an individualized written plan of care, including short term goals for the family. A parent consultant provided assistance for family support as needed (Farmer et al., 2005).

The NP made a total of 1,086 contacts with the 51 families, an average of 21.4 contacts per family ranging from 3 to 112 contacts. Issues included addressing unmet needs with physicians, community resources, and other health related professionals. These contacts were made in person, (mean 3.9, SD 4.4), by telephone (mean 10.0, SD 13.0), and by mail (mean 7.5, SD 4.8) (Farmer et al., 2005).

Children in this study needed four to five health and health related services on average at both the initial and follow up assessments. Mothers reported improved access to mental health services, with an increase from 29% at time one to 45% at time two for the 51 children who needed mental health services during the intervention. No changes were reported in the number who received primary care, preventive care, specialty care, inpatient care, emergency care, or dental care services during the intervention. Parents' report of in-home nursing care (n = 50) remained the same during the intervention (Farmer et al., 2005).

In this study, parents reported a significant increase in satisfaction with the care coordination and access to mental health support services. They also reported a decrease in family needs and caregiver strain. Fewer CSHCN missed 13 or more days from school (28% at baseline versus 14% after the intervention). However, fewer mothers missed 10 or more days due to their child's condition and reported a significant decrease in the frequency of visits to primary and specialty care providers during the intervention. Thirty-two percent of the mothers reported more than eight visits in the previous 12 months. Only 12% reported more than eight visits after the intervention. Overall, the study showed comprehensive primary care had a positive effect on CSHCN health and functioning and the health and functioning of their family, including those who lived in the more rural areas (Farmer et al., 2005).

Lawson and colleagues (2010) conducted a study to compare parent-reported outcomes for CSHCN receiving practice-based care coordination with CSHCN receiving standard care. The design of the study was a cross-sectional analysis of families with CSHCN who received individualizes care coordination services for a year compared to families with CSHCN that received usual services in their primary care pediatricians' offices. The intervention included state employed care coordinators in six community health centers and hospital-based primary care centers. The care coordinators spent 15-30 hours per week at the site working with the referred families helping to coordinate medical and mental health services; needed therapies; community-based supports, access to durable medical equipment, transportation, educational services and housing; and some legal services. All new referrals were invited to participate in this study. Children with a chronic condition in the comparison group were randomly selected from practices in the community health center without a care coordinator. The comparison sample was from a previous study.

The sample initially consisted of 245 families (118 in the intervention and 127 in the comparison group). Data from the one year follow-up included 130 families (61 in the intervention and 66 in the comparison group). The majority of children in both groups were males and were 10 years or younger. Overall child's health was significantly different between the groups (x^2 = 35.19, p < .01). The majority in the intervention group reported overall health status were fair and good (n = 18 and n = 21), whereas the comparison group reported overall health status were very good and excellent (n = 22 and n = 31). The race/ethnicity was significantly different between the groups (x^2 = 21.14, p = .01). The majority in the intervention group were Latino (n = 33) and White (n = 20), whereas the comparison group were White (n = 46) and Latino (n = 11). There were no differences in the mothers' educational level. The majority in both groups had a high school or some college education. There was a significant difference in the income levels x^2 = 44.80, p < .01). The majority in the intervention group had less than $10,000 (n = 20) and between $10-19,999 (n = 13) family income compared to income over $50,000 (n = 29) in the standard care group. Insurance coverage was significantly different between groups (x^2 = 4 2.95, p < .01). The majority in the intervention group had public insurance (n = 58) and the majority of the comparison group had private insurance (n = 38) and (n = 28) had public insurance (Lawson et al., 2010).

Data were collected from both groups in 2006 one year after the enrollment into the study. Survey questions were taken from established surveys used to assess differences in access to care, practice help and support, satisfaction with services, and the physical and mental health of the parents. Access to care was measured by the frequency of the child's visits to the PCP and of specialty visits during the past year; and the unmet needs. Practice help and support was measured through surveys developed by the Massachusetts Department of Public Health included the Primary Care Physician Office Help instrument and the Overall Care and Support. The families' views on the parent-professional partnership were assessed using the NS-CSHCN Family/Professional Partnership measure. Parental physical and mental health status was measured using the SF-12 version two, a standardized measure of adult health (Lawson et al., 2010).

Families in the intervention group reported more visits to the PCP (t = - 4.29, p < .01) and the specialty (t = - 6.27, p < .01) than the comparison group. Families in the intervention group reported receiving care coordination for needed services (t = 2.25, p = .05) and reported a higher degree of care coordination (t = - 2.42, p = .02) than the comparison group. Families in the intervention group reported better practice help and support than the comparison group. There were no significant differences between the groups in the parental physical and mental health status (Lawson et al., 2010).

Families caring for their CSHCN perceived care coordination as helpful to them evidenced by improved use of their PCP, specialty, and access of community support services. A care coordinator connects the families to services outside of the pedestrian's office.

In summary, families with adequate resources including care coordination were associated with positive child health and functioning outcomes and positive family health and functioning outcomes. Families with children whose chronic condition were severe benefitted the most from the care coordination interventions. Health care service use, such as primary care visits and specialty visits increased with care coordination can improve child health and functioning and benefit family health and functioning.

Medical Day Care Setting

Alternative care settings, such as specialized day care or medical day care are options that are rarely offered, encouraged, or available within the same community where the family resides (Sullivan-Bolyai, et al., 2003). The prescribed pediatric extended care (P-PEC) nursing center is a community-based, family-centered, and provides comprehensive nursing care (Harrigan, Ratliffe, Patrinos, Tse, 2002; Pierce, Freedman, 1987).

The REACH Project (Rural Efforts to Assist Children at Home) evolved as a research initiative of the Children's Medical Services (CMS) of the state of Florida's Medicaid program with support from Robert Wood Johnson Foundation in 1983. The proposal was to develop and implement an alternative health care delivery model, called a prescribed pediatric extended care (P-PEC), for children who received Medicaid benefits and were medically dependent children in rural areas in central Florida. The goal of the project was to improve the quality of life of the CSHCN and their families (Freedman, Pierce, & Reiss, 1987).

Sixteen experienced nurses were hired by the Florida Department of Health and Rehabilitation Services as part of a post baccalaureate internship in nursing with the State University System. Training included courses in Case Management of Pediatric Chronic Illness, Growth & Development in Rural Chronically Ill Children, Communication Skills for Healthcare Coordinators, and a Practicum in Case Management of Pediatric Chronic Illness. These nurses became the Health Care Coordinators and provided instruction, consultation, coordination, and supervision of health care services in collaboration with the University of Florida Health Center. Over 1000 CSHCN and their families were served during the 3 years of the project (Pierce & Freedman, 1983).

When children were enrolled in the P-PEC center, a multidisciplinary team completed a comprehensive assessment of the child and the family. Team members included pediatricians, nurses, specialty therapists, social worker, psychologists, and child life specialists. Based on the assessment results and in collaboration with the family, progress-oriented plan of care with short- and long-term measurable goals was developed. The plan of care was a working therapeutic plan with measureable outcomes for the child's health and functioning and the family's health and functioning (Pierce & Freedman, 1983).

Benefits to the child were cognitive, psychomotor, and psychosocial improvements, as well as physical health. With daily health assessments, healthcare professionals were able to identify and treat acute illnesses or exacerbations before the condition deteriorated enough to warrant hospitalization. Thus, interruptions in the child's developmental progress and added periods of stress were reduced or avoided. The child also benefited from the social interactions with other children that is unavailable with the homebound care. Developmental interventions were designed specifically for each child's needs. Self-care activities, for those mature enough, play therapy, and relaxation methods were for optimal cooperation. Monthly reports and every six months evaluations were conducted by the team members and the family to compare the child's rate of progress (Pierce, Freedman, & Reiss, 1987).

Benefits to the family included emotional and technical support, training and education needed to manage the medical needs of their CSHCN, assistance to address financial needs, and respite care. Through the parental training component, families were taught the skills needed to become self-sufficient in managing their child's medical condition. They learned to discriminate between expected and unexpected changes in their child's condition and when to call for help. Parents were able to continue their employment while their CSHCN were cared for in the P-PEC center. Respite care allowed the CSHCN to remain in the skilled nursing care environment while the family engaged in leisure or recreational activities or just to attend to necessary daily activities of living (Pierce, Freedman, & Reiss, 1987).

Benefits to the health care delivery system included the establishment of standards of care for an alternative care setting (P-PEC) for children with complex medical needs. The costs for providing care in this alternative setting were estimated to be 20% of the cost for a week in an acute care setting and 66% of the cost of an in-home skilled nursing care (Pierce, Freedman, & Reiss, 1987).

In 2002, a longitudinal study on early child care of CSHCN was conducted by Booth for the Maternal and Child Health Research Program. The purpose was to describe child-care use for CSHCN and the influence of the different types of child-care used on child and family health and functioning outcomes. In this prospective longitudinal study, 226 families were recruited in the State of Washington from 17 clinics or agencies providing early intervention services or follow-up services, 166 (73%) families agreed to participate. Reasons for not participating were the family was too busy, moving, not interested in the study, child was too sick, child in a foster home, or already in another study. Of the 166 children in this sample 89 were diagnosed with a disability and 77 children were at risk for developing a disability. The children's diagnoses included Down syndrome 26, spina bifida six, cerebral palsy five, delayed with unknown etiology 45, and other syndromes 7.

Data were collected by the project staff when the children were 12 months through 45 months of age. Home visits and assessments were conducted at the child's 12, 15, 30, and 45 months of age and families were contacted by phone at 14, 22, 29, 37, and 44 months. Families visited the laboratory playroom at 30 and 45 months for assessments. Data were collected about the child, family, and child-care information. Measures included demographic variables, mothers' attitudes on employment, childrearing, separation anxiety, and child-care issues. The home environment was measured for quality of caregiving with the Observational Record of the Caregiving Environment by a trained observer. Other variables of child-care included the age of entry and number of hours with the caregiver. At 12 months the child's characteristics were measured for mental, motor, and behavioral organization by the revised Bayley Scales of Infant Development (BSID- II). Adaptive behavior was determined using the Wisconsin Behavior Rating scale. Temperament was measured using the Revised Infant Temperament Questionnaire. At 45 months child outcomes were assessed with the Differential Abilities Scale, BSID-II, Vineland Adaptive Behavior Scales, Preschool Language Scale, and Child Behavior Checklist. Interobserver reliability was evaluated between the home and child-care environments at both the 15 month and 30 month visits. Reliability values for positive caregiving ratings across the combined cycles were for 15 months home care (n = 6 observations, cycles = 24) kappa = .91; for 15 month child care (n = 6 observations, cycles = 14) kappa = .86. Reliability for 30 months home care (n = 6 observations, cycles = 24) kappa = .82; for child care (n = 6 observations, cycles = 12) kappa = .75. The author reviewed the discrepancies with the observers to guard against observer drift (Booth, 2002).

The findings showed CSHCN in this sample entered child care at an older age and for fewer hours compared with typically-developing children from the census data. The CSHCN in this sample were more likely to have "informal" care with a parent, other relative, or have in-home care with a non-relative. The CSHCN were less likely to transition into a more formal care setting as they grew older. CSHCN who were not in child care had lower adaptive behavior scores if their mothers said the special health care need (SHCN) kept the child out of child care, compared with children whose mother did not indicate that the SHCN was an issue. CSHCN with significant developmental delays or at risk factors for developing delays who used child care services did not differ on mental, motor, adaptive behaviors or attachment security at age 30 months from those CSHCN staying at home with their mothers. The older the child when entering into child care predicted more favorable outcomes. Neither the quality nor quantity of child care was significant predictors of outcomes. None of the analyses provided significant effects for the different types of child care provided in this study (Booth, 2002).

Child care problems reported by the parent included finding affordable, good quality care, distance and transportation issues, the integration of other services, and special equipment needs. This study indicates that CSHCN may benefit from more one-on-one home care when the child is very young in order to develop optimal patterns of behavior (Booth, 2002).

There are limited data on innovative, effective, cost-efficient alternative care settings such as prescribed pediatric extended care centers for children with medical and technology-dependence and their families. However, research shows neither the quality nor quantity of child care had significant effects on the health and functioning of the CSHCN in different types child care provided (Booth, 2002).

Long-term Care Setting

The general trends toward deinstitutionalization began with increasing awareness of the dehumanizing conditions within the institutions. Deinstitutionalization was a first step toward more effective and humane practice. Benefits of deinstitutionalization have been established by four decades of research. Benefits include: improved behavioral outcomes (Klein & Strully, 2000); apply equally to more and less severe disabilities (Kim, Larson, & Lakin, 1999); include enhanced life satisfaction; and greater levels of competence in activities of daily living (Klein & Strully, 2000).

Approximately 89,000 children reside in a health-related institutional setting according to the 2000 Decennial Census (Newacheck & Kim, 2005). If a child was in a vegetative state, parents may be offered a nursing home facility, if one was available in their community (Sullivan-Bolyai, et al., 2003). Skilled nursing facilities (SNF) services may be provided in a free-standing or hospital facility. Services provided in SNF include nursing services, nursing assistants, physical, occupational, and speech therapists, social workers, recreational assistants, as well as room and board. There are no comprehensive national or state surveys concerning the health outcomes of institutionalized children or their families.

In the 1970s and 1980s, legislative developments were created to protect the welfare of people with physical and mental disabilities in the US. Congress also passed the Developmental Disabilities Assistance and Bill of Rights Act, which created Protection and Advocacy systems, developmental disability planning councils, and university affiliated facilities in each state. This was the beginning of deinstitutionalization and community-based integration for alternative residential care settings for adults and children with special needs.

In the 1980s many changes were occurring in the health care system. A study was conducted in 1988 by the Committee on Children with Disabilities to describe the changes in the California state pediatric residential population, the children's increasing medical complexity, and the health services they required. The children were identified using the Office of Technology Assessment (OTA, 1987) definition of a technology-dependent child as one from birth to 21 years old having a chronic disability, who needed "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". Of the 865 children residing in a California state residential developmental center, 441 (51%) were technology-dependent and lived in a skilled or acute nursing care program. The other 424 children were admitted for social development, sensory development, behavior adjustment, and rehabilitation and were not considered technology-dependent. Another 500 children were also excluded because their emotional disorders were not described as having special health care needs (Crain, Mangravite, Allport, Schour, & Biakanja, 1990).

Questionnaires developed by the authors included questions regarding total number of children and their ages; physician and service resources; routine dental protocol, education, therapy, and equipment; and about the general trends over the past decade. The second guide profiled the children's characteristics: date of birth, date of admission, diagnosis, cause of disability, specific nursing care requirements, equipment needs, state of responsiveness, and medications (Crain et al., 1990).

Of the seven California State Department of Developmental Services centers only five centers had pediatric patients due to lack of resources, including trained personnel, equipment, and budget constraints. According to OTA, the groups of children who were technology-dependent were: Group one which included ventilator-dependent children (n = 11, 2.5%); Group two included prolonged intravenous drugs or nutrition use, (n = 0); Group 3 included any child with one or more of the following: gastrostomy (n = 291, 66%), nasogastric or orogastric tubes (n = 26, 6%), tracheostomy (n = 115, 26%), or oxygen support (n = 56, 13%); Group 4 included cardio respiratory monitors (n = 40, 9%) and included substantial nursing care which included caring for urinary catheters, colostomies, or jejunostomies (n = 441, 51%). The most common etiologies were perinatal hypoxia for 82 children and near drowning for 59 children. Another 25 children had disabilities from unshunted massive hydrocephalus, 14 postnatal anoxia including accidental suffocation, perisurgical anoxia, and attempted suicide. Of the 441 children identified in this study, 244 or 55% were described as being in a vegetative state (Crain et al., 1990).

The physician-to-patient ratio on the acute care units varied from 1:13 to 1:66. The latter ratio included both adults and children. The nurse-to-patient ratios on the acute care units varied with shifts 1:4 to 1:6. The ratio on the skilled nursing facility units were 1:6 to 1:12. In 1978 only 7.7% of the physicians at the developmental centers were pediatricians. At the time of this study, 20% were board-certified pediatricians (Crain et al., 1990).

In 1978, there were 3,500 children or 22% of the total population and in 1988, 1,099 children or 16% residing in California state hospital developmental centers. Another trend change was the opportunity for people with disabilities to be “normalized” by providing more community visibility. Several children from the skilled nursing facility were transported by bus to attend local special education classes in the public schools. Fewer than half of the children’s biological parents maintained contact, although the centers encouraged ongoing involvement. Staff reported that the families described the ongoing contact with their severely disabled child as too painful (Crain et al., 1990).

The authors concluded that the residential developmental center functioned as an expensive alternative to an even more expensive hospital unit. In 1978, the hospital costs for children ranged from $60 to $150 per day. In 1988, the hospital costs for children increased to $108 to $271 per day. The costs of acute medical care at different developmental facilities in 1988 ranged from $189.31 to $ 555.46 per day or $69,098 to $203,837.90 per year. The average costs for a ventilator-dependent child was $200,000 per year. The costs of care at the developmental center included all the program components: housing, 24-hour medical and skilled nursing services, laboratory, x-ray, dental and other ancillary health services, medical equipment, oxygen, special diets, clothing, special education programs, and field trips. Other specialized care alternatives, specialized foster medical home, or family care with in-home nursing services were not available for these technology-dependent children within the community (Crain et al., 1990).

A study conducted by Chavez & Schwab (1985) in Columbus, Ohio was to pilot a pediatric long-term care hospital model. This was accomplished through collaboration with the Children's Hospital, Inc., Northland Terrace Nursing and Rehabilitation Center, and the State of Ohio Department of Human Resources. The purpose was threefold: 1) to provide care coordination for four chronically ill, technology-dependent children placed in a skilled nursing extended care facility (SNECF); 2) to provide specialized educational programming to the nurses in the SNECF; 3) and to provide ongoing collaborative support and consultation service for the SNEC. The SNECF was designed and remodeled in existing space within the hospital to provide for constant observation of the children and central monitoring. A local home health agency provided equipment and medical supply needs. Medical coverage was provided by specialists from Children's Hospital (Chavez & Schwab, 1985).

The initial process began with assessments of financial capabilities, space availability, equipment needs, and nursing staff's abilities related to pediatric nursing care. The SNECF administration projected a cost savings to the state of over $900,000 compared to the hospitals charges for the children for the first year. The hospital provided consultation and educational services. Specialized nursing education for the SNEF staff was provided by the Education Department of Children's Hospital. The instruction included a multidisciplinary approach regarding the needs of the CSHCN and their families, psychosocial needs, and related pediatric assessment skills, treatment/procedures, and growth and development knowledge. A home health care company provided assistance with equipment and medical supply needs. The hospital medical staff was provided in coordination with the specialists (Chavez & Schwab, 1985).

The transfer process began with the child being placed on a portable ventilator while in the hospital environment. This provided time for the child to adjust to the equipment and increase mobility. Because the first four children, ages two to eight years old, to be transferred had resided in the hospital for two to five years, the family and professional attachments were strong. A planned multidisciplinary and interagency approach was used to ease the transition process. Each child had their own primary care nurse who coordinated the activities. Each child was transferred separately as planned for a smooth transition for the child, family and staff (Chavez & Schwab, 1985).

Difficulties associated with the transfer were resolved easily with room arrangements and staff assignments. Evaluation of the nurses' educational instruction indicated that the experience was beneficial and effective. The SNECF residents responded favorably to the addition of the children on the ward. Families expressed an overall positive attitude with the placement (Chavez & Schwab, 1985).

The children experienced fewer readmissions to the hospital and each child reached at least one new milestone. Each day was structured to accommodate normalization for each child. Some activities included infant stimulation, tutoring, time for homework, play and rest. Each child learned how to communicate their needs. When behaviors were inappropriate, disciplinary actions were taken. By increasing social interactions and mobility, each child was able to participate in a greater variety of activities, such as visiting a zoo. Families expressed an overall positive attitude with the placement and the care received. This model successfully demonstrated a cost-efficient, appropriate, home-like environment for CSHCN through collaboration with multiple stakeholders (Chavez & Schwab, 1985).

Some technology-dependent children cannot or should not live at home. For these CSHCN access to the full spectrum of medical services, equipment, monitoring, intensive nursing care, medical backup with emergency services are essential for life. Many hospitals developed “step-down” units with the capacity for intensive care with an emphasis on transition to a less intensive setting. Transitional care can be provided in a special hospital unit or a rehabilitation sub acute care facility when the CSHCN is stable. It includes an emphasis on family education and training and gradually increasing the care the family provides.

LeBonheur Children’s Medical Center developed the Transitional Care Unit (TCU) in 1991. The TCU was designed to prepare the family for the transition to home care, which included training and education on the prescribed home care regime. A study by Storgion and Stutts (2000) was conducted to assess the efficiency of the TCU. A convenience sample of 10 charts of ventilator-dependent children was selected for retrospective chart review. Data were collected on length of stay (LOS), daily cost, and nursing charges based on the hospital’s acuity scale for pre-TCU days and days while in TCU prior to discharge (Storgion & Stutts 2000).

Patients were referred to the TCU when medically stable, technology-dependent, up to 18 years of age with rehabilitation potential, and there were family educational needs for home bound/alternative living arrangements. The intervention included a multidisciplinary team approach to discharge planning. The team members included pediatric intenstivists, pediatric pulmonologist, primary care pediatrician, staff nurses, a social worker, a respiratory therapist, and a developmental /rehabilitation specialist. The patient and family were invited as team members throughout the process. This team met weekly to discuss the family needs (Storgion & Stutts 2000).

During the first month, parents and other caregivers were taught how to position, suction, hold, feed, and use the bag-ventilation. During the second month, parents were trained to perform other necessary therapies. As the parents' confidence increased, more difficult aspects of care were taught. In the home, the durable equipment representative determined adequacy of space and electrical needs, access to running water and a telephone. Any recommendations were completed prior to the child's discharge. At least 2 weeks prior to discharge, the child needed to use the equipment from home. The caregivers (family and alternate caregivers) were then required to "room-in" and provide all the care for 48 hours to ensure competency (Storgion & Stutts 2000).

Study findings included a 32-35% decrease in daily costs while in TCU versus ICU (intensive care unit). Nursing service charges decreased by 18% due to the increased nurse: patient ratio from 1:1-2 in ICU to 1:3-4 in TCU. Effective communication and collaboration were instrumental in meeting the discharge needs of the CSHCN and their family decreasing LOS from 13 months to six months for infants and three months for children. The TCU effectively used scarce hospital resources while saving health care service costs for the family and the institution (Storgion & Stutts 2000).

In summary, some medically fragile/technology-dependent children need access to the full spectrum of medical services, equipment, monitoring, intensive nursing care, medical backup with emergency services essential for life. In the 1970s and 1980s, legislative developments were created to protect the welfare of people with physical and mental disabilities. This was the beginning of deinstitutionalization and community-based integration for alternative residential care settings for adults and children with special needs.

Child Health and Functioning

Effects and outcomes of chronic conditions vary according to the age and stage of the child's development. Instruments used to capture the health and functioning of CSHCN include disease-specific measures, generic measures, or measures that assess multiple dimensions of quality of life, such as physical health, mental health, and functioning including social and school participation (Schmit, Garratt, & Fitzpatrick, 2001). Self-report or patient-reported outcomes measure the individual's perception of the effects of the chronic condition on the child's health and functioning. However, there are situations when the child is too young, too cognitively impaired, too ill or fatigued to fill out the questionnaires. Parent-proxy reported outcomes have been used in such cases. Although, this method may provide generally accurate information for the pediatric measures, there are areas where differences may occur. Agreement between parent and child are more likely to occur with observed physical and functional items compared with items which are more subjective, such as emotional or social items (Schmit et al., 2001). Parents may be influenced by their knowledge of other children and their expectations and hopes for their child (Marino, Tomlinson, Drotar, Claybon, Aguirre, Ittenbach, et al., 2009; Uzark, Jones, Slusher, Limbers, Burwinkle, & Varni, 2008; Waters, Davis, Nicolas, Wake, & Lo, 2007).

Marino and colleagues (2009) conducted a study to evaluate how heart disease affected the quality of life (QOL) of the pediatric cardiac patient from the perspective of the pediatric patient, parent, and health care providers. Out of 409 patients, 375 met eligibility and 126 participated: 25 children, 29 parents of children, 29 adolescents, 25 parents of adolescents, and 18 health care providers. This qualitative study used structured focus group techniques with children 8 to 12 years old with heart disease (HD), parents of children with HD, adolescents 13 to 18 years old with HD, parents of adolescents with HD, and health care providers of all pediatric cardiac patients. The participants were patients with either a congenital or acquired heart disease, eight to 18 years old, spoke English, and had at least one cardiac-related admission to the Children's Hospital of Philadelphia (CHOP) over the previous two year period. Exclusion criteria included patients with significant comorbidities or a significant developmental delay. A randomized selection of eligible patients was used to contact families. One family member was used in the patient-parent dyad. The health care providers were recruited from the pediatric cardiology center at CHOP (Marino et al., 2009).

The most common diagnoses were arrhythmias, conotrunical anomalies, single ventricle congenital heart disease, heart transplantation, and septal defects. These conditions accounted for 60% in the children and 64% in the adolescent groups. The average age of the children was 10.1 ± 13 years; 52% were female; 84% were White and 16% were Black. The average of the adolescents was 15.5 ± 1.5 years; 45% were female; 76% were White and 24% were Black. Average age of the parents was 42.5 ± 6.4 years; 72% were mothers and 28% were fathers. Eight physicians participated, 75% were male, 88% were White and 12% were Asian. Ten nurses participated, 90% were female, 80% were White and 10) Black and 10% Asian (Marino et al., 2009).

A total of 14 different focus groups participated according to age and role which included three groups each of children, adolescents, parents, and two groups of the health care providers. Each focus group had 6-10 participants and developed a list of items they perceived might affect the patient's quality of life. The participants then ranked the top five items which were tabulated following each focus group discussion. The items were categorized into pre-identified dimensions of physical functioning, psychological functioning, social functioning, school functioning, and other (Marino et al., 2009).

The physical limitation was the most common item identified across the groups of patients, parents, and providers affecting the patients' lives. The child group identified psychological items the least often compared with other groups (7.2% to 21.3%-37.8%). Both the children and parents of children selected items that negatively affected the child, such as receiving special treatment, altered physical appearance (scars), and medication burden. Some of the items identified by the children in the physical dimension were: I miss recess; I get tired of taking medicine; in the psychological dimension: I feel life is unfair; in the social dimension: I have a hard time making friends; I am teased a lot at school; my heart beats fast; other dimension: God has a special plan for me. The school items received the lowest percentage of votes in all the groups except the child group that selected items which negatively affected school and social functioning. However, the parents of children selected items that were more positive, such as the children were more compassionate (Marino et al., 2009).

Differences between the child and adolescent groups were seen in psychological issues (7.2% and 29.6%) and in school issues (11.2% and 2.1%) items. Some of the items identified by the adolescents in the physical dimension were: I am in pain; I take medicine that causes bad side effects; I can't play sports that I want to play; in the psychological dimension: I am embarrassed about my scar; I feel helpless; in the social dimension: I lost friends because I missed school and had to quit sports; I was held back in school-embarrassing; other dimension: I don't take life for granted. These may be age-related differences where the adolescent was more mature compared to the child. Adolescence is a precursor to adulthood and is filled with physical and psychological changes which lead to other stresses. The adolescent with HD may have been able to benefit from additional support systems to cope with or adjust to their limitations (Marino et al., 2009).

Parents and health care providers identified different items beyond the physical functioning. Health care providers selected the psychological items more frequently than patients or parents (28.8% compared to 7.2%-21.3%). Health care providers spend less time with the patients, often usually during stressful situations or periods of critical illness where psychological issues were manifested. Health care providers identified psychological items related to in-hospital management, such as separation anxiety while hospitalizes, fear of procedures/needles, and loss of control/privacy. While parents focused on social and physical issues, such as medication burden and feeling different than peers (Marino et al., 2009).

The results of this study demonstrate that the perceptions of health and functioning from the patient, the parent, and the health care professional may be different in pediatric cardiac conditions. Similar perceptions of health and functioning between patient and parent were found in physical dimension however, differences were found in the psychological dimension including school issues. In this sample, physical health issues were reported important to all the participants; mental health issues were important to the adolescents; and functioning issues (school) were important to the children.

Uzark and colleagues (2008) conducted a quantitative study to evaluate and compare parent-reported and child self-reported health related quality of life (HRQL) outcomes of children with cardiovascular disease (CVD) with a healthy population across age groups and to determine the relationship between the perceived HRQL and the severity of the CVD. A convenience sample of 500 children five to 18 years old with CVD and their parents were recruited from the pediatric cardiac clinic at Cincinnati Children's Hospital Medical Center. Out of 500 patients, 475 families met eligibility with 347 children (250 children able to self-report). Charts were reviewed to determine child eligibility which included age of the child, had a previous diagnosis of heart disease, at least more than 6 months post cardiac surgery (if needed), no major developmental delays, or an associated noncardiac condition that may be expected to affect HRQL (Uzark et al., 2008).

HRQL was measured using the PedsQL 4.0 Generic Core which has a large normative database of ethnically diverse healthy children and children with chronic conditions for comparisons (Varni, Burwinkle, Seid, & Skarr, 2003). The instrument was 23-item scale that encompasses both physical health (8 items) and psychosocial health and functioning (emotional, social, role) (15 items). The 5-point response scale is the same (0 = never a problem, to 4 = almost always a problem). The higher the scores indicate the better the HRQL or health and functioning (Varni, Limbers, Burwinkle, 2007). The PedsQL scores from the children were compared with the healthy children norms across the age groups (toddlers 2-4 years old, young children 5-7 years old, children 8-12 years old, and teenagers 13-18 years old) using independent sample *t* tests. Differences in means for PedsQL across the four categories of severity were determined using analysis of variance with Tukey Post-hoc tests. Agreement in parent-report and child self-report was determined through intraclass correlations (Uzark et al., 2008).

Severity of the CVD was rated by a clinician who was blinded to the study's outcomes. The CVD was categorized: 1) mild requiring no therapy or treated effectively with nonsurgical catheter therapy; 2) moderate requiring no therapy or corrected with surgery; 3) surgically treated with 1 or more procedures with significant residuals or need for additional surgery; 4) complex or severe CVD which is uncorrectable or palliated (includes single ventricle). This population included 78 (16.4%) in category one; 138 (29.1%) in category two; 130 (27.4%) in category three; and 129 (27.2%) in category four (Uzark et al., 2008).

The majority of parent-proxy respondents were mothers (83%). The average age of the children was 9.7 ± 4.8 years; including 120 toddlers, 73 young children, 142 children, 140 teenagers; 44.2% were female; 88% were White. 9.5% were Black, and 2.5% other. Most families were from the middle class; were high school graduates; 1/3 of the parents had college degrees. There were no differences between groups (parents and children with CVD) in age, disease severity, gender, race/ethnicity, or SES (Uzark et al., 2008).

By child self-report, the PedsQL scores for children with CVD were significantly lower than the healthy pediatric norms for physical health and psychological health and functioning across all age groups. Comparison of the mean scores showed the most differences from children with CVD and the healthy children norms related to school functioning scores (mean = 72.67 ± 18.15 in children with CVD and 81.57 ± 16.60 in healthy children, $p < .001$). Differences in physical health scores were significantly lower for children in the more severe (3 & 4) categories and cognitive functioning scores were significantly lower for children in the most severe category (4). Seventy-seven of the children had more than one surgical procedure and 32.8% were currently taking medications. The disease severity was significantly correlated with the number of daily medications (r = .47, $p < .01$). Children with CVD taking medications had significantly lower overall PedsQL scores (mean = 73.29 ± 14.88) than children with CVD who were not taking medications (80.21 ± 13.96, $p < .001$) (Uzark et al., 2008).

By parent-proxy report, the physical health in children with mild disease was significantly higher than an age-matched healthy group comparison. Parent-proxy report for psychological health and functioning scores was significantly different across the disease severity categories as the mean score decreased, the disease severity increased. Parents may be more aware of the severity of the disease process which influenced their perceptions than their children (Uzark et al., 2008).

The most frequently reported physical health issue identified by parents than patients was difficulty running or getting out of breath with exercise. Feeling angry was the most frequent emotional problem reported by both parents and patients. Twelve percent of the children reported worrying about what was going to happen to them. Seventeen percent of the children eight to 18 years old reported having difficulties talking to nonmedical people about their heart disease (Uzark et al., 2008).

By both parent-proxy and child self-report, the PedsQL overall scores were negatively correlated with the number of medications (r = .38 and r = .35, $p < .001$, respectively) regardless of disease severity. Differences were noted in the total percentage of children with significant impairment in the psychological dimension reported by parent-proxy (15.7%, including toddlers) and by child self-report for children eight years and older (21%). This may reflect the parent's perception of their child's vulnerability due to the condition (Uzark et al., 2008).

Overall, this study demonstrated children with CVD reported significantly lower health and functioning scores compared with healthy children. Although, the majority of the children perceived their health and functioning as good the data revealed that one in five children reported significant psychological impairments including those with mild or correct CVD. Child self-reported HRQL outcomes on physical health, mental health and functioning should be considered, parent-proxy report can be a valid alternative when the child cannot self-report. Focusing exclusively on either parent or child self-reports may result in the loss of valuable information. Parents may lower their expectations of their child, underestimate the child's physical capabilities, or overestimate the affect physical functioning their child has on the psychological functioning. Similar perceptions of health and functioning between patient-report and child self-report were found in the physical dimension, such as physical health and functioning. However, differences were found in the psychological dimensions, such as cognitive and emotional health (Uzark et al., 2008).

Waters, Davis, Nicolas, Wake, & Lo (2007) conducted a cross-sectional study on the effects of chronic childhood conditions on the child's quality of life using the Child Health Questionnaire completed by the parents of CSHCN. This Health of Young Victorians school based study recruited children and adolescents aged five to 18 years old (n = 5,414, response rate of 72%) from different school sectors and geographic locations of the state of Victoria, Australia. Demographic characteristics of the children included 49.9% females and average age of the children was 11.1 ± 3.5 years. The majority of parent-proxy were females 85.5% (n = 4,629), partnered 86.4% (n = 4,678), primary caregiver employed full time 31.4% (n = 1,699), and the primary caregiver was a high school graduate or more 72.6% (n = 3,926). The most commonly identified health conditions were asthma (20.6%), dental (17.9%), vision (10.19%), chronic allergies (11.35%), attention problems (9.45%), and behavior problems (8.8%). The number of children with one physical condition was 29.8%, with two physical conditions was 12.5%, and with three or more physical conditions was 6.2%. The number of children with one mental health condition was 10.5%, with two mental health conditions 5%, and with three or more mental health conditions 4.4%.

The participating parents completed the Child Health Questionnaire (CHQ) 50 item parent report. This questionnaire includes health domains that measure physical functioning, role/social-emotional/behavioral functioning, bodily pain, mental health, self-esteem, and general health of the child. Parental impact was measured by emotional functioning, time, family activities and family cohesion. All the questions were answered with best recall over the past four weeks. An additional list of 19 health and illness related conditions was included for parents to report whether their child had the condition or not. Multiple analysis of variance and post hoc tests were conducted. The results indicated there were significant differences in health and well-being across the comorbidities for physical conditions $F(39, 15156) = 23.77$, $p < .01$. Post hoc tests showed children with one physical health condition reported lower scores for the CHQ domains than children without any reported health condition. As the number of concurrent health conditions increased, the overall health and functioning scores decreased significantly for physical health domain by 14 points (-7.69 to -21.51) and for mental health domain by 28 points (-5.15 to -33.81) (Waters et al., 2007).

For children five to 12 years old, conditions such as sleep disturbance, chronic respiratory problems, chronic orthopedic problems, attention problems, depression, behavior, learning and anxiety problems were associated with lower scores on seven domains of the CHQ. For children 13 to 18 years, conditions such as chronic allergies, sleep disturbance, chronic rheumatic problems, behavior, learning and anxiety problems, and depression were associated with lower scores in seven or more domains. Data demonstrated relationship of the health condition on the child's overall health and functioning. Chronic orthopedic problems were associated with lower bodily pain scale scores; behavior problems were associated with lower behavior scale scores; depression was associated with lower mental health and self-esteem scale scores; diabetes was associated with lower general health scores, parents' emotions and time, and behavior problems, reduced family activities and family cohesion scores (Waters et al., 2007).

There were significant differences in health and functioning across the morbidity groups for physical and mental health conditions, *F*(39, 6,360) = 22.50, $p < .01$. As the number of physical health comorbidities increased, the scales measuring general health, bodily pain, the impact of parent time and family activities, decreased 20 points or more. As the mental health comorbidities increased, the scales measuring impact on social and emotional, behavior, self-esteem, impact on parent time and emotions, and family activities, decreased 20 points or more. This study showed the use of a multidimensional measure of health and functioning could report and quantify an increased burden on health and functioning that resulted from concurrent health conditions and the cumulative effects on the child and the family (Waters et al., 2007).

Level of Condition Severity

The level of condition severity may be measured in terms of functional status or activity limitations by the frequency or the degree the condition affected the child's ability to do the things done by other children of the same age (van Dyck et al., 2004). Functional status or activity limitation refers to an individual's inability, due to a chronic physical, mental, emotional, or behavioral condition, to participate fully in age-appropriate activities. Activity limitation is a broad measure of health and functioning affected by a variety of chronic health conditions. Age-appropriate activities for children ages 5–17 consist of a child's ability to complete regular school work and perform other activities, including self-care and walking (Stein et al., 1993).

According to the 2005-2006 NS-CSHCN Survey, parents' reported the functional status of their CSHCN: 57% had difficulty with any bodily function, such as eating, dressing, or bathing; 50% had difficulty with participation in any activity, such as walking or running; 42% had emotional or behavioral difficulties. Seventeen percent of CSHCN had all three types of limitations and 15% had none of the limitations; 27% had only bodily function difficulties; 9% had only activity limitations; and 3% had only emotional or behavioral limitations. Thirty-seven percent of CSHCN are never affected in their daily activities, 39% of CSHCN are moderately affected some of the time, and 24% of CSHCN are affected by their condition usually or a great deal of the time. This reflects the critical role of medical services, therapies, and prescription drugs in maintaining children’s ability to function normally. Of the children whose conditions affect them a great deal, nearly half require specialized therapies, 42% need mental health services, and 63% needed specialty medical care (HHS, 2007).

About half (52%) of the CSHCN missed 0-3 days of school in the previous 12-month period; 20% missed 4-6 days; 13% missed 7-10 days; and 14% missed 11 days or more due to the child’s condition. Children who missed 11 or more days had a condition with a greater impact on functioning: more than 25% had conditions that affected their daily activities almost always compared to 5% whose condition never affected their daily activities (HHS, 2007).

Level of condition severity can also be measured by the number and types of elevated need for services such as medical care/interventions, specialized therapies, and/or prescription medications. However, in a study by Porterfield & McBride (2007), data from the 2001 NS-CSHCN was used to determine associations between poverty and caregiver educational status on perceived needs and access to health care services from 38,866 CSHCN nationwide. The dependent variables were perceived need for and access to specialist physician services, therapy services, and prescription medications. The independent variables included the parent’s perception of health status which included the severity of CSHCN condition and whether or not the child was limited or prevented in any way to do the thing most children of same age can do.

The average age of the CSHCN in this sample was 9.9 years, with 18.4% from birth to five years; 54.1% from six to 13 years; and 26.6% from 14 to 17 years old. Health status was reported as very low (17%); low (37.9%); medium (31.7%); and high (13.4%). The most common need identified was prescription medications (87.9%);

followed by a specialty physician (51%); then therapy services (23.5%). More than 1/3 of the parents (37%) reported annual income below 200% poverty level and 43.5% of the mothers were high school graduates or less. Seventy percent of the CSHCN were insured during the previous year through a private insurer; 11% were uninsured for at least one month during the previous year (Porterfield & McBride, 2007).

Results showed lower-income, less-educated families were less likely than higher-income and more-educated families to say their CSHCN needed specialized services, such as prescription medications and specialty therapies. It is probable that lower-income and less-educated families do not recognize the need for these services or were not aware of the availability of the services. The two most common reasons for the parent of the CSHCN who did not access needed services were that the service cost too much or that there was a health plan problem. Private health plans and capitation practices may also be a barrier for lower-income families with the private insurer to access needed services. This may result in an underrepresentation of CSHCN living in families of lower-income levels and/or less-education (Porterfield & McBride, 2007).

In summary, effects of the condition on the child's health can be measured through the physical health, mental health, and functioning, or HRQL of the CSHCN through the perspective of the child, parent, or health care professional. The level of the condition severity may be measured in terms of functional status or activity limitations by the frequency or the degree the condition affected the child's ability to do the things done by other children of the same age. Several other proxy variables, such as the number and types of care, specialists, therapies, or the need for medications may indicate the level of condition severity or the frequency and degree that the condition affects the child.

However, neither the MCNB definition nor the CSHCN Screener addresses the issues of severity of the condition or the effects of the severity on the child or the family.

Family Health and Functioning

Families with medically fragile/technology dependent children are seldom able to plan for this situation. In many cases where the prognosis is uncertain, the degree of control over the situation is difficult for the family. The diversity among families, such as their composition, ethnic/racial heritage, age, education, relationships, economic stability, and commitment to the individual members, is linked to their children's well-being (AAP, 2003). Other factors influencing how families react under these circumstances include family stage, life history and experiences, maturity, available support systems, understanding about the condition, acceptance of the diagnosis and prognosis, and perceived control over the situation (Carnevale, Alexander, Davis, Rennick, Troini, 2006; Knafl, Breitmayer, Gallo, & Zoeller, 1996). Other sources of stress are the caregiver's own physical and psychological health (Brehaut et al., 2009), daily care management of the child's medical condition (Heaton et al., 2005; Jerrett, 1994; Youngblut et al., 1994), financial difficulties including income, employment, out-of-pocket expenses, and insurance coverage (Kuhlthau et al., 2005), unmet needs for the CSHCN and the family (Benedict, 2008), and concerns for their child's future (Reeves, Timmons, Dampier, 2006; Sullivan-Bolyai et al., 2003).

Family Health

It is not uncommon to find high levels of stress in the caregivers and other family members of CSHCNs which result in depression, fatigue, poor physical health, and social isolation. A recent quantitative study by Brehaut and colleagues (2009) used a Canadian population-based data set, National Longitudinal Survey of Children and Youth 1994-1995, to evaluate the health status of caregivers of children with health problems. Out of a total sample of children, ages birth to 11 years (n = 13,790), children with health problems (n = 2,495 or 26.5%) and healthy children (n = 3,633 or 38.6%) were randomly selected for a finale sample of 9,401 children and primary caregiver pairs.

The caregiver group status was determined by four key indicators used to identify children with health problems and the comparison group of healthy children. The four key indicators were functional problems, activity limitations, a diagnosis by a health professional of a chronic condition from a checklist, and elevated service use. Children with health problems were defined as those identified with at least two of the four key indicators. The comparison group of healthy children was identified as not having any key indicators. The Health Utility Index (HUI) was used to measure functional problems in eight domains: vision, hearing, speech, ambulation, dexterity, cognition, emotion, and pain. A summary score was derived based on population preferences: perfect health was represented by a score of 1.0 and 0.0 represented death. Negative scores represented a functional impairment that was considered worse than death according to the population values. Activity limitations were based on whether the child was limited at home, school, at play, or any other activity. Chronic conditions were reported by the caregiver included: asthma, allergies, bronchitis, cerebral palsy, epilepsy, heart conditions or diseases, mental handicap, or "other". Elevated service used was determined using four of the five CSHCN Screener questionnaire: 1) the need or use of prescription medications; 2) the need or use of more medical care, mental health, or educational services than generally used by children of same age; 3) special therapy, such as speech, physical, and occupational; and 4) treatments or counseling for emotional, behavioral, or developmental problems (Brehaut et al., 2009).

Out of the total sample of children, 52.7% were males; average age was 7.5 ± .02 years old; 37.4% had a chronic condition; 6.6% had an activity limitation; 10.8% had a functional limitation; and 43% had elevated health service use. The primary caregivers were mothers (90%); average age was 35.8 years old; majority was two-parent families (82%); educational level high school or more (65%); and was nonsmokers (67.8%). Families of children with health problems compared to families with healthy children were more likely single-parent families (22.5% versus 16.3%; $x^2 = 12.6$, $p < .001$); had younger caregivers (35.4 years versus 36.1 years; $\mathrm{t} = 2.7$, $\mathrm{p} < .007$); and were more likely to have a caregiver who was a daily smoker (32.5% versus 24.5%; $x^2 = 20.1$, $p < .001$). Caregivers of children with health problems compared to caregivers of healthy children were more likely to have a chronic condition (56.6% versus 34.5%; $x^2 = 110.8$, $p < .001$); and more likely to have an activity limitation (16.3% versus 7.3%; $x^2 = 50.7$, $p < .001$). Caregivers of children with health problems compared to caregivers of healthy children indicated more depressive symptoms (5.9 versus 4.2, range 0-36; $t = 6.3$, $p < .001$). Mean scores did not differ on measures of family functioning, social support, or marital satisfaction (Brehaut et al., 2009).

The study results suggested that the health of caregivers of children with health problems was significantly poorer than the health of caregivers of healthy children. However, family functioning and social supports were not different between the groups of caregivers in this sample (Brehaut et al., 2009).

Raina and colleagues (2005) completed a 2-step quantitative study that examined determinates of physical health and psychological health of adult caregivers of children with cerebral palsy (CP). The study population was available from a previous study on the development of the children with CP, Ontario Motor Growth (OMG) study. The OMG sample was recruited from 18 regional centers and one hospital-based therapy program in Ontario. Out of 657 children and their families still involved at the end of the OMG study, 632 were invited to participate in this study. Eligibility included having a child in the OMG study; being the primary caregiver who lives with the child; and resided in Ontario. The final total of 468 caregivers participated in this study.

The standardized self-completed questionnaires collected information on the caregiver, the child, and the family were used as well as a face to face structured interview with the caregiver in the home. Information was collected on the caregiver, the child, and the family; the child's ability for activities of daily living (ADL); the child's day-to-day health and behavior; caregiver's stress management strategies; caregiver's perceptions of formal care in the previous 12 months; and the caregiver's perception of his/her own general health and well-being. The home interview collected information about the caregiver's own physical and mental health, emotional well-being, mastery and self esteem; family functioning; informal assistance; job conflicts, and family income (Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, et al., 2005).

The average age of the children was 10.6 ± 2.7 years; 56% were males. According to the Gross Motor Function Classification System (GMFCS), which measures the child's disability, 28% of the children walked without assistance, 11% walked without assistive devices, 19% walked with assistive mobility devices, 21% were nonambulatory, self-mobile with limitations, and 20% were severely limited. The majority of caregivers were females 94.4%. The average age of the caregiver was 40.3 ± 6.7 years; 81% were married or partnered; almost 70% had high school education or more; 24.3% had family income less than $29,999 and 40% had family income more than $60,000; 44.4% of the primary caregivers worked more than 30 hours per week, 21.4% worked less than 30 hours per week, and 34.1% did not work for pay. The caregiver's main activity included 58.1% caring for family and working for pay; 37% caring for family; 1.1% working for pay (Raina et al., 2005).

The results indicated that child behavior, family functioning, and caregiver demands influenced the physical health ($R^2 = 0.50$) and psychological health ($R^2 = 0.50$) of the caregivers. An increase in reported child behavior problems was associated with a decrease in both physical ($B_4 = -0.18$) and psychological ($B_3 = -0.22$) health of the caregiver. Higher reported family functioning was associated with improvements in both physical ($B_{16} = 0.33$) and psychological ($B_{15} = 0.33$) health of the caregiver. Decreased caregiving demands were associated with an increase in physical ($B_7 = 0.23$) and psychological ($B_6 = 0.12$) health of the caregiver (Raina et al., 2005).

In this sample of caregivers of children with CP, the health and functioning of the caregivers were influenced by the child's behavior and the demands on the caregiver. However, family functioning played an influential role in the health and functioning of these caregivers of children with CP.

A study by Inkelas and colleagues (2007) used data from the NS-CSHCN 2000-2001 to examine the rates and predictors of unmet mental health needs of the CSHCN and their families. In this secondary analysis, the definition of need was parent report that the child “needed mental health care or counseling at any time in the past 12 months.” A child was considered to have a chronic emotional, behavioral, or developmental problem (EBDP) if the parent answered positively to this item. Social demographics included age, gender, race/ethnicity, family income; mother’s educational level; and insurance status. Family care burden measures included: more than one CSHCN in the household; family members reducing work hours or needing additional income to care for the child; family members spending more than one hour per week arranging the child’s care.

The characteristics of the sample weighted to CSHCN nationally included: the majority were younger, males, and White non-Hispanic. Family incomes included: 45% above 300% poverty level and 37% were 199% to below 100% poverty level. Mother’s education level included: 45% with a high school diploma or less and 56% with some college or more. The child’s medical coverage included: 72% in a private health plan, 22% public insurance, and 5% were uninsured. Family burden included: 33% of the families cared for more than one CSHCN; 65% of family members had to reduce work hours or needed additional income to care for the child’s medical expenses; and 48% of the family members spent more than one hour per week to arrange care for the child. The CSHCN health conditions included; 29% with EBDP; 39% with more functional limitations; 37% with frequently changing health status (Inkelas et al. 2007).

About 25% of the parents reported their CSHCN needed mental health services. This study found that the rates of unmet needs were higher for CSHCN with a chronic EBDP need (67%) compared to CSHCN with a mental health need but not a chronic EBDP (9%). Among CSHCN with a chronic EBDP, African American children had greater odds of unmet needs; CSHCN of Spanish language families had greater odds of unmet needs compared to the other CSHCN. Parents of more than 1/3 of the CSHCN with EBDP and parents of 5% of the CSHCN without EBDP reported mental health needs among family members due to the child's special needs (Inkelas et al., 2007).

A quantitative study conducted by Hatzmann and colleagues (2008), examined the HRQL of parents of chronically ill children compared to parents of healthy children. The study sample of parents with chronically ill children was recruited from Emma Children's Hospital and through parent organizations in Amsterdam, Netherlands. A total of 533 parents of chronically ill children and 425 parents of healthy children participated. Parents of the chronically ill children were eligible if their chronically ill children were between the ages of one to 19 years, diagnosed more than 1 year prior to study, the condition lasted longer than three months, or had at least three disease episodes during the past year, and lived at home. The comparison group of parents of healthy children was recruited from two elementary schools and one high school located near the hospital. Parents in the comparison group were eligible if their children were not chronically ill, aged between one to 19 years old, and lived at home.

A self-report questionnaire to measure the caregiver's health and functioning was the TNO-AZL Questionnaire which consists of 45 questions divided into 12 domains: gross motor functioning, fine motor functioning, pain, sleeping, cognitive functioning, social functioning, daily activities, sexual activity, vitality, happiness, depressive moods, and aggressiveness. Each item assessed the prevalence of a health problem or a limitation in the past month and emotional response to that health problem or limitation. A single score is attributed to each combination. Scores of each subscale are normalized to a scale ranging from 0 to 100, with higher scores indicating better health and functioning (Hatzmann, Maurice-Stam, Heymanus & Grootenhuis, 2008).

The health and functioning of the parents of chronically ill children was compared to the health and functioning of the parents of healthy children by univariate analysis of variance for each scale and for each disease group with age and educational level as covariates. The authors created a further distinction between parents "at risk" and parents "not at risk" for impaired health and functioning based on the percentile norms of the healthy comparison group. Parents in the comparison group who scored below the 25th percentile were placed in the quarter the most impaired parents. Binomial tests were used to compare the percentage of parents of chronically ill children scoring below the value of the 25th percentile of the parents of healthy children ($p < .008$, alpha .05) (Hatzmann et al., 2008).

Overall, the groups had similar demographics, except for educational level, with a larger percentage of higher educated parents in the comparison group ($p < .1$). The majority of the respondents were mothers; 88% were partnered; average age 42.1 years; average number of children in the family was 2.25 children; average time since diagnosis was 8.2 years; average age of children 9.6 years. Out of 533 chronically ill children, 16% had asthma; 7% had brain tumors, 5% had diabetes, 11% had Duchene Muscular Dystrophy, 19% had Down Syndrome, 3% had end stage renal disease, 22% had a metabolic disease, 2% had profound complex handicaps, 11% had Sickle Cell Disease, and 4% had spina bifida (Hatzmann et al., 2008).

Parents of the chronically ill children had significantly lower physical health, mental health, and functioning, particularly with sleep, social functioning, daily activities, vitality, positive emotions and depressive emotions. Overall, 45% of the parents were at risk for health and functioning impairment (Hatzmann et al., 2008).

In summary caregivers of children with medical problems were more likely to report poorer health conditions, physical limitations, and more depressive symptoms than caregivers of healthy children. However, there are some protective factors, such as family functioning and social supports that may influence the caregivers' health and functioning.

Family Functioning

The concept of family health and functioning includes the conditions where the family's needs are met, and members enjoy their life together as a family, and have a chance to do things that are important to them (O'Brien, 2001; Park, et al., 2003).

In a phenomenological study, Jerrett (1994) investigated the lived experiences of parents involved in the day-to-day caring for children with juvenile arthritis. Nineteen parents from 10 two-parent families participated with both parents being interviewed separately. One father declined to be interviewed. The initial interview was open to allow the parents to tell stories about their learning experiences. Themes that evolved included the initial response-turmoil and confusion; struggling to know; a different way of knowing; and taking charge. The diagnosis of a chronic condition altered the parents' perceptions of their role in the child's life. All the parents had difficulty dealing with the new role of providing time consuming painful exercises, distasteful medications, splints and frequent office visits. Most felt overwhelmed and isolated. As the parents became involved in the management of the child's illness through day-to-day care, they learned to manage time while they became more competent in the care. They became "expert" in the care of their children and started taking charge. The findings showed the patterns of how the parents learn through the events and activities involved in the daily care of their CSHCN (Jerrett, 1994). This study acknowledges the contributions the family made toward the health and functioning of CSHCN by caring for them at home.

Youngblut and colleagues (1994) described day-to-day caregiving experiences of families with medically fragile children in this mixed methods study. A convenient sample of 10 families with medically fragile children was chosen by the medical director of the pediatric rehabilitation hospital within 6 months after discharge. Family members responded to open-ended questions and two structured questionnaires. The interview questions asked the family to identify decisions and problems regarding the day-to-day care of their medically fragile child and who or what support did they seek for help. The structured surveys included the Family Strengths Survey which measured family strengths and the Family Crisis-Oriented Personal Evaluation Scale (F-COPES) which identified coping strategies used.

The caregivers included three single-mothers, three mother-father dyads, one grandparent dyad, one grandmother and father, a grand aunt-uncle dyad, and one legal guardian-spouse dyad. The total number in each household ranged from two to seven people with an average of 4.8 ± 1.87 people. The children included equal number of girls and boys with an average age of 5.3 ± 5.5 years. Five of the children had neurologic conditions, including cerebral palsy, closed head trauma, paralysis, and seizure disorder; four children had respiratory conditions, including bronchopulmonary dysplasia and asthma; one child had chronic renal failure. Seven of the children used wheelchairs; four used crutches, braces, or a walker; one child was oxygen dependent; three needed respiratory treatments and cardiopulmonary monitoring; two needed hearing aids or glasses; one child needed a feeding pump; and one child needed a dialysis machine. Seven of the children required daily medication administration ranging from one to five drugs per day with an average 3.7 (SD = 1.11). Some medications included bronchodilators, anticonvulsants, and antibiotics or antifungal drugs (Youngblut et al., 1994).

The results of the Family Strengths Survey identified a moderate amount of measured strengths which included trusting each other, shared values and beliefs, family loyalty and pride, and the belief that things will work out well despite worrying about them. The results of the F-COPES showed a moderately high use of coping strategies. The coping strategies used the most included sharing difficulties with other relatives, asking for information from the family physician, seeking professional counseling and help, accepting gifts and favors from neighbors, and having faith in God (Youngblut et al., 1994).

Many families reported frequent use of health care services. These services included physicians, specialty therapists, caseworkers, and educational services. Many families reported using both informal (family, friends, and neighbors) and formal (paid health care professionals) as sources of support. However, families in this sample frequently reported needs for additional financial resources and alternative child care for both respite and daycare services. Many caregivers asked family and friends for solutions to problems like toilet training, sleep/wake patterns, nutrition, and discipline. However, caregivers consulted with health care professionals when making decision concerning medical needs of their children (Youngblut et al., 1994).

Knafl and colleagues (1996) conducted a qualitative study that identified different types of family responses to childhood chronic illness called Family Management Styles. A purposive sample was recruited from one central Illinois and two Chicago health centers. Participants included 63 families with school-aged children seven to 14 years old with chronic conditions. The childhood chronic conditions were defined as having a duration lasting longer than three months, being stable or having a progressive illness course, having an active ongoing treatment management, and despite the condition the children had a normal lifespan. Eligible families included two adult members and all needed to speak English. Exclusion criteria included the child with the chronic condition had no other major physical or psychological impairments (Knafl et al., 1996).

Out of the 63 families, 210 members participated including 66 children with a chronic condition (three families had two ill children), 62 mothers, 53 fathers, one adult other, and 28 healthy siblings. There were equal numbers of female and male ill children; the majority was younger than 14 years; the majority was White, 10 were African American, and two were Asian. The childhood chronic conditions includes 36 children with diabetes, seven with asthma, seven with renal conditions, six with juvenile rheumatoid arthritis, and nine with other types of condition (Knafl et al., 1996).

Data were collected longitudinally from several family members including the child with the chronic condition, parents, and healthy siblings of school age using open-ended interview guides 12 months apart. Separate interview guides were used with the parents, siblings, the ill children for the first and second interview sessions. The questions asked how the individual defined their situation, what management behaviors they engaged in, and what factors, such as the healthcare system and the school system influenced their responses to the illness situation. Five Family Management Styles were identified as Thriving, Accommodating, Enduring, Struggling, and Floundering. The five family management styles reflected three dimensions of the chronic illness experiences defined by the families. These dimensions were the illness experience, management goals and approaches, and the perceived consequences of the illness (Knafl et al., 1996).

This study identified different types of family responses to childhood chronic illness as the beginning framework for Family Management Styles. Family health and functioning affect their ability to care for the CSHCN whose conditions are chronic and most are incurable. Family functioning influences how well the CSHCN adjusts to the illness as evidenced by the child's health and functioning. Better family functioning is related to support systems, available resources, and fewer stressors.

A mixed methods study by Knafl and Zoeller (2000) compared the views of mothers' and fathers' within the same family about their experiences caring for a chronically ill child and its impact on family life. This was part of a larger study on family responses to childhood chronic conditions. Families with chronically ill children seven to 14 years old were selected using purposive sampling techniques. A total sample of 43 couples and seven mothers whose husbands did not participate was used in this study. Qualitative data were collected through open-ended questions on how they defined the illness, how they managed the illness, and how the illness affected the family. All interviews were conducted individually. Quantitative data on the parents' perceptions of the effects of the child's illness on the family and functioning was measured by the Feetham Family Functioning Survey (FFFS) and the Profile of Mood States (POMS) survey. The FFFS is a 25-item measure that reflects the difference between parents' views of actual and ideal family functioning. The POMS is a 65-item survey that measures psychological functioning.

The sample included equal numbers of female and male children with diabetes, asthma, or juvenile arthritis; the majority was younger than 14 years; the majority was White, 10 were African American, and two were Asian. The families represented a wide range of socioeconomic status and educational levels (Knafl & Zoeller, 2000).

The results from the qualitative interviews and quantitative surveys showed parents in the same family typically had similar or shared views on the major aspects of the child's condition. Overall levels of mother-father agreement ranged from 60% to 100%. Parents agreed the least, 60%, in regards to their ability to manage the treatment regime for the child effectively. One reason may be that seven fathers and one mother considered themselves as observers of the care and not responsible for the care. However, the mothers were primarily responsible for the care. Mothers were more likely to view their child as not normal, lack confidence in their ability to care for the child, feel that the illness was the focus of the family, and feel that this experience had made them a different person (Knafl & Zoeller, 2000).

According to the FFFS, parents had similar levels of satisfaction with their overall family functioning, as well as their parenting. Mothers had higher scores on the POMS which may reflect the emotional costs of caregiving. In general, the couples' scores on the POMS were more similar than different. The results from the seven mothers whose husbands did not participate in the study were also reviewed. These mothers had a more negative view of the illness experience than mothers whose husbands participated in the study. The FFFS scores were higher suggesting a greater dissatisfaction with family life.

In this study, very few couples reported a negative view as a shared experience. Perhaps the fathers who did not participate in the study were having more difficulties adjusting to the illness experience (Knafl & Zoeller, 2000).

O'Brien (2001) examined the long-term home care for a technology-dependent child from the families' point of view through qualitative interview in the home. A purposive sample was recruited from health care agencies, social service agencies, and parent support groups. Inclusion criteria included children aged 3-12 years old who were technology-dependent according to the Office of Technology Assessment (1987). The sample collection continued until data saturation occurred and no new data were being obtained.

Out of 15 participating families, 11 mothers and four two-parent couples were interviewed. Seventy-three percent of the families consisted of the two biological parents and the number of other children in the house ranged from one to five with an average of 3.37 siblings. All of the parents were White and only one technology-dependent child was Black. The average age of the parents was 36.9 years with a range of 26 to 52 years. All the parents graduated from high school with 57% having a college degree. Eleven out of the 15 mothers were employed outside of the home with 4 mothers employed full time. Twelve of the 13 fathers were employed full time with one unemployed. All the families received Medicaid health benefits for their technology-dependent child, with 80% receiving additional financial resources from private or other state founded programs for the disabled. Twelve or 80% of the families received home health care services from three to 18 hours a day (O'Brien, 2001).

The sample of children included 10 boys and six girls with varied diagnoses from complications of prematurity, congenital anomalies, sequelae from acquired diseases, and trauma. The children were technology dependent and cared for at home from two to nine years with an average of 5.84 years. All the children attended school outside the home at least part of the day except for two. The technology-dependence included 13% dependent on ventilators, 13% receiving prolonged intravenous nutritional support, and 75% needing other technologies, such as tracheostomy, frequent suctioning, oxygen support, or gastrostomy feedings. Over half were dependent on more than one technology (O'Brien, 2001).

The interview question asked the family what it meant to have a technology-dependent child, how did they manage daily life and how did they adapt. Each family had unique experiences, however commonalities were found. Families reported struggling to find a reason why this happened. They had adapted fairly well using positive attitudes and remaining vigilant. However, seeing their child being happy, being pain free and achieving of the best possible health and functioning enabled them to find and use their talents and strengths. They became more knowledgeable over time, acquiring the technological skills, organizational skills, and creativity needed to care for the technology-dependent child. The families in this study felt they had a choice about how to deal with life despite the constraints associated with the need for medical technology to sustain their child's life (O'Brien, 2001).

The qualitative study by Heaton and colleagues (2005) examined the organization and consequences of home care regimes for technology-dependent children and their families. Purposive sampling strategy was used to provide a diverse group which included a minimum of six single parent families, six ethnic minority families, 12 technology-dependent children aged from birth to 18 years living at home, and 12 siblings to be interviewed. Families were recruited from hospitals, hospice, a previous study, and Family Fund based in Northern England. Semistructured interviews lasted between one to two hours. Interviews with the technology-dependent children and siblings were facilitated by the use of time-line drawings that described ‘good’ and ‘bad’ days in a 24-hour chart.

A total of 36 families participated with 75 family members, including 13 technology-dependent children with eight boys and five girls, average age of 10.1 years range of frou to 19 years. Families consisted of 34 mothers and 12 fathers and one grandparent, average 37.3 years with a range of 22 to 52 years; 15 siblings, eight brothers and seven sisters, average age 14.3 years with a range of two to 22 years. None of the single parents were employed; 22% of the mothers were employed and 70% of the fathers were employed. All of the families received a type of disability living allowance and several received additional income support and housing benefits. Only 20 families owned their own homes, while the remainder rented (Heaton et al., 2005).

The children had a variety of diagnoses including one or more of the following: 24% neuro-disability, 24% respiratory, 21% renal disorder, 13% neuro-degenerative disease, 13% gastrointestinal disorder and 24% other conditions. There were variations in the number and types of technologies including 55% of the children needed artificial nutrition, 26% needed tracheostomy care with suctioning of the airway, 21% needed renal dialysis, 16% needed assisted ventilation, and 11% needed oxygen therapy. Eleven children used one device; nine used two devices; and five used five or more medical devices (Heaton et al., 2005).

The qualitative findings were separated into three themes: 1) “rhythms and routines” described the care related to the various medical devices; 2) “time demands of technical care” related to associated care routines and the respective roles of the parents and health care service providers performing any technical care during the day/night at home care or other settings; 3) “effects of care regimes on the technology-dependent children, siblings, and parents” described the extent they were able to participate in education, employment, and social life in general (Heaton et al., 2005).

Daily family routines were arranged around the patterns of use of different types of technology; for example, the continuous use 24 hours a day, of a ventilator; regular intermittent use at set times during the day or night, such as peritoneal dialysis 9-10 hours a night for six or seven nights a week or enteral feeding pumps used at regular intervals throughout the day and night; or on a more irregular pattern, or as needed basis, such as suction machines or in an emergency oxygen therapy. Although these technical processes were programmed around the child’s needs, they reflected the family’s needs as well. For instance, peritoneal dialysis can be programmed to start at a time that allows the child to prepare for school in the morning at its completion. Alternately, the families’ schedules were adapted around the technical routines. When the equipment was not in use, extended family or babysitters employed for the short time. However, if the technology use was more irregular or unpredictable, the family found it difficult to commit to any regular activities, such as paid work, or to plan ahead for holidays (Heaton et al., 2005).

Although many of the children in this study had home health care services, the family was responsible in the absence of the nurse. In this sample, eight out of twelve families had allocated help at night: one family never received the nurse; one family had overnight nurses for only two nights a week and one on the weekends, which allowed the family to get some needed sleep every other night. The other families had allotted hours ranging from one hour to eight hours per day, however the latter was never provided or difficult to use. Families were reluctant to book the service well in advance for special nights out since they did not know if the child would be well enough to leave with another caregiver, or if they would be feeling too tired to go out after having a bad night (Heaton et al., 2005).

Kirk, Glendinning & Callery (2005) conducted a qualitative study using grounded theory techniques to discover how families experience caring for a technology-dependent child. Families were purposively recruited from three children's hospitals in England. The sample of children included a diversity of medical technologies, length of time that the child was cared for at home, and the type of support received at home. The participants included 23 mothers and 10 fathers. Nine children were from two-parent families, five from single-parent families (four female-headed and one male-headed).

The characteristics of the children (n = 24) in this study included 11 females and 13 males; 13 children were under age five years, six were 5-11 years old, and five were 12-18 years old; type and number with technological dependence included: tracheostomy 10, oxygen therapy eight, mechanical ventilation six, intravenous drugs four, parental nutrition two, peritoneal dialysis two, and gastrostomy and others 13. One child had six different technological dependencies; two children had 15; two children had received home care for 10 or more years, two children had home care for 4-9 years, 11 children had home care for 1-3 years, and eight children had home care less than one year (Kirk, Glendinning & Callery, 2005).

Findings described the parents' accounts of their homes being transformed into "mini-hospitals." The nature of the care parents were providing involved the usual aspects of parenting as well as a wide range of clinical procedures. The tasks, such as administering medications or oxygen therapy, changing tracheostomy tubes, suctioning airways, passing nasogastric tubes or foley catheters, administering intravenous infusions, and giving injections were traditionally completed by nurses. Parents described performing these procedures as being the most distressing part of caregiving. They had to cope with their own feelings of distress as well as their child's reactions. The parents contrasted their feelings of distress with what they assumed to be routine experiences of the nurses. They wanted to see themselves as parents not as nurses (Kirk et al., 2005).

All parents experienced the intrusion of medical equipment and supplies as well as the professional assigned to the child's care. The families felt that the lack of privacy opened their lives for public inspection and judgment. Parents described their expertise from two types of knowledge: the knowledge associated with the formal instruction provided by the hospital professionals; and their experience knowledge from caring for their child. Parents described how their experiences, combined with their medical knowledge, allowed them to personalize the care to meet the needs of their child. However, they knew there was a potential conflict with the professionals over "appropriate" care of the child (Kirk et al., 2005). Parents must manage a role that is both parent and nurse which alters their meaning of parenting.

A qualitative study conducted by Carnevale and colleagues (2006) detailed the family experiences with caring for a ventilator-assisted child at home. Participants were recruited through the Quebec Program for Home Ventilatory Assistance located in the Montreal Chest Institute, McGill University Health Center. Eligible families were caring for a child at home with assisted ventilation for at least two years and were able to speak English or French. Out of 15 families, 12 families participated including 11 mothers, six fathers, and eight siblings. Data were gathered through semistructured interviews with the whole family and three families consented to an additional two hour observational interview. The questions included describing their experiences with the child and the equipment needed for breathing; situations when the family made decisions and whether they felt 'right or wrong' (Carnevale et al., 2006).

The findings showed every aspect of their lives was complicated and overwhelming adding to the psychological costs incurred by these families. Parents devoted an extraordinary amount of care and attention to their child's needs. They struggled significantly with emotional strain, physical and psychological dependency of the child on them, impact on each family member and family relationships, and living with the daily threat of death. Parents devoted efforts toward a stable family and home life, creating common routines. Sometimes their striving for stability was limited by financial constraints, family cohesion and the unpredictability of the child's condition. Families felt that the reactions from the community, including healthcare professionals, devalued their child's life, referred to as a life not worth maintaining. Families felt unsupported by the medical system as well as extended families and friends in light of the extreme medical needs of their child. Some parents questioned having these children permanently institutionalized or ‘disconnected from the ventilator’ (and life) would eliminate all the tensions and stress. However, those options were not something these families even considered. It was not a choice (Carnevale et al., 2006).

Reeves, Timmons, & Dampier (2006) explored what parents experienced when negotiating care of their technology-dependent child while in the hospital. In this qualitative study, six parents were interviewed at their convenience in their home using a formulated interview guide. Four themes emerged from the data: 1) living with technology; 2) expert parents; 3) power and control; and 4) negotiation of care. Parents described “living with technology” as the combined roles of performing nursing care and being a parent. Technology was stripping away their role as a parent. As “expert parents”, they became skilled in the tasks of caring for their child. They knew their child best- what worked, what didn’t. Parents with technology dependent children are in control of the care in the home. However, while in the hospital, they must relinquish control to the nurses. This describes the “power and control” theme. “Negotiation of care” is the process each nurse and parent go through when discussing the plan of care for the child. Reeves and colleagues highlight the need for nurses in the hospital to practice family-centered care and negotiation when discussing the child’s care with the parent. To carry this out, parental support, both physical and emotional, from the nurses as well as community support was an important component for optimal health outcomes for the CSHCN and their family after hospital discharge (Reeves et al., 2006).

A qualitative study conducted by Branstetter and colleagues (2008) identified communication themes in families of children with chronic conditions. A convenience sample of 30 parent-well sibling dyads was obtained from a larger randomized clinical trial, The Sibling Project (N = 225). Data were collected after participating in the randomized clinical trial (RCT) educational and experiential sibling camp intervention. Parents and well siblings were recruited from clinics and community agencies serving five diagnostic groups for pediatric chronic conditions: cancer, cystic fibrosis, diabetes, spina bifida, and developmental disabilities. Structured, face-to-face interviews were conducted separately and qualitative analysis was completed through a reflexive and iterative process.

Four themes emerged: 1) “family relationships and roles” concerning the effect of the chronic condition on the family, shifting roles and responsibilities between parent and well sibling, coping patterns manifested by the internal stress related to the chronic illness; 2) “giving voice” concerned family communication, such as parents anticipating and responding to the needs of the well sibling, and the well sibling being able to express their emotional and informational needs; 3) “staying connected” despite busy schedules as the family remained available for communicating with each other, being able to communicate, spending time together, and seizing the moments for communicating together; 4) “struggling for normalcy” problem-solving processes for family understanding within the context of the chronic condition, regrouping and using creative strategies from all family members. Communication was described as fragmented, distressed, insufficient, and dysfunctional. Some siblings reported difficulty in voicing questions, concerns, fears, and needs about the chronic illness (Branstetter, Domian, Williams, Graff, & Piamjariyakul, 2008).

Research indicates families with medically fragile/technology dependent children experience a range of emotions. The parenting role can become confusing due to the additional necessary nursing role parents perform when they do treatments or procedures to their CSHCN. The very nature of their 'home' is altered by the intrusion of the medical equipment, supplies, and professional personnel the CSHCN require. Families incorporated medically fragile/technology dependent child's "special care needs" into the normal routines of work, school, housekeeping, child care, and transportation. Each family responds differently to the CSHCN according to their Family Management Style. Many families reported using both informal (family, friends, and neighbors) and formal (paid health care professionals) as sources of support. However, all families want what is best for their CSHCN, but have different approaches.

Cost of Care Burden

Children with special needs increase time and caregiving demands on the family. Time requirements may be irregular and unpredictable, which may reduce the likelihood of parental employment (Okumura, Van Cleave, Gnanasekaran, & Houtrow, 2009). However, the likelihood of employment may be higher due to the greater need for health insurance which may be accessed through their employer.

Kuhlthau and colleagues (2005), used data from the NS-CSHCN 2000-2001 to determine the financial burden experienced by families with CSHCN. A total of 38, 886 CSHCN were identified and 61% completed the interview process in this study. Family finance-related burden was measured by 1) whether the child's condition has created a financial problem; 2) the need for additional income to pay for the child's medical expenses; 3) whether the family members had to cut hours of work to care for the child; 4)whether a family members have stopped work due to the child's health.

The percentage of families reporting finance-related problems included 18% with children with the least severe conditions compared to 72% with children with the most severe conditions. Half of the families with CSHCN aged birth to five years reported financial problems; 40% for ages six to 12 years; and 38% for ages 13 to 18 years old. Half of the families who were multiracial, 45% African American families and 39% White only with CSHCN reported financial problems. More than 1/3 of the families with a mother with a college degree and 28% of the families living at or above the 400% poverty level reported at least one finance-related problem. Results showed financial problems related to caring for their CSHCN were noted in over 20% of the families; 18% needed additional income; over 25% had to cut back hours from their employment and 13% stopped being employed (Kuhlthau et al., 2005).

Regardless of race/ethnicity, socio-economic status, insurance status, child's age or health status, a considerable percentage of the families experienced finance-related family problems. This study shows that even families with high incomes experience finance-related problems. The finance-related problems included increased out-of-pocket expenses for the medical needs of the child, and reduced parental employment, inadequate insurance coverage (Kuhlthau et al., 2005).

Chevarley (2006) presented a profile of medical care use and expenditures for CSHCN using data from the 2000 Medical Expenditure Panel Survey (MEPS). This was the first national data set collected on health care use, expenditures, sources of payment, and insurance coverage for the non-institutionalized population. This survey uses an overlapping design in which data were collected over a 2 ½ year period by a series of five interviews. The overall response rate for the survey was 65.8%. A total of 6,965 children under the age 18 years were included in the survey, with 16% (n = 949) identified as CSHCN. A knowledgeable adult, usually a parent, provided information by phone or in person. No statistically significant differences were found by region, metropolitan area, or by family income (Chevarley, 2006).

Out-of-pocket expenses were used as an indicator of the family financial burden resulting from the medical care their child needed. The average out-of-pocket expense for CSHCN was $409 and the average for children without special needs was $251. The share of total expenses paid by the family with CSHCN compared to the family without children with special needs was 17% vs. 28%. The difference here may reflect CSHCN having an the increased number of inpatient hospital days and using more home health services usually covered by insurance compared to healthy children. Among CSHCN, children living in poor or near poor families and those living in low-income families were more likely to have their family spend more of their total income on medical expenses than CSHCN living in high-income families (15% of poor or near poor CSHCN and 14% of low-income CSHCN vs. 6% CSHCN high-income families). The presence of insurance coverage was associated with a lower proportion of income paying for out-of-pocket expenses. However, low-income families were underinsured relative to the high-income families with respect to the available financial coverage insurance provides against the financial burden (Chevarley, 2006).

Burton & Phipps (2009) conducted a secondary analysis from 2001 Participation and Activity Limitation Survey (PALS) on family economic costs associated with the disability level of the child's condition severity in Canada. Out of 4,561sample, 3,183 children were identified for this study. Eligibility included children five to 14 years of age with disabilities described as difficulties with activities of daily living or who have a physical, mental, or health problem that reduces the kind and amount of activities they can do. Study variables included both explicit and implicit economic costs that take the form of missed opportunities. Explicit costs were expenditures associated the child's disability which included costs for medication, services, or specialized equipment not covered or not fully covered by insurance, and any other non-medical expenditure such as transportation to and from appointments or therapy sessions. Implicit costs, or opportunity costs of caregiving which includes giving up a paid job, working fewer hours, and not getting promoted.

The majority of parent/guardian respondents 62.7% were fathers; 19.3% from single-parent households; 16.7% were an ethnic minority; and 18.5% lived in a rural region. In the sample of children, the average age was 9.8 years; 62.7% were males; and 68.3% had a chronic condition. Chronic conditions included heart conditions, kidney conditions, cancer, epilepsy, cerebral palsy, spina bifida, cystic fibrosis and muscular dystrophy. The most frequently reported problems were learning disabilities 65.6%; problems with speech 44.7%; psychological and developmental problems 33.6% and 30.3% respectively. Level of condition severity was based on the PALS point index based on the intensity and frequency of activity limitations. About half of the children were diagnosed with the chronic condition before age three years. The percentage of children in this sample with mild disabilities was 28.4%; moderate level 25.7%; severe 27.6%; and very severe 18.3%. Children with early onset before 3 years old were more likely to have very severe condition (27.4% versus 9.3%) and were more likely to have multiple conditions (46.4% versus 29.2%) compared to children with later onset of condition (Burton & Phipps, 2009).

The majority of parents of children with chronic conditions (62.2%) reported out-of-pocket (OOP) expenditures associated with their child's condition. The average annual total OOP paid was $1,159; help at home $1,248; health services $1,005; specialized equipment and aids $890; medication $486; and transportation $433. However, the most common type of expense was medication 36.5% and transportation 32%. This is a result that the distribution of expenditures is not normal. Many families have small OOP expenses while a few spend a great deal more than the mean. For example, a very small number of parents pay more than $5,000 annually for OOP. Of those parents, 4.8% pay for help at home; 3.1% pay for specialized equipment and aids for their children with disabilities (Burton & Phipps, 2009).

Children with very severe conditions had higher expenditures for help at home, health services, and transportation compared to children with mild disabilities. However, expenditures that did not increase as the condition severity increased were medications and specialized equipment and aids. Children may require the medications regardless of their condition severity (Burton & Phipps, 2009).

This study demonstrated that parents caring of children with chronic conditions at home have a need to pay for help with everyday activities which allows the parents to attend to their family or other personal activities.

Bumbalo and colleagues (2005) examined economic factors that affect the financial burden and health-related factors experienced by families with CSHCN. The study sample included 750 families with CSHCN residing in New Hampshire that responded to the NS-CSHCN and 2,975 children without special needs participated. Independent variables included family income, type of insurance, and effect of the child's condition on the family. Outcome measures included economic impact, adequacy of insurance, and the need for professional care coordination help. Economic impact was measured by reports of any family member reducing employment hours or stopping work to care for the child in the home, reports of financial problems, and the need for additional income. Adequacy of insurance was measured by whether or not the plan offered benefits the child needed, the costs of not covered services were reasonable, and if the plan allowed specialty referrals (Bumbalo, Ustinich, Ramcharran, & Schwalberg, 2005).

The results showed the two populations, CSHCN and children without special needs, differed significantly in family income distribution and types of insurance. More than half of the CSHCN had functional conditions that affected the family always, usually, or a great deal.

Compared to children without special needs, CSHCN were more likely to have public insurance (12% vs. 21%) and less likely to live in high-income families (56% vs.48%). Among CSHCN, 31% had adequate insurance, families of 21% had financial difficulties, parents of 27% had to cut back hours of employment, and 15% reported needing professional care coordination help. The families with private insurance were more likely to have spent at least $250 to $500 out-of-pocket expenses in the previous year. However, families with public insurance were more likely to have spent less than $250. The condition of the CSHCN was associated with the effect on the family; the type of insurance was associated with out-of-pocket expenses, and income was associated with all the effects on the family (Bumbalo et al., 2005).

Socioeconomic variables, such as family income and type of insurance, influence the financial burden of the families with CSHCN. The parents with children with a greater level of functional impairment were more likely to report financial difficulties, needs for additional income, inadequate insurance or cutbacks in employment hours than parents of children less consistently affected by their condition. They were also more likely to report a need for professional care coordination. This study showed that the child's activity limitations had a greater degree of influence on the families' burden of care (Bumbalo et al., 2005).

Viner-Brown & Kim (2005) conducted a cross-sectional study to determine the impact of caring for children with special health care needs on the family in terms of finances and employment. Data was from the 2001 NS-CSHCN on families residing in Rhode Island. Out of a total of 6,134 identified CSHCN, 750 families completed the survey. Financial problems were measured using two questions: "Has the child's health condition caused any financial problems for your family?" and "Have you needed additional income to cover the child's medical expenses?" Employment problems were measured using two questions: "Have you or a family member cut done on hours of work to care for the child?" and "Have you or a family member stopped working because of your child's health condition?"A positive response to any one of these questions, classified the family as having a financial or employment problem. If all the responses were positive, the family was classified as "with impact"; if all the responses were negative, the family was classified as "without impact".

The overall impact of caring for CSHCN in Rhode Island was lower (33.7%) compared to families caring for CSHCN nationwide (40.4%). Families with young children (birth to five years) were more than likely to have financial problems (31.6%) than families with teenagers (14.2%). More than 1/3 families with incomes below 200% poverty level had financial problems compared to 12.3% of the families with incomes above 200% poverty level. Families whose child's health condition usually or always affected their activities were 4.2 times more likely to have financial problems compared to families whose child's health condition never affected their activities (37.6% versus 9.0%)(Viner-Brown & Kim, 2005).

Employment problems were more likely to occur among families with young children, families with income below 200% poverty level, and families whose child's health condition affected their activities. More than half of the families reported having to cut their hours of work or stop working. Families whose child's health condition usually or always affected their activities were three times more likely to have employment problems compared to families whose child's health condition never affected their activities (52.1% versus 14.4%). Overall impact, financial and employment problems was 3.2 times more likely in families whose child's health condition usually or always affected their activities compared to families whose child's health condition never affected their activities (59.3% versus 18.5%)(Viner-Brown & Kim, 2005).

A study by Chen & Newacheck (2006) used data from the NS-CSHCN 2000-2001 to examine the effects of insurance coverage on financial burden and work loss of families with CSHCN. The independent variables were family income and insurance coverage. The dependent variable, measures of family burden included “work loss/cut back” and “experiencing financial problems”.

The majority of the study sample were older (41.1%), White (68.9%), males (59.8%), from families with continuous insurance coverage for the entire year (88.4%). The percentage of families with financial problems or had a need to cut back on work were families with younger children (40.1%); Hispanic ethnicity (42.4%); from poor income families (43%); had gaps in insurance coverage (43.3%); from one adult families (35.2%); and their child’s health condition affected their activities usually always (53.3%)(Chen & Newacheck, 2006).

This study showed if the family had continuous insurance coverage, there was a significant reduction in the likelihood the family would experience financial difficulties across every income level. However, the lower-income families experienced financial problems and work loss despite having insurance coverage. Many of these families face the reality that one or both parents must cut back work hours or stop working due to their child’s health condition. The families of CSHCN with income levels between 100-199% poverty level were more likely than those families with CSHCN below 100% poverty level to experience financial problems. These are vulnerable families with CSHCN with high enough income not to qualify for Medicaid or other federal assistance programs (Chen & Newacheck, 2006).

In the study by Burton & Phipps (2009), implicit costs, or opportunity costs of caregiving which includes giving up a paid job, working fewer hours, and not getting promoted were examined from the secondary analysis from 2001 PALS. Of the total 3,183 respondents, 62.7% were fathers.

In this sample of parents with children with disabilities, less than half (42.3%) reported having no work related problems associated with their child's condition; 17.6% reported one problem; and 40% reported more than one problem. The most common work related problem reported was working fewer hours (36.2%); changing work schedule (34.3%); and not taking a job (29.2%). It is possible that fathers may not quit their jobs or reduce their hours; nevertheless, they may have encountered other work related difficulties not addressed in this study. Parents who were not currently in the workforce would report no work related problems (Burton & Phipps, 2009).

Parents of children with a chronic condition were more likely to report work related problems than parents of children without a chronic condition. Parents of children with a very severe condition were more likely not taken a job due to the child's condition compared to parents of children with a mild condition. Single-parents were more likely to have quit a job and not taken a job than married parents. This reflects the added difficulties of working for pay and caregiving responsibilities (Burton & Phipps, 2009).

Okumura and colleagues (2009) conducted a study to determine the factors associated with work loss for families caring for CSHCN. A secondary analysis was done on data from the NS-CSHCN 2005-2006 national survey. The independent variables included child and family factors and the presence of the medical home which were operationalized by five criteria: having a personal doctor or nurse, having a regular source of care, receiving family-centered care, having no problems receiving referrals when needed, and receiving effective care coordination.

Majority of the study population were older (61.6%), White non-Hispanic (65.3%), males (59.3%), with a condition that affects the child's activities to a great deal

(37.8%), and had health care needs that changed frequently (34.1%). Most CSHCN lived in 2-parent families (64.9%), one parent had at least some college (70.5%), family income less than 200% below poverty level, nearly all were insured (95.5%). Nearly all the CSHCN had a personal doctor or nurse, half of the CSHCN had a medical home, and less than half reported adequate care coordination (40.8%)(Okumura et al., 2009).

Work loss related to the condition of the CSHCN was reported by 23.7% of the families. There were 16.1% of the families reported a family member had to cut back work and 13.3% of the families reported a family member had to stop work to care for their CSHCN. The odds of work loss increased significantly as the functional limitations (OR: 12.2 [95% CI: 10.6-14.1]) and the condition instability (OR: 6.2 [95% CI: 5.3-7.2]) increased. Families with younger CSHCN (OR: 0.8 [95% CI: 0.7-0.9]) had increased odds of work loss compared to families with older CSHCN (OR: 0.6 [95% CI: 0.5-0.7]). Black families (OR: 1.3 [95% CI: 1.1-1.4]) and Hispanic families (OR: 1.7 [95% CI: 1.5-2.0]) families had increased odds of work loss compared to White families. Uninsured families (OR: 2.5 [95% CI: 2.1-3.0]) and families with both public and private insurance (OR: 2.9 [95% CI: 2.5-3.3]) were associated with greater odds of work loss (Okumura et al., 2009).

The proportion of families with CSHCN who experienced work loss if they met the criteria for having a medical home was the lowest 13.9% [95% CI: 14.1-15.9] compared to those who did not meet medical home criteria 31.3% [95% CI: 30.3-32.5]. This suggests the presence of the components of a medical home was strongly associated with a lower likelihood of work loss for the family members with CSHCN (Okumura et al., 2009).

Wilson and colleagues (2005) conducted a study to determine the economic burden of caring for children with chronic conditions. The sample was recruited from 3 sites: New York City, San Francisco, and Oakland, California. Data were collected from maternal caregivers of 97 children with HIV, 101 children with any moderate-to-severe disease or condition other than HIV, and 102 healthy children using structured interviews, each lasting about two hours baseline and 6-month with 86% completed both interviews. Controlling for the basic care needs of healthy children, comparisons were made of the types, amounts, and costs of care for the children with HIV and children with chronic conditions. To determine condition severity, the children's functional status was measured using the Revised Functional Status II Survey (Wilson et al., 2005).

The respondents were asked to indicate the total number of minutes spent by the caregivers over the previous two weeks for three different types of care: technical, nontechnical, and health care management. Technical care consisted of medication administration and procedures or therapies. Nontechnical care consisted of activities of daily living and instrumental activities of dialing living related to the child's care. Health care management consisted of time spent managing the care associated with the child's condition, such as making appointments, travel time to and from the appointments. The caregiving value was determined according to national hourly earnings and fair market replacement value of services provided. Value of lost production includes loss of actual income from lost work and loss of leisure time calculated as an opportunity cost by hours of care provided (Wilson et al., 2005).

'Standard of care' is assumed in the estimate of costs. Substitutions for that standard would most likely be paid in-home care or a combination of respite and unpaid home care versus the institutionalization care. However, institutional care is more costly than paid in-home care (Wilson et al., 2005).

An average for baseline and six month care estimates in hours per day were summed across the groups and types of care to obtain a total annual home care time values. Healthy children differed from the other 2 groups including functional status, type of insurance, and income level. Chronically ill children required significantly more care time than HIV+ children (7.8 vs. 3.9 hours per day). Paid care accounted for 8% to 16% of the care time. Annual costs were estimated at $9,300 per HIV+ child and $25,900 per chronically ill child. National annual costs were $86.5 million for HIV+ children and $155 to $279 billion for chronically ill children. The cost for chronically ill children was calculated at $98 per day ($35,897 per year) nearly twice that for HIV + children at $53 per day ($19,335 per year). Nearly 31% of the caregivers were employed while caring for the HIV+ children and 42% of caregivers of chronically ill children and 61% of caregivers of healthy children (Wilson et al., 2005).

Research indicates caring for children with chronic conditions affects their families in both economic costs and caregiver time costs. Economic costs are measured in reduction of employment hours or stopping work to care for the child at home; the need for additional income to pay for the child's medical expenses; and adequacy of health insurance coverage. The economic value of the caregiver's time caring for the child is a hidden indicator of societal costs.

Summary

What We Know

Technological advances made during the past thirty years have dramatically improved survival rates for children with life-threatening conditions caused by preterm births, congenital anomalies, disease, or injury (Perrine, Bloom & Gortmaker, 2007). The consequences of these advances in medical technology are that a small group of children will need continuous medical and nursing services that enable them to survive. As a result, the population of children living with chronic illness or disability is growing. This small group of CSHCN accounts for a disproportionately large part of the health care costs (Chevarley, 2006). Although the magnitude of healthcare costs for these children is great, it is the driving force for health care providers and insurers to become more aggressive about placing these children in less costly settings. At the same time, the health care system has been altered by economic and workforce instability. As a result, a greater proportion of children with chronic illness or disability are living at home with their families (Bethell, Read, Blumberg, & Newacheck, 2008).

Home care isolates the CSHCN from their peers. Long-term care separates the CSHCN from their families. The medical day care provides socialization for the CSHCN and family respite. However, a growing proportion of CSHCN are cared for at home. Home care requires tremendous financial, emotional, and time commitments and resources from the family (Parish 2005). The medically complex child's "special" routine and health care needs are incorporated into normal routines of work, school, transportation, child care, and housekeeping (Kirk, Glendinning & Callery, 2005). Family members are often required to perform tasks that are provided by professional health care staff. Some of the medical interventions may include administering medications or oxygen therapy, changing tracheostomy tubes, suctioning airways, passing nasogastric tubes or foley catheters, administering intravenous infusions, giving injections, or providing continuous and sometimes painful therapeutic regimes (Heaton, Noyes, Sloper, & Shah, 2005). The long-term care of children with complex needs places a strain on the parents' marriage and on the siblings. It is not uncommon to find high levels of stress in the caregivers and other family members which results in depression, poor physical health, fatigue, social isolation, increased financial strain, and uncertainty about the future (Reeves, Timmons, Dampier, 2006; Sullivan-Bolyai, Knafl, Sadler, Gillis 2003).

Support services may be available, but the burden of care falls on the family. With support services, the CSHCN and the family are more likely to experience lower rates of poor health outcomes and functioning limitations (Benedict, 2008; Stein & Silver, 2005). Better family health and functioning is related to support systems, available resources, and fewer stressors (Knafl, Breitmayer, Gallo, & Zoeller, 1996). Families who are able to care for their CSHCN are an economic value of the hidden societal costs of care. The value of these costs associated with this care is a large resource to the health care system (Wilson, Moskowitz, Acee, Heyman, Harmatz, Fernando, & Folkman, 2005). .

What We Don't Know

Little has been documented and reported comparing the effects of care settings on child and family health and functioning and health service use for families with CSHCN. Studies of care in the home for CSHCN focus on the medical home care coordination. Studies in long-term care have focused on adults. Studies on the effects of the medical day care setting are nonexistent. This is true despite the increasing numbers of pediatricians prescribing or writing orders for children to use medical day care. Compared to the home care setting and the long-term care setting, the care coordination function of medical day care settings, such as a P-PEC may be an effective and cost efficient use of health care services by reducing duplication or omission of needed services. Such data are essential for developing cost effective strategies for CSHCN and their families. The purpose of the proposed research is to fill this knowledge gap by comparing the effects of care in the home care setting, the prescribed pediatric extended care (P-PEC) setting, and the long-term care setting.

Chapter 3

Methods

Research Design

This non-experimental study compared the effects of home settings, prescribed pediatric extended care settings, and long-term care settings on child and family health and functioning, and health care service use in families with a special health care needs child. Child health and functioning outcomes included the child's physical and mental health, and functioning including social and school participation. Family health and functioning outcomes included caregiver physical and mental health, functioning (family relationships, employment, and social participation), and family cost of care burden (out-of-pocket expenses, time spent traveling to and from doctor visits and other health care services, lost employment time, lost leisure time, and time spent caring for the child at home). Health care service use included routine doctor office visits (primary and specialty), acute care, urgent care, and emergency room visits, hospitalizations (frequency and length of stay), ancillary care (nursing services, physical and occupational therapy, speech pathology, and respiratory therapy). Data were collected monthly for five months.

Settings

The source of home care settings included primary care pediatric practices located in North Miami and South Dade County which serves over 100 families with CSHCN. The prescribed pediatric extended care settings included four centers in Miami-Dade County: Jackson Infant/Toddler Center, capacity 30 children; Children's Rehab Network, North and South capacity 50 children; and PATCHES P-PEC, capacity 60 children. The long-term care settings included the Miami Cerebral Palsy Residential Services, Inc., capacity 24 children; the Sabal Palms Health Care Center of Largo, Florida, capacity 35 children; and several independent congregate group homes in Broward and St. Lucie Counties.

Sample

The projected sample size for the study was 100 children and 100 parents/guardians (33 children and 33 caregivers in each of three settings). A sample size of 27 CSHCN and 27 parents/guardians in each of the 3 health care settings (total sample 81) was the minimum necessary for a statistical power of .80, using a two-tailed alpha of .05 and a moderate effect size of .70 for a statistical analysis with chi-square test and analysis of variance with the appropriate variables (Duffy, 2006; Nunnally & Bernstein, 1994). This number was sufficient to capture the differences across the settings. To compensate for attrition, 100 CSHCN and 100 parents/guardians were enrolled to have a sample of 81 assuming a 20% attrition rate.

Inclusion Criteria- CSHCN

Inclusion criteria for the children include ages two to 21 years having a medically fragile or complex medical condition that requires continual monitoring. A medically complex child is defined one who has chronic debilitating diseases or conditions of one or more physiological or organ systems that requires 24-hour medical, nursing or health supervision or interventions. A medically fragile child is defined as one who is medically complex and whose medical condition requires dependence on medical technology or a procedure to sustain life such as, total parenteral nutrition (TPN), ventilator dependent, or is dependent on intense medical supervision to sustain life, and without such services is likely to expire without warning (Special Needs Children in Florida, 2003).

Children included in this study sample had two or more of the following inclusion criteria as a medically complex or medically fragile child based on the literature: 1) having a diagnosed health problem involving at least one body system, 2) having multiple medical specialist with each referral expected to last at least 12 months, 3) being dependent on medical technology, such as gastrostomy, tracheostomy, continuous positive airway pressure, oxygen, ventilator, or a mechanical bed, 4) being dependent on a wheelchair, 5) having an on-going need for home- or school-based health care services, 6) having early intervention involvement for biological risks and/or developmental impairment (for children < three years), 7) having great difficulty in coordination treatment and rehabilitation due to complexity of the child's care needs.

Since the condition severity of CSHCN varies widely, in order to compare condition severity in each of the three health care settings, the sample was stratified by level of condition severity using three of the 5-point Glasgow Outcome Scale (GOS). The scale consists of five categories: 1) dead; 2) vegetative state; 3) severe disability (conscious, but disabled); 4) moderate disability (disabled, but independent); 5) good recovery (minor deficits). On this scale, score five corresponds to good recovery referring to normal participation in social, vocational and physical life. A score of four indicates moderate disability describing the child who is independent but physically or cognitively disabled and requiring an altered physical, social, psychological or vocational environment for participation. Children with severe disabilities received scores of three and are totally dependent in managing a normal or modified environment whereas a score of two corresponds to a vegetative state whereby the child is totally dependent with no awareness of the environment (Pettigrew, Wilson, Lindsay, Teasdale & Graham, 2003; Rimel, Giordani, Barth, & Jane, 1982).

The total sample included 84 CSHCN and 84 parents/guardians. The sample consisted of 28 children and their parents/guardians from the home care setting, 29 from the P-PEC care setting, and 27 from the LTC setting.

Exclusion Criteria- CSHCN

Exclusion criteria for the children included those with a single system behavioral or mental health disorders, such as attention deficit/hyperactivity disorder or autism.

Inclusion Criteria- Caregivers

Inclusion criteria for the caregiver included 18 years of age or older, both genders, being the primary caregiver for the child participating in this study, English or Spanish speaking, and being available for an interview once a month for the next five months.

Exclusion Criteria- Caregivers

Exclusion criteria included major physical or mental disability that prevents them from participating in the study and completing the study instruments.

A $10.00 gift card from Wal-Mart was given to the parent/guardian and participating child after the each interview by the principle investigator (PI).

Procedures

After approval from the Institutional Review Board (IRB) at Florida International University and access from key administrators in the health care organizations, a convenience sample of eligible children and their families was identified as prospective participants with the assistance of the site contacts. The site contacts included the primary care physicians caring for CSHCN in a home setting; the Director of Nursing or designees in the patient care facilities (P-PEC and the LTC) facilities. The site contacts communicated with the families who meet inclusion criteria and provided the interested family members the study information sheet with contact information for the study. The family members were asked permission for their name and telephone number to be given to the PI. The PI contacted the interested family members by the telephone and scheduled a home visit or a site visit (P-PEC setting or LTC setting) whichever was the most convenient for the family. At the home or site visit, the PI and the research assistant (RA) (bilingual in English and Spanish) discussed the purpose of the study with the family member in the language of his/her choice (English or Spanish) and answered any questions to his/her satisfaction. The PI obtained the written consents from the parent/guardian and conducted the Time 1 baseline interview. The PI and RA conducted the Spanish only interviews together with the RA translating.

The data on child health and functioning was collected using the Pediatric Quality of Life Inventory (PedsQL^{TM}). Data on family health and functioning was collected using the PedsQL Family Information Form and Family Impact Module Parent Report. Data on health service use was collected using questions from the PedsQL Family impact Parent Module, and Impact on the Family section from the National Survey of Children with Special Health Care Needs and National Survey Children and Families. All of these data were collected at the Time 1-Time 5 at scheduled monthly interviews.

The interviews were conducted in the family home for those in the home care settings; at the P-PEC centers for those in the P-PEC settings; and at the LTC settings. The PI asked the parent/guardian whether their child was capable of responding to the questions verbally. If yes, the PI read the questions aloud to the child and marked the child’s answers. If the child was not capable of responding verbally but had the capacity for self-report by pointing to an answer sheet with a choice anchored to a smiley face or to a sad face scale, the child self-reported after the PI read the question aloud. The PI conducted the interviews by reading the questionnaire items to the parent/guardian and child separately. The completion of the questionnaires for both took approximately 20 to 40 minutes.

The RA was: bilingual in English and Spanish, baccalaureate prepared registered nurse with knowledge of normal child development, and experience working with children and their families. The RA was trained in the study protocol, consent procedures, and interview techniques by PI. The RA had at least one 4-hour training session interviewing with CSHCN and the parent/guardian provided by the PI. The RA completed the NIH on-line course for human subjects’ protection prior to any interaction with participants. There were weekly research team meetings to discuss the progress of the study along with any difficulties, changes, updates, and reinforcement of study protocols.

Instruments

Child Physical Health, Mental Health and Functioning

Child physical health, mental health, and functioning were measured using the Pediatric Quality of Life Inventory (PedsQL^{TM}) Generic Core Module 4.0. The 23-item PedsQL Generic Core Scales 4.0 were designed to measure child physical health functioning (8-items), emotional functioning (5-items), social functioning (5-items), and school functioning (5-items).

The PedsQL had parallel child self-report and parent proxy-report formats. The child self-report form was for children ages 5-7, 8-12, 13-18, and 19-25 years for young adults. The differences in age group forms included age appropriate language. Each parent/guardian completed a parent-proxy report for their child's age group: 2-4, 5-7, 8-12, 13-18, 19-21 years, which assessed the parent's/guardian's perception of their child's physical health, mental health, and functioning including social and school participation. The items on each form were conceptually identical, differing only in age-appropriate language, using first or third person tense. The participating parent/guardian completed the appropriate age parent-proxy questionnaire and each CSHCN capable of responding to the questions completed the appropriate age questionnaire.

The instructions asked how much of a problem each item had been during the past month with the 5-point response scale (0 = never a problem, 1 = almost never a problem, 2 = sometimes a problem, 3 = often a problem, 4 = almost always a problem). Items were reverse-scored and transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 – 25, 4 = 0). Higher the scores indicated better the health and functioning. The transformed scale scores were computed as the sum of the items divided by the number of items answered accounting for missing data (Varni, Limbers, Burwinkle, 2007).

Previous research with the PedsQL 4.0 demonstrates good internal consistency (Cronbach's alpha child = .88, parent = .90) and construct validity in healthy children group and children with acute or chronic health conditions group (Varni, Seid, Kurtain 2001; Varni, Seid, Knight, Uzark, Szer, 2002). In a study by Aitken and colleagues (2009) measuring children's general health outcomes after traumatic brain injury, internal consistency reliability (range .74–.93), test-retest reliability (range .75–.90), and discriminate validity of the PedsQL scales were reported (Aitken, McCarthy, Slomine, Ding, Durbin, Jaffe, Paidas, Dorsch, Christensen, MacKenzie, & the CHAT Study Group, 2009).

The PedsQL Family Information Form asked the parent/guardian about the child's health in the past month, "Has the child missed school due to their condition?"; "How many days has the child been sick in bed or too ill to play?"; and "How many days did the child need someone to care for him/her due to their condition?"

Family Physical Health, Mental Health, Functioning and Cost of Care Burden

Parent/guardian physical health, mental health, and functioning and family relationships were measured using the PedsQL Family Impact Module. The PedsQL Family Impact Module measured the parent's/guardian's self-report of the physical health, mental health, and functioning including social participation and family daily activities and relationships (Varni, Sherman, Burwinkle, Dickinson, Dixon, 2004). The 36-item PedsQL Family Impact Module encompasses six scales measuring parent/guardian self-reported functioning in the following domains: physical health (6-items); mental health including emotional functioning (5-items); cognitive functioning (5-items); communication (3-items); worry (5-items); and functioning including social participation (4-items); family daily activities (3-items) and relationships (5-items). Parents/guardians rated each item on a 5-point scale (never a problem = 0 to always a problem = 4). Items were reversed-scored and transformed to a 0-100 scale, 0 = 100 to 4 = 0, so higher scores indicated better functioning or less negative impact. Statistical analysis determined the internal consistency reliability Cronbach's alphas to be .88 to .97. Construct validity was determined using the known groups' method which compares scale scores across groups known or expected to differ in the investigated construct (Varni et al., 2004).

The PedsQL Family Information Form completed by the parent/guardian contains demographic information including the child's date of birth, gender, race/ethnicity, and parental education and occupation information. One question asked the parent/guardian to report on the presence of a chronic condition defined as a physical or mental health condition that had lasted or is expected to last at least five months and interferes with the child's activities. If the parent/guardian said "yes", they were asked to state the name of the chronic health condition. A second question asked about healthcare service used in the past month "Has the child had any overnight visits to the hospital?"; "How many times has your child been hospitalized?"; "What was wrong?" and "Any emergency room/urgent care visits?" The parent/guardian was asked about their ability to work in the past month, "How many days has the parent/guardian missed from work due to the child's condition?" and "In the past month has the child's health interfered with the parent's/guardian's daily routine or their ability to concentrate?"

Family cost of care burden included out-of-pocket costs, time spent providing transportation to and from appointments, lost employment time, lost leisure time, time spent providing care for the CSHCN and were measured using questions from Impact on the Family section from the NS-CSHCN survey. Questions included "During the past 12 months and the past month (Time 1), and in the past month (Time 2-5), how much out-of-pocket expenses would you say that your family paid for any type of health related needs for your CSHCN including co-pays, deductibles, medications, special foods, formula, adaptive clothing, durable equipment, home modifications or any kind of therapy? How many hours per week did you or another family member spend providing transportation for your CSHCN for appointments or other health related services? Have you or another family member cut down on the hours of work to care for your CSHCN at home? How many hours over the past month did you or another family member cut down on from work to care for the CSHCN? Have you or another family member stopped working because of your CSHCN's health condition? What age was the CSHCN when you or another family member stopped working? How many hours per week did you or another family member spend providing health care at home last week? What kind of care did you or another family member do for your child such as changing bandages, care of feeding or breathing equipment, giving medication and therapies? Have you or another family member needed respite care (having someone care for your child so that you or other family members could do other things in the past month? How many times during the past month did you or another family member need respite care?

Health Care Service Use

Health care service use included routine doctor office visits (primary and specialty), acute care, urgent care, and emergency room visits, hospitalizations (frequency and length of stay); additional care services included nursing services, physical and occupational therapy, speech pathology, and respiratory therapy. Health care service use was measured by questions on the PedsQL Family Information Form and the Access to Care: Utilization section from the NS-CSHCN survey.

The PedsQL Family Information Form, completed by the parents/guardians, contains demographic information including the child's date of birth, gender, race/ethnicity, parent's/guardian's marital status, educational status and employment information as well as health care service use in the past month. PedsQL questions included “Has your child had any overnight visits to the hospital and the length of stay; any emergency room/urgent care visits and how many times?” (Varni, Seid, & Kurtin, 2001).

Questions from the Access to Care section of the NS-CSHCN survey included “During the past 12 months (Time 1), and in the past month (Time 2-5), how many times did your child visit a doctor or other health care providers for routine visits, specialty visits, and acute illness visits? “During the past 12 months (Time 1), and in the past month (Time 2-5), did your child use nursing services, physical therapy, occupational therapy, speech therapy, or respiratory therapy? “During the past 12 months (Time 1), and in the past month (Time 2-5), how many hours did your child use nursing services, physical therapy, occupational therapy, speech therapy, or respiratory therapy?”

Data Management

All data from CSHCN and the parent/guardian remained together as a single case. A family identification number (ID) was written on each form and placed together in a file. The ID number, date of the interview, and the corresponding time point was written on each questionnaire. A master log book with the assigned case code number with the names and contact information of the participants was kept in a separate locked cabinet. All files remained under lock and key in the space provided for the PI at the university. Computer access was password coded for the PI. A master contact log for each month listed the dates and times the families was contacted and the date and time each interview was completed. The PI reviewed the list daily and made the appropriate calls and visits. The PI telephoned the parent/guardian the day before the visit to confirm the meeting.

The PI entered the data into the computer weekly and verified the data to minimize errors. The PI used the Statistical Package for Social Science, SPSS for Windows 18.0 to examine frequencies and descriptive statistics to find possible data entry errors and missing data.

The Statistical Package for Social Science, SPSS for Windows 18.0 subprograms descriptive statistics and reliability testing was used to compute the instruments psychometric properties. Descriptive statistics were conducted on child characteristics including age, gender, race (White only, Black only and other), ethnicity (Hispanic, non-Hispanic), level of condition severity, and general health status. Descriptive statistics were conducted on parent/guardian characteristics including relationship to child (biological parent, biological family member, friend, hired support, other), age, gender, educational status, employment status, and general health status. Descriptive statistics were calculated for the family cost of care burden including out-of-pocket expenses, time spent traveling, time spent caring for the child, lost employment time, and lost leisure time. Descriptive statistics were calculated for health care service use including routine doctor and other health related visits, acute care, urgent care, and emergency room visits, hospitalizations with length of stays, care services including nursing home health hours services, physical and occupational therapy, speech therapy, and respiratory therapy hours.

All the assumptions, such as mutually exclusive groups, homogeneity of variance, normal distribution, linearity of the covariate, and homogeneity of regression needed for the valid use of analysis of variance (ANOVA) and regression were verified. Differences among the level of condition severity were identified for all demographic variables using chi square or ANOVA as appropriate. There were no significant interaction between the covariate (level of condition severity) and the independent variable (home care settings, P-PEC settings, and LTC settings); analyses of covariance (ANCOVA) with Post-hoc comparisons were conducted.

Data Analysis

RQ #1

Comparing the three health care settings (home care settings, P-PEC settings, and LTC settings) and controlling for the level of condition severity were there differences in child health and functioning outcomes (physical health, mental health, and function including social and school participation)?

Hypothesis 1

The null hypothesis was that the child's health and functioning will not differ by health care setting (home care settings, P-PEC settings, and LTC settings) controlling for level of condition severity at each time point and/or across time.

The alternative hypothesis was that the child's health and functioning will differ by health care setting (home care settings, P-PEC settings, and LTC settings) controlling for level of condition severity at each time point and/or across time.

Child health and functioning was measured using the PedsQL Generic Core Scales. The scores were transformed from a 0-4 scale items to 0-100 (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0). The physical health summary score was the same as the physical functioning scale score. The mental health or psychosocial summary score was the mean computed as the sum of the items over the number of items answered in the emotional, social, and school functioning scales. The GOS was used as the covariate in the

ANCOVA with Post-hoc comparisons to determine if the care settings differ in child health and functioning outcomes at each time point and/or across time.

RQ # 2

Comparing the three health care settings (home care settings, P-PEC settings, and LTC setting) and controlling for the level of condition severity, were there differences in family health and functioning outcomes (physical health, mental health, functioning (family relationships, employment, and social participation), and family cost of care burden (out-of-pocket expenses, time spent traveling to and from doctor visits and other health care services, lost employment time, lost leisure time, time spent caring for the child at home)?

Hypothesis 2

The null hypothesis was that the family health and functioning will not differ by health care setting (home care settings, P-PEC settings, and LTC settings) after controlling for the level of condition severity at each time point and/or across time.

The alternative hypothesis was that the family health and functioning will differ by health care setting (home care settings, P-PEC settings, and LTC settings) after controlling for condition severity and at each time point and/or across time.

Family health and functioning was measured using the PedsQL Family Impact Module. Items were reverse-scored and linearly transformed to a 0–100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), so that higher scores indicate better functioning (less negative impact). Scale scores [Parent health related quality of life (HRQL) Summary (physical functioning, emotional functioning, social functioning, and cognitive functioning) and Family Functioning (communication, worry, daily activities, and family relationships)] were computed as the sum of the items divided by the number of items answered (this accounts for missing data). Differences in the Impact scores with the GOS as the covariate in the ANCOVA with Post-hoc comparisons were used to determine if the care settings differ in family health and functioning outcomes at each time point and/or across time.

RQ # 3

Comparing the three health care settings (home care settings, P-PEC settings, and LTC setting and controlling for the level of condition severity, are there differences in health care service use (routine doctor office visits (primary and specialty), acute care, urgent care, and emergency room visits, hospitalizations (frequency and length of stay), ancillary care including nursing services, physical and occupational therapy, speech pathology, and respiratory therapy?

Hypothesis 3

The null hypothesis is that health care service used (routine doctor office visits, specialty visits, acute care, urgent care, and emergency room visits, hospitalizations (frequency and length of stay), ancillary care including nursing services, physical and occupational therapy, speech pathology, respiratory therapy will not differ by health care setting (home care settings, P-PEC settings, and LTC settings) controlling for the level of condition severity at each time point and/or across time.

The alternative hypothesis is that health care service used (routine doctor office visits, specialty visits, acute care, urgent care, and emergency room visits, hospitalizations (frequency and length of stay), ancillary care including nursing services, physical and occupational therapy, speech pathology, respiratory therapy will differ by health care setting (home care settings, P-PEC settings, and LTC settings) controlling for the level of condition severity at each time point and/or across time.

Health care service uses were measured by the PedsQL Family Information Form and the Access to Care: Utilization section from the NS-CSHCN survey. ANCOVA with Post-hoc comparisons were conducted using the dependent variable (routine doctor office visits, specialty visits, acute care, urgent care, and emergency room visits, hospitalizations (frequency and length of stay), nursing home health services, physical and occupational therapy, speech pathology, respiratory therapy) and the independent variable (home care settings, P-PEC settings, and LTC settings) controlling for condition severity. MANOVA was used to compare the differences in the health care service use controlling for the level of condition severity over the period for this study.

Chapter IV

Results

As indicated previously, the purpose of this study was to compare effects of home care settings, prescribed pediatric extended care settings (medical day care) and long-term residential care settings (hospital, transitional care unit, long-term care) on child and family health and functioning, and health care service use of families with CSHCN. The study's research questions were: Comparing three health care settings, home care setting, prescribed pediatric extended care setting, and long-term care setting and controlling for child's condition severity, are there differences in: 1) Child health and functioning outcomes: physical health, mental health, and functioning (social and school participation); 2) Family health and functioning outcomes: physical health, mental health, functioning (family relationships, employment, and social participation), and family cost of care burden (out-of-pocket expenses, time spent traveling to and from doctor visits and other health care services, lost employment time, lost leisure time, time spent caring for the child at home); 3) Health care service use: routine doctor office visits (primary and specialty), acute care, urgent care, and emergency room visits, hospitalizations (frequency and length of stay), nursing home health services, physical and occupational therapy, speech pathology, and respiratory therapy?

Sample

A total sample of 84 children two to 21 years of age having a medically fragile or medically complex condition that required continual monitoring were recruited from local pediatric primary physician offices, prescribed pediatric extended care centers (P-PEC), and long-term residential care facilities (LTC). The sample consisted of 28 children and their parents/guardians from the home care setting, 29 from the P-PEC care setting, and 27 from the LTC setting. Eight families were lost to attrition: four were unable to be contacted (two from home care and two from P-PEC settings), one moved out of the area (from P-PEC setting), one parent refused to continue (from LTC setting), and one child (from P-PEC setting) and one parent (from LTC setting) expired. The final sample size was 76 dyads of parent/guardian and their child. The final sample consisted of 25 children and their parents/guardians from the home care setting, 27 from the P-PEC care setting, and 24 from the LTC setting.

Total Sample - CSHCN

Characteristics of the CSHCN are presented in Table 1. Twenty seven percent of the children were 13 to 18 years age, 56% were male, 44% were Hispanic the largest race/ethnicity, 51% were severely disabled, and 66% were in good to excellent health. Chronic conditions included Seizure disorders (29%), Cerebral Palsy (25%), Asthma/respiratory problems (20%), Autism (9%), and Down Syndrome (8%). More than half of the children had up to five different chronic conditions with a range of one to 11 different conditions. Forty two percent of the children were diagnosed with their first condition from birth to two months old, with a mean of 9.9 months (SD 28.6) and a range from birth to 5 1/2 years old. Eighty nine percent of the children needed help or were dependent on help for activities of daily living (ADL) due to physical or cognitive problems. Fifty five percent of the children needed five or more medications daily with a mean of 5.5 medications (SD 3.7) and a range of zero to 22 different drugs; 46% had daily treatments with three or more medical technology devices (MTD) with a mean of

4.1 devices (SD 3.0); and 46% used three or more assistive devices daily. Over half of the children (52%) were seen by more than five specialists.

Eighty nine percent of the children needed help feeding including modified diets such as pureed or thickened liquids, inability to feed themselves because of physical and/or cognitive problems swallowing or chewing difficulties requiring gastrostomy tube feedings; 92% needed help bathing, 89% grooming and 64% dressing; and 85% needed help toileting including use of diapers for incontinence, catheterizations, or assistance cleaning up or dressing before and after toilet use. Fifty seven percent of the children needed help with mobility, 48% ambulated without help; 38% were bed bound and unable to balance sitting up. This required one or two people to transfer them into a special chair or wheelchair with braces and supports; and 19% were independent with some assistive device including a wheelchair or a walker.

Ninety two percent of the children receive multiple prescribed medications daily which included 68% using respiratory medications; 62% medications for gastrointestinal reflux, constipation or diarrhea; 55% medications for pain, sedation including sleep, anti-spasmodic, or anti-seizure medication for breakthrough seizures; 49% daily anti-seizure medications; 27% allergy medications; 21% medications for skin issues; 12% renal medications; 13% cardiac medications; and 6% immune medications.

Medical technology devices (MTD) were used to sustain and/or monitor bodily functions daily for 69% of the children with a mean of 4.1 MTD (SD 3.0) and a range of one to 11 devices. These MTD included tracheotomy (24%), ventilators (10%), oxygen (24%), pulse oximetry (29%), apnea monitors (17%), suction machines (42%), nebulizer machines for breathing treatments (64%), gastrostomy feeding tubes (48%), and feeding pumps (29%), humidifiers (16%), compression vest for chest physiotherapy (13%), intravenous (IV) pump for intravenous medication administration (2%), continuous positive airway pressure masks (CPAP) (1%). About half of the children use some of these devices as needed as well as daily.

Assistive devices were used by 70% of the children to improve independence in daily activities. The assistive devices included wheelchairs for 49% of the children, 50% used ankle-foot-orthosis (AFO) a soft, malleable support to control position or motion of the ankle, 27% used hand or arm splints, 12% wore helmets for protection against head injury from falls, 8% wore a trunk brace, 29% used bath chairs, 26% mechanical or hospital bed, 21% used standers or therapeutic equipment to position the child upright with/without weight bearing abilities, 16% mechanical or Hoyer lift, 14% glasses, 5% hearing aid, 6% adaptive utensils, and 18% a communication device. All of these devices were needed and used daily by the children.

One hundred percent of these children needed and used specialty physicians. Specialties used by more than 50% of the children included Neurology, Gastrointestinal/Genitourinary (GI/GU), Pulmonary, Orthopedic, Dentist, and Ophthalmology.

Only 51% of the CSHCN received professional nursing services at home. Ninety-five percent received physical therapy (PT) and occupational therapy (OT). However, 3.5% of the parents/guardians reported PT and OT needs were not met. Speech Pathology (SP) was provided to 88% of the CSHCN, yet 6% reported SP needs were not met. Twenty-seven (32%) of the parents/guardians reported their child had a need for treatment or counseling for emotional, developmental, or behavioral problem.

Table 1. Characteristics of the Children

	Total **N = 84**	**Home care** **n = 28 (33%)**	**P-PEC care** **n = 29 (35%)**	**LTC** **n = 27 (32%)**	**Test statistic**
Age in years M(SD)	**10.1 (6.2)**	**9.5 (6.0)**	**6.3 (4.4)**	**14.9 (5.1)**	***F* = 19.6****
2-4 years old n (%)	19 (23%)	8 (29%)	10 (35%)	1 (4%)	**X^2 = 30.5****
5-7 years old	20 (24%)	5 (18%)	12 (41%)	3 (11%)	
8-12 years old	14 (17%)	6 (21%)	4 (14%)	4 (15%)	
13-18 years old	23 (27%)	8 (29%)	3 (10%)	12 (44%)	
19-21 years old	8 (10%)	1 4%)	0	7 (26%)	
Gender					
Male n (%)	47 (56%)	15 (54%)	16 (55%)	16 (59%)	X^2 = 0.8
Female	37 (44%)	13 (46%)	13 (45%)	11 (41%)	
Race/Ethnicity					
Hispanic n (%)	37 (47%)	18 (69%)	11 (44%)	7 (27%)	**X^2 = 18.4****
White Non-Hispanic	19 (25%)	3 (11%)	5 (12%)	13 (50%)	
Black Non-Hispanic	22 (27%)	5 (19%)	11 (44%)	6 (23%)	
General Health Status					
Excellent n (%)	11 (13%)	3 (11%)	5 (17%)	3 (11%)	X^2 = 4.2
Very good	17 (20%)	6 (21%)	5 (17%)	6 (22%)	
Good	28 (33%)	9 (32%)	10 (35%)	9 (33%)	
Fair	20 (24%)	5(19%)	8 (28%)	6 (22%)	
Poor	9 (11%)	5 (18%)	1 (3%)	3 (11%)	
Condition Severity					
Moderate disability	25 (30%)	7 (25%)	14 (48%)	4 (30%)	**X^2 = 10.9***
Severe disability	43 (51%)	18 (64%)	10 (35%)	15 (56%)	
vegetative	16 (19%)	3 (11%)	5 (17%)	8 (30%)	
ADL Score M(SD) range 0 - 100	**38.5 (33.2)**	**43.2 (30.7)**	**46.4 (35.7)**	**25.2 (30.6)**	***F* = 3.5***
Age of diagnosis in months M(SD)	9.9 (28.6)	8.2 (14.4)	5.5 (3.6)	17.1 (46.4)	*F* = 0.40
Birth – 1 month n (%)	34 (42%)	11 (39%)	13 (45%)	10 (40%)	X^2 = 3.6
1 – 3 months	21 (26%)	6 (21%)	10 (35%)	5 (20%)	
4+ months	27 (33%)	11 (39%)	6 (21%)	10 (40%)	

* p < .05 ** p < .01

Group Comparisons - CSHCN

There was a significant difference in the mean age of the children across the settings (*F* = 19.6, *p* = .001). P-PEC had the youngest children with a mean age of 6.3 years (SD 4.4). LTC had the oldest children with a mean age of 14.9 years (SD 5.1). Males outnumbered females across the settings (Table 1).

There was a significant difference in the race/ethnicity across the settings (x^2 = 18.4, p = .002) with more Hispanic children in home care and more White non-Hispanic children in LTC. Home care settings had more Hispanic children (69%) than Black non-Hispanic (19%) or White non-Hispanic children (11%). P-PEC had the same number of Hispanic and Black non-Hispanic children (44%). LTC had more White non-Hispanic children (50%) than Hispanic (27%) or Black non-Hispanic children (23%). There was a significant difference in condition severity across the settings (x^2 = 10.9, p = .03) with 64% of home care children and 56% of LTC children being severely disabled; 48% of P-PEC children being moderately disabled; and 30% of LTC children in a vegetative condition (Table 1).

While the overall health status was perceived as good to excellent for 66% of the children, there was no significant difference in the overall health status across the settings. Parents/guardians rated the children's health as good to excellent for 64% of the children in home care, 66% in LTC, and 69% in P-PEC care settings. The poorest health status was reported for 11% of the children: 18% in home care, 11% in LTC, and 3% in P-PEC care settings (Table 1).

There was no significant difference in the number of specialists used across the settings. However, there was a significant difference in the type of specialist used including the Dentist (DDS) (x^2 = 14.1, p = .001), the Interventional Radiologist (IVR) (x^2 = 11.9, p = .003), and the Psychologist (x^2 = 8.8, p = .02) across the settings (Table 2). In this sample, more children in LTC used all three specialties and children in P-PEC used them the least.

DDS and IVR appointments require cognitive and physical cooperation from the child to complete an assessment and/or any procedure. Use of conscious sedation and/or general anesthesia as well as adjuncts to behavioral management (restraints) may be needed for these children. The IVR is a sub-specialty of radiology that uses minimally-invasive image-guided procedures in nearly every organ and vascular system for diagnosis and treatments.

Table 2. Specialists

	Total **N = 84**	**Home care** **n = 28 (33%)**	**P-PEC care** **n = 29 (35%)**	**LTC** **n = 27 (32%)**	**Test statistic**
Number of Specialists M (SD)	8.2 (4.6)	8.1 (4.6)	7.7 (4.2)	8.7 (4.6)	$F = 0.24$
≤ 5 n (%)	26 (38%)	10 (40%)	6 (30%)	10 (42%)	$X^2 = 4.7$
6 – 10	22 (32%)	7 (28%)	10 (50%)	5 (21%)	
11+	21 (30%)	8 (32%)	4 (20%)	9 (38%)	
Types of Specialty					
Pulmonology n (%)	49 (58%)	16 (57%)	18 (62%)	15 (56%)	$X^2 = 0.27$
Gastroenterologist/ Genitourinary	56 (67%)	17 (61%)	19 (66%)	20 (74%)	$X^2 = 1.1$
Cardiology	39 (46%)	14 (50%)	15 (52%)	10 (37%)	$X^2 = 1.4$
Neurology	69 (82%)	23 (82%)	23 (79%)	23 (85%)	$X^2 = 0.33$
Pedi surgery	41 (49%)	13 (46%)	16 (55%)	12 (44%)	$X^2 = 0.74$
Orthopedics	49 (58%)	17 (61%)	14 (48%)	18 (67%)	$X^2 = 1.5$
Immunology	16 (19%)	4 (14%)	6 (21%)	6 (22%)	$X^2 = 0.64$
Endocrinology	16 (19%)	4 (14%)	6 (21%)	6 (22%)	$X^2 = 0.64$
Ears, Nose &Throat	35 (42%)	14 (50%)	11 (38%)	10 (37%)	$X^2 = 1.2$
Dermatology	20 (24%)	3 (11%)	8 (28%)	9 (33%)	$X^2 = 4.2$
Ophthalmology	43 (51%)	17 (61%)	14 (48%)	12 (44%)	$X^2 = 1.6$
Dentist	**44 (52%)**	**15 (54%)**	**8 (28%)**	**21 (78%)**	$X^2 = 14.1^{**}$
Nephrology	14 (17%)	4 (14%)	6 (21%)	4 (15%)	$X^2 = 0.52$
Hematology	31 (37%)	12 (43%)	13 (45%)	6 (22%)	$X^2 = 3.7$
Neuro-surgery	13 (16%)	5 (18%)	4 (14%)	4 (15%)	$X^2 = 0.19$
Nutritionist	34 (41%)	12 (43%)	10 (35%)	12 (44%)	$X^2 = 0.66$
Infectious Disease	22 (26%)	8 (295)	6 (21%)	8 (30%)	$X^2 = 0.70$
Genetics	26 (31%)	7 (25%)	8 (26%)	11 (41%)	$X^2 = 1.8$
Interventional Radiologist	**13 (16%)**	**4 (14%)**	**0**	**9 (33%)**	$X^2 = 11.9^{**}$
Craniofacial	2 (2%)	2 (7%)	0	0	$X^2 = 4.1$
Oncology	3 (4%)	2 (7%)	0	1 (4%)	$X^2 = 2.1$
Allergist	7 (8%)	3 (11%)	0	4 (15%)	$X^2 = 4.3$
Psychologist	**6 (7%)**	**1 (4%)**	**0**	**5 (19%)**	$X^2 = 8.8^{*}$

* $p < .05$ ** $p < .01$

There was no significant difference in the number of daily medications used by the children or in the types of medications across the settings (Table 3). Children in LTC received the largest cumulative number of different medications. P-PEC children received the greatest number of respiratory, cardiac, renal, and immunosuppressive medications. Home care children and LTC children received most medications for allergies; and LTC children received the most medications for skin conditions.

Table 3. Medications

	Total N = 84	**Home care n = 28 (33%)**	**P-PEC care n = 29 (35%)**	**LTC n = 27 (32%)**	**Test statistic**
Number of Daily medications M (SD)	5.5 (3.7)	5.2 (2.9)	5.0 (3.6)	6.3 (4.4)	$F = 0.91$
≤ 4 n (%)	31 (40%)	10 (44%)	13 (48%)	8 (30%)	$X^2 = 3.0$
5 – 6	26 (34%)	6 (26%)	9 (33%)	11 (40%)	
7+	20 (26%)	7 (30%)	5 (19%)	8 (30%)	
Children receiving medications n (%)	77 (92%)	23 (82%)	27 (93%)	27(100%)	$X^2 = 5.9$
Types of Medications					
Respiratory	57 (68%)	16 (57%)	24 (83%)	17 (63%)	$X^2 = 4.7$
Gastrointestinal	52 (62%)	15 (54%)	18 (62%)	19 (70%)	$X^2 = 1.6$
Cardiac	11 (13%)	5 (18%)	5 (17%)	1 (4%)	$X^2 = 3.1$
Seizure	41 (49%)	11 (39%)	13 (45%)	17 (63%)	$X^2 = 3.4$
Sedation, pain, spasms	46 (55%)	15 (54%)	15 (52%)	16 (59%)	$X^2 = 0.34$
Allergy	23 (27%)	9 (32%)	5 (17%)	9 (33%)	$X^2 = 2.3$
Renal	10 (12%)	3 (11%)	3 (10%)	4 (15%)	$X^2 = 0.32$
Skin	18 (21%)	3 (11%)	6 (21%)	9 (33%)	$X^2 = 4.2$
Immunosuppressive	10 (12%)	0	6 (21%)	4 (15%)	$X^2 = 5.9$

* $p < .05$ ** $p < .01$

There was no significant difference in the number of medical technology devices (MTD) used daily or in the types of devices used across the settings (Table 4). A greater number of children in P-PEC used MTD compared to the other care settings. Eight children in LTC used more than six MTD compared to only five children in home care. Six children in P-PEC used six or more devices. Most MTDs were used to assist the children in breathing and eating.

Table 4. Medical Technology Devices

	Total N = 84	**Home care n = 28 (33%)**	**P-PEC care n = 29 (35%)**	**LTC n = 27 (32%)**	**Test statistic**
Number MTD Used Daily M (SD)	4.4 (3.0)	4.2 (3.2)	4.0 (3.4)	5.0 (2.4)	$F = 0.64$
≤ 2 n (%)	23 (37%)	8 (47%)	12 (50%)	3 (14%)	$X^2 = 7.4$
3 – 5	20 (32%)	4 (24%)	6 (25%)	10 (48%)	
6+	19 (31%)	5 (29%)	6 (25%)	8 (38%)	
PRN MTD [M(SD)]	3.3 (6.5)	2.2 (1.5)	2.3 (1.5)	5.4 (10.8)	$F = 1.3$
≤1 n (%)	21 (36%)	7 (41%)	11 (50%)	3 (15%)	$X^2 = 6.8$
2 -4	31 (53%)	8 (47%)	10 (46%)	13 (65%)	
5+	7 (12%)	2 (12%)	1 (5%)	4 (20%)	
Children using MTD daily n (%)	58 (69%)	16 (57%)	22 (76%)	20 (74%)	$X^2 = 22.6$
Types of MTD					
Tracheostomy	20 (24%)	6 (21%)	7 (24%)	7 (26%)	$X^2 = 0.16$
Ventilator	8 (10%)	1 (4%)	3 (10%)	4 (15%)	$X^2 = 2.1$
Oxygen	20 (24%)	6 (21%)	8 (28%)	6 (22%)	$X^2 = 0.35$
Suction machine	35 (42%)	8 (29%)	12 (41%)	15 (56%)	$X^2 = 4.1$
Pulse oximetry	24 (29%)	6 (21%)	8 (28%)	10 (37%)	$X^2 = 1.7$
Apnea monitor	14 (18%)	5 (18%)	4 (14%)	5 (19%)	$X^2 = 0.27$
Nebulizer	54 (64%)	15 (54%)	23 (79%)	16 (59%)	$X^2 = 4.5$
Gastrostomy tube	40 (48%)	11 (39%)	12 (41%)	17 (63%)	$X^2 = 3.8$
Humidifier	13 (16%)	5 (18%)	7 (24%)	1 (4%)	$X^2 = 4.6$
IV pump	2 (2%)	0	1 (3%)	1 (4%)	$X^2 = 1.0$
Feeding pump	24 (29%)	6 (21%)	7 (24%)	11 (41%)	$X^2 = 2.9$
Compression vest	11 (13%)	4 (14%)	3 (10%)	4 (15%)	$X^2 = 0.30$
C-PAP machine	1 (1%)	0	0	1 (4%)	NS

* $p < .05$ ** $p < .01$

There was a significant difference in the number of assistive devices used daily by the children ($F = 4.1$, $p = .02$) across the care settings (Table 5). Children in LTC used the greatest number of assistive devices with a mean 5.4 (SD 2.8) compared to the children in P-PEC 3.1 (SD 2.2) and 4.2 (SD 2.8) in home care. While 48% of the children in LTC used seven or more assistive devices daily, 47% of the children in P-PEC and 42% in home care only used two assistive devices or fewer. There was a significant difference in the types of assistive devices including the communication device ($X^2 = 14.7$, $p = .001$), bath chair ($X^2 = 13.8$, $p = .001$), and mechanical bed ($X^2 = 10.8$, $p = .004$) across the care settings. Children in the LTC settings used these devices significantly more than the children from the other two groups. Forty one percent of the children in LTC used a communication device, 11% in home care, and 3% in P-PEC. Fifty two percent of the children in LTC used a bath chair, 29% in home care, and 7% in P-PEC settings. Forty eight percent of the children in LTC used a mechanical bed, 21% in home care, and 10% in P-PEC settings.

Table 5. Assistive Devices

	Total N = 84	**Home care n = 28 (33%)**	**P-PEC care n = 29 (35%)**	**LTC n = 27 (32%)**	**Test statistic**
Number of Assistive devices used daily M (SD)	**4.3 (2.7)**	**4.2 (2.8)**	**3.1 (2.2)**	**5.4 (2.8)**	***F* = 4.1***
Number of Assistive Devices					
≤ 2 n (%)	21 (34%)	8 (42%)	9 (47%)	4 (17%)	$X^2 = 8.5$
3 – 6	22 (36%)	6 (32%)	8 (42%)	8 (35%)	
7+	18 (30%)	5 (26%)	2 (11%)	11 (48%)	
Children using assistive devices	59 (70%)	17 (61%)	19 (66%)	23 (85%)	$X^2 = 4.4$
Wheelchair	41 (49%)	13 (56%)	10 (35%)	18 (67%)	$X^2 = 5.9$
AFO	42 (50%)	12 (43%)	15 (52%)	15 (56%)	$X^2 = 0.94$
Splints	23 (27%)	6 (21%)	5 (17%)	12 (44%)	$X^2 = 6.0$
Vision	12 (92%)	3 (11%)	3 (10%)	6 (22%)	$X^2 = 2.1$
Hearing	4 (5%)	1 (4%)	0	3 (11%)	$X^2 = 3.9$
Communication device	**15 (18%)**	**3 (11%)**	**1 (3%)**	**11 (41%)**	$X^2 = 14.7$**
Helmet	10 (12%)	3 (11%)	3 (10%)	4 (15%)	$X^2 = 0.32$
Stander	18 (21%)	8 (29%)	3 (10%)	7 (26%)	$X^2 = 3.3$
Bath chair	**24 (29%)**	**8 (29%)**	**2 (7%)**	**14 (52%)**	$X^2 = 13.8$**
Mechanical bed	**22 (26%)**	**6 (21%)**	**3 (10%)**	**13 (48%)**	$X^2 = 10.8$**
Lift	13 (16%)	3 (11%)	3 (10%)	7 (26%)	$X^2 = 3.3$
Adaptive utensils	5 (6%)	2 (7%)	1 (3%)	2 (7%)	$X^2 = 0.50$
Trunk brace	7 (8%)	2 (7%)	1 (3%)	4 (15%)	$X^2 = 2.4$
Potty chair	4 (5%)	2 (7%)	0	2 (7%)	$X^2 = 2.2$

* $p < .05$ ** $p < .01$

There was a significant difference in the mean activities in daily living (ADL) score across the settings ($F = 3.5$, $p = .04$). Children in LTC scored the lowest in overall ADL mean 25.2 (SD 30.6) or were the most dependent compared to the other two groups.

Children in P-PEC settings scored the highest in overall ADL mean 46.4 (SD 35.7) or were the most independent. There was a significant difference in mobility across the settings (X^2 = 12.1, *p* = .02). Sixty two percent of the children in P-PEC settings were independently mobile compared to only 22% of the children in LTC settings. Seventy eight percent of the children in LTC needed help with mobility compared to 58% in home care and 38% in P-PEC settings. There was not a significant difference in feeding, bathing, grooming, dressing, or toileting subscale scores across the settings (Table 6).

Table 6. Activities of Daily Living (ADL)

Parent report	**Total**	**Home care**	**P-PEC care**	**LTC**	**Test statistic**
ADL Score M (SD) Range 0-100	**38.5 (33.2)**	**43.2 (30.7)**	**46.4 (35.7)**	**25.2 (30.6)**	***F* = 3.5***
Feeding n (%)					
Independent for age	9 (11%)	4 (14%)	4 (14%)	1 (4%)	X^2 = 4.8
Needs help	27 (32%)	7 (25%)	11 (38%)	6 (22%)	
Dependent	48 (57%)	17 (61%)	14 (48%)	20 (74%)	
Bathing					X^2 = 5.6
Independent for age	7 (8%)	2 (7%)	5 (17%)	0	
Needs help or constant monitoring	24 (29%)	8 (29%)	8 (28%)	8 (30%)	
Dependent	53 (63%)	18 (64%)	16 (55%)	19 (70%)	
Grooming					X^2 = 2.7
Independent	9 (11%)	3 (11%)	5 (17%)	1 (4%)	
Needs help	21 (25%)	8 (29%)	24 (83%)	7 (26%)	
Dependent	54 (64%)	17 (61%)	18 (62%)	19 (70%)	
Dressing					X^2 = 1.4
Independent for age	11 (13%)	5 (18%)	4 (14%)	2 (7%)	
Needs help	19 (23%)	6 (21%)	6 (21%)	7 (26%)	
Dependent	54 (64%)	17 (61%)	19 (66%)	18 (67%)	
Toileting					X^2 = 7.1
Independent for age	13 (16%)	5 (18%)	7 (24%)	1 (4%)	
Needs help	12 (14%)	3 (11%)	1 (3%)	8 (30%)	
Dependent	60 (71%)	21 (71%)	21 (72%)	18 (67%)	
Mobility					**X^2 = 12.1***
Independent for age	36 (43%)	12 (43%)	18 (62%)	6 (22%)	
Needs help	16 (19%)	8 (29%)	2 (7%)	6 (22%)	
Dependent	32 (38%)	8 (29%)	9 (31%)	15 (56%)	

* p < .05 ** p < .01

Total Sample – Parents/guardians

Characteristics of the parent/guardian sample are presented in Table 7. Most parents/guardians were biological mothers of the children. Average age of the parents/guardians was 40.2 years (SD 10.3) with a range of 22 to 64 years. Sixty six percent of the parents/guardians considered themselves Hispanic, 35% White non-Hispanic, 58% Black non-Hispanic, and 16% were mixed races/ethnicities. English only was spoken at home in 54% of the homes, Spanish only in 13% of the homes, French or Creole in 3% of the homes, both English and Spanish in 20%, and both English and Creole in 9% of the homes.

Sixty five percent of the families were two-parent families; 91% had a high school education or more; 71% were employed; 19% were going to school with six or more credit hours at the time of the first interview; 54% had an annual income of less than $39,999; 74% received additional financial assistance such as Supplemental Security Income (SSI), the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) or food stamps; and 88% of the families had Medicaid health insurance coverage for the CSHCN.

Eighty nine percent of the respondents were female: most biological mothers, followed by grandmothers, adoptive mothers, and guardians. There were eight biological fathers and one male guardian. The average number of years with a spouse or partner was 13 years (SD 10). Most parents/guardians were very happy (39%) with their relationship with their spouse or partner, followed by mostly happy (18%), then a little happy to mostly unhappy (5%).

Table . 7 Characteristics of the Parents/Guardians

	Total N = 84	**Home care n = 28 (33%)**	**P-PEC care n = 29 (35%)**	**LTC n = 27 (32%)**	**Test statistic**
Relationship to child n (%)					**X^2 = 18.9***
Biological mother	63 (75%)	26 (93%)	23 (79%)	14 (52%)	
Biological father	8 (10%)	0	4 (14%)	4 (15%)	
Grandmother	4 (5%)	1 (4%)	1 (3%)	2 (7%)	
Guardian	5 (6%)	0	0	5 (19%)	
Adoptive mother	4 (5%)	1 (4%)	1 (3%)	2 (7%)	
Age M(SD)	40.2 (19.5)	41.2 (8.7)	36.4 (9.8)	43.1 (11.4)	*F = 2.1*
≤ 33 years old n(%)	22 (27%)	7 (25%)	10 (36%)	5 (19%)	
34-40 years old	23 (28%)	8 (29%)	9 (32%)	6 (22%)	
41-47 years old	19 (23%)	6 (21%)	6 (21%)	7 (26%)	
48 ≥ years old	19 (23%)	7 (25%)	3 (11%)	9 (33%)	
Marital Status					
Two-parent family	55 (65%)	17 (61%)	19 (73%)	15 (68%)	X^2 = 1.0
Single parent family	29 (35%)	11 (39%)	7 (27%)	7 (32%)	
Educational Status					
< High school	8 (10%)	3 (11%)	2 (7%)	3 (11%)	X^2 = 1.6
High school	19 (23%)	6 (21%)	8 (28%)	5 (19%)	
> High school	57 (68%)	19 (68%)	19 (66%)	19 (70%)	
Employment Status					
Employed	60 (71%)	16 (57%)	20 (69%)	21 (91%)	
Student	15 (19%)	5 (18%)	8 (28%)	2 (9%)	
Annual Income					
≤ $14,999	18 (25%)	8 (29%)	7 (24%)	3 (11%)	X^2 = 11.0
$15,000 - $39,999	21 (29%)	8 (29%)	6 (21%)	6 (22%)	
$40,000 - $69,999	21 (29%)	5 (18%)	8 (28%)	6 (22%)	
$70,000 +	13 (18%)	5 (18%)	1 (3%)	7 (26%)	
Insurance Coverage					
Public (Medicaid)	72 (88%)	22 (85%)	26 (90%)	24 (89%)	X^2 = 2.2
Private	8 (10%)	4 (15%)	2 (7%)	2 (2%)	
Both	2 (2%)	0	1 (3%)	1 (4%)	

* p < .05 ** p < .01

A total of 101 other adult family members lived in the households of the respondents. Most were biological fathers (34%), followed by step fathers, adoptive fathers, biological mothers, step mothers or adoptive mothers, partners of the respondents, grandmothers, grandfathers, great grandmothers, aunts and uncles of the CSHCN, and other types of relatives. There were also 56 siblings of the CSHCN, with a mean of two siblings per household (SD 1.3) with a range of one to seven siblings per household. Average age of the siblings was 12.6 years (SD 9.6) with a range of two months to 36 years of age including nine adult sisters and five adult brothers. Most parents were very happy (57%) with their family, followed by mostly happy (29%), then a little happy to mostly unhappy (14%).

Group comparisons – Parents/Guardians

There was no significant difference in the parents/guardians' ages across the care settings. The youngest parents/guardians (40 years old or younger) had children in the P-PEC (23%) and the older parents/guardians (41 years old or older) had children in the LTC (19%).

There was a significant difference in the relationship of respondent (parent/guardian) to the child across the settings $X^2 = 18.9$, $p = .015$). The majority of biological mothers were from home care and adoptive mothers were from LTC. All of the non-biological legal guardians were from LTC. The biological fathers were evenly divided between children from P-PEC care and LTC.

There was no significant difference in marital status, education, employment, annual income, insurance, or supplemental income across settings. The largest number (19) of children with two-parent families was from P-PEC and the largest number (11) of children with single parent families was from home care. Parents/guardians from home care had the highest level of education with some college, vocational or technical school, college graduate, or professional degree as well as the lowest (high school education or less), the latter was shared with those from LTC. In examining employment status of the parents/guardians or the number of weekly hours worked, 71% were employed working an average of 36.8 hours (SD 13.5) per week with a range of 1–65 hours. The greatest number of those employed was from LTC. Over half of the parents/guardians were working full time (40 hours per week) including 29% from LTC, 21% from P-PEC care, and 16% from home care. Thirty four percent of parents/guardians were working part time (< 40 hours per week) including 13% from P-PEC, 11% from LTC, and 11% from LTC. Twenty one percent were working up to 60 hours per week including 13% from LTC care, 6% from P-PEC, and 2% from home care.

Of the families with an annual income between \$3,000 and \$14,999, most had children in home care; the least were in LTC. Of the families that had an annual income between \$15,000 and \$69,999, a greater percent had children in P-PEC care. Of those families with an annual income of \$70,000 or more, a greater number had children in LTC. The majority of children were covered by Medicaid; a much smaller number had private insurance and two children in home care had no insurance during the study.

Seventy one percent of families reported a need for additional income to cover their child's health-related medical expenses including 25% each from home care and P-PEC care and 23% from LTC. Types of additional income received included SSI (63%), WIC/food stamps (28%), trust funds (5%), and child support (3%). Out of the 55 families, 91% received SSI and 25% received WIC as additional income.

Other life changes happened in the lives of 24 of the parents/guardians during the study follow-up period. Ten of the parents/guardians moved into new residents, three had significant-other relationship changes, four changed jobs, two had a death of their own parent, three had another baby, one spouse had a major medical episode, one spouse had a minor medical problem requiring him to take a leave from work and not allowing him to care for their CSHCN, one graduated from school and is planning to take a state board certification exam, and one had major surgery.

Outcomes

Child Health and Functioning – Parent/Guardian Proxy Report

Question 1: Comparing the three care settings, were there differences in Child health and functioning outcomes: physical health, mental health, and functioning (social and school participation)?

Child health and functioning outcomes were measured using the PedsQL^{TM} 4.0 Generic Core Scales for the parent/guardian-proxy report. Higher mean scores indicated better health-related quality of life with a range of zero to 100. These are presented in Table 8.

The Total Summary Score included the Physical Health Summary Score plus the Psychosocial Health Summary Score. The Total Summary Score overall mean was 44.2 (SD 33.2); the Physical Health Summary Score overall mean was 43.5 (SD 32.7) and the Psychosocial Health Summary Score overall mean was 60.7 (SD 29.2).

Table 8. Parent/Guardian Report on Child Health and Functioning

Parent proxy	**Total N = 84**	**Home care n = 28 (33%)**	**P-PEC care n = 29 (35%)**	**LTC n = 27 (32%)**	**Test statistic**
Total Summary Score M (SD)	44.2 (33.2)	46.9 (35.0)	41.8 (35.9)	44.0 (29.1)	*F* = 0.74
Physical Health Summary Score	43.5 (32.7)	46.4 (34.0)	51.3 (32.8)	31.9 (29.1)	*F*= 0.50
Walking	31.8 (42.4)	38.4 (43.3)	37.1 (45.1)	19.4 (36.9)	*F*= 0.60
Running	30.4 (43.9)	33.9 (45.8)	37.1 (47.5)	19.4 (36.9)	*F*= 0.14
Sports & playing	37.8 (46.6)	38.4 (44.9)	50 (50)	24.1 (42.4)	*F* = 0.49
Lifting something heavy	39.3 (46.3)	44.6 (46.3)	51.7 (49.1)	20.4 (38.0)	*F*= 1.6
Bath by his/herself	30.7 (44.6)	32.1 (45.6)	43.1 (48.1)	15.7 (36.1)	*F*= 0.78
Chores	37.2 (46.6)	43.8 (49.8)	48.3 (47.2)	18.5 (36.4)	*F*=1.1
Hurts & pains	51.8 (35.7)	53.6 (35.8)	60.7 (36.3)	40.4 (33.2)	*F*= 0.92
Low energy level	55.7 (36.1)	54.5 (37.9)	65.5 (35.6)	46.2 (32.9)	*F*= 0.50

Psychosocial Health Summary Score	60.7 (29.2)	57.6 (27.7)	58.0 (31.0)	66.7 (29.0)	*F* = 2.7
Emotional Functioning:	68.8 (31.1)	66.1 (28.8)	71.9 (30.2)	68.5 (35.2)	*F* = 0.18
Afraid or scared	62.5 (35.4)	58.9 (32.8)	63.4 (36.3)	65.6 (38.2)	*F* = 0.37
Sad or blue	66.3 (30.9)	63.4 (26.8)	76.9 (29.4)	57.6 (34.9)	*F* = 1.4
Angry	48.8 (27.8)	40.2 (29.1)	57.1 (25.3)	49.0 (26.9)	*F* = 2.8
Trouble sleeping	**64.8 (39.8)**	**48.2 (42.5)**	**77.7 (33.6)**	**68.5 (38.4)**	***F* = 4.2***
Worrying	76.1 (33.8)	76.1 (34.9)	80.8 (31.1)	69.7 (36.9)	*F* = 0.56
Social Functioning:	63.3 (32.8)	59.7 (31.8)	68.8 (35.5)	61.0 (31.3)	*F* = 0.34
Getting along with others	77.2 (36.3)	68.5 (39.6)	81.3 (35.1)	82.0 (33.5)	*F* = 1.4
Others not being friends	80.1 (32.6)	68.3 (39.1)	83.0 (29.7)	89.6 (24.4)	*F* = 2.8
Getting teased	85.6 (27.1)	75.0 (35.4)	97.3 (10.4)	84.4 (25.3)	*F* = 5.3
Unable to do same things	47.2 (43.8)	56.0 (45.2)	51.9 (44.1)	30.0 (38.6)	*F* = 1.7
Keeping up with others	46.6 (45.4)	47.0 (46.4)	58.3 (45.5)	31.8 (41.7)	*F* = 1.0
School Functioning:	53.9 (32.5)	56.7 (34.9)	53.4 (35.5)	51.4 (32.5)	*F* = 0.15
Paying attention in class	44.2 (43.8)	50.0 (46.4)	49.1 (44.6)	31.38.6)	*F* = 0.59
Forgetting things	52.6 (39.9)	54.3 (40.3)	61.1 (38.2)	37.5 (39.5)	*F* = 1.0
Keeping up schoolwork	48.2 (41.1)	50.0 (44.5)	53.8 (36.5)	38.2 (47.8)	*F* = 0.15
Missing school- Not feeling well	**62.5 (32.4)**	**45.3 (34.4)**	**69.4 (26.5)**	**68.3 (32.1)**	***F* = 3.5***
Missing school- appointments	**56.6 (29.9)**	**51.5 (27.2)**	**45.8 (23.1)**	**67.3 (33.0)**	***F* = 3.7***
Cognitive Functioning:	30.5 (35.0)	31.5 (38.5)	39.7 (35.9)	18.8 (26.8)	*F* = 1.0
Hard to keep attention on things	29.1 (36.1)	26.9 (36.0)	42.0 (37.9)	16.7 (30.1)	*F* = 1.2
Hard to remember what people tell me	50.0 (41.1)	43.5 (45.4)	62.0 (36.2)	40.6 (39.7)	*F* = 1.1
Hard to remember what I just heard	48.4 (43.3)	37.5 (45.5)	57.0 (40.5)	50.0 (43.8)	*F* = 1.0
Hard to think quickly	50.8 (42.8)	46.7 (46.7)	63.5 (39.7)	37.5 (38.7)	*F* = 0.85
Trouble remembering what I was just thinking	47.9 (44.6)	48.4 (48.7)	53.9 (39.0)	38.5 (39.0)	*F* = 0.12
Trouble doing more than 1 thing at a time	33.7 (42.2)	36.5 (47.2)	42.0 (42.5)	20.0 (33.0)	*F* = 0.38

* p < .05 ** p < .01

Total Sample - Child Health and Functioning – Parent/Guardian Proxy Report

The children’s Physical Health Summary or Physical Functioning score overall mean score was 43.5 (SD 32.7). As per parent/guardian report, 78% of children had problems with walking some of the time, often, or almost always; 74% had problems having hurts and pains; 72% had problems running; 71% had problems bathing; 67% had problems having a low energy level; 64% had problems participating in sports or playing; and 64% had problems doing chores or picking up toys.

The children’s Psychosocial Health Summary score included Emotional Functioning Score, Social Functioning Score, and School Functioning Score. The Emotional Functioning or mental health overall mean score was 68.8 (SD 31.1). On the Emotional Functioning scale, the parents/guardians reported that 86% of the children had problems with being angry some of the time, often, or almost always; 62% being sad or blue; 60% being afraid or scared; 53% having trouble sleeping; and 38% worrying.

The Social Functioning overall mean score was 63.3 (SD 32.8). Parents/guardians reported that 65% of their children had problems doing the same things as peers some of the time, often, or almost always; 63% keeping up with the others; 34% making friends; 32% with getting along with others and 28% getting teased.

The School Functioning overall mean score was 53.9 (SD 32.5). Here parents/guardians reported that 76% of children had problems missing school when not feeling well some of the time, often, or almost always; 73% keeping up with schoolwork; 70% forgetting; 67% paying attention in class; and 55% missing school for doctor or hospital appointments.

Group Comparisons - Child Health and Functioning – Parent/Guardian Proxy Report

There were no significant differences in the Total Summary Score, the Physical Health Summary Score, or the Psychosocial Health Summary Score across the care settings as reported by parents/guardians.

There was no significant difference in the Physical Functioning Score across the care settings. Physical Functioning overall mean scores were highest (least problems) in the P-PEC care setting 51.3 (SD 32.8) and lowest (most problems) in the LTC setting 31.9 (SD 29.1). Children in LTC had the greatest physical functioning problems in all of the dimensions compared with the children in home care and P-PEC settings. Children in the P-PEC had the least physical functioning problems in running, sports or playing, lifting something heavy, bathing, having hurts and pains, and having low energy levels. Children in the home care setting had the least physical functioning problems in walking compared to children in P-PEC and LTC settings.

There was no significant difference in the overall Emotional Functioning Score across the care settings. The Emotional Functioning overall mean was highest 71.9 (SD 30.2) in the P-PEC setting and lowest 66.1 (28.8) home care setting. There was a significant difference in the dimension of trouble sleeping (*F* = 4.2, *p* = .02) across the care settings. Children in the P-PEC setting scored the highest mean 77.7 (SD 33.6) or had the least trouble sleeping compared to children in home care setting mean 48.2 (SD 42.5). Children in the P-PEC also had the least emotional functioning problems in being sad or blue, angry, trouble sleeping, and worrying. Children in LTC had the most emotional functioning problems being sad or blue and worrying compared with children in P-PEC and home care settings.

There was no significant difference in the overall Social Functioning Score across the care settings as reported by parent/guardian; the overall mean was highest 68.8 (SD 35.5) in the P-PEC setting and lowest mean 59.7 (SD 31.8) in the home care setting. Children in LTC had the least social functioning problems in getting along with others and making friends compared to children in P-PEC and home care settings.

There was no significant difference in the School Functioning Score across the care settings; the overall mean was highest 56.7 (SD 34.9) in home care settings and lowest 51.4 (SD 32.5) in LTC settings. There was a significant difference in missing school when not feeling well ($F = 3.5$, $p = .04$) and missing school for doctor or hospital appointments ($F = 3.7$, $p = .03$) across the care settings. Children in the P-PEC setting scored the highest mean 69.4 (SD 26.5) and had the least problems in missing school when not feeling well compared to the lowest 45.3 (SD 34.4) in home care settings. However, children in P-PEC setting scored the lowest mean 45.8 (SD 23.1) and had the most problems missing school for doctor or hospital appointments compared to the highest mean 67.3 (SD 33.0) in LTC setting.

Child Health and Functioning – Child Self-report

Child health and functioning outcomes were measured using the PedsQL^{TM} 4.0 Generic Core Scales for the child self-report and are presented in Table 9. The Total Summary Score included the Physical Health Summary Score plus the Psychosocial Health Summary Score. The Total Summary Score overall mean was 52.5 (SD 26.9); the Physical Health Summary Score overall mean was 61.3 (SD 36.1) and the Psychosocial Health Summary Score overall mean was 62.7 (SD 23.6).

Table 9. Child Self-Report on Child Health and Functioning

Self-report	**Total N = 10 (11.9%)**	**Home care n = 3 (10.7%)**	**P-PEC care n = 3 (10.3%)**	**LTC n = 4 (14.8%)**	**Test statistic**
Total Summary Score M (SD)	52.5 (26.9)	41.7 (38.2)	66.7 (28.9)	50.0 (17.7)	*F* = 0.62
Physical Health Summary Score	61.3 (36.1)	54.2 (43.9)	83.3 (14.4)	50.0 (42.1)	*F* = 0.77
Walking	47.5 (47.8)	33.3 (57.7)	83.3 (28.9)	31.3 (47.3)	*F* = 1.1
Running	45.0 (49.7)	33.3 (57.7)	50.0 (50.0)	50.0 (57.7)	*F* = 0.07
Sports & exercise	40.0 (45.9)	33.3 (57.7)	66.7 (57.7)	25.0 (28.9)	*F* = 0.65
Lifting something	**50.0 (47.1)**	**16.7 (28.9)**	**100 (0)**	**37.5 (47.9)**	***F* = 6.4***
Bath by his/herself	55.0 (49.7)	33.3 (57.7)	100 (0)	37.5 (47.9)	*F* = 3.1
Chores	60.0 (45.9)	50.0 (50.0)	100 (0)	37.5 (47.9)	*F* = 2.8
Hurts & pains	57.5 (37.4)	50 (0)	66.7 (57.7)	56.3 (42.7)	*F* = 0.48
Low energy level	75 (37.4)	75 (43.3)	83.3 (28.9)	68.8 (47.3)	*F* = 0.19
Psychosocial Health Summary Score	62.5 (23.6)	54.2 (19.1)	75 (25)	59.4 (27.7)	*F* = 0.59
Emotional Functioning:	67.5 (39.2)	58.3 (52.0)	83.3 (14.4)	62.5 (47.9)	*F* = 0.30
Afraid or scared	62.5 (46.0)	58.3 (52.0)	83.3(28.9)	50.0 (57.7)	*F* = 0.30
Sad or blue	67.5 (40.9)	41.7 (38.2)	100 (0)	62.5 (47.9)	*F* = 1.3
Angry	72.5 (38.1)	58.3 (38.2)	100 (0)	62.5 (47.9)	*F* = 1.2
Trouble sleeping	**70 .0 (35.0)**	**33.3 (28.9)**	**100 (0)**	**75.0 (28.9)**	***F* = 5.9***
Worrying	69.4 (42.9)	58.3 (52.0)	75.0 (35.4)	75 (50)	*F* = 0.04
Social Functioning:	65.0 (36.2)	54.2 (50.5)	83.3 (28.9)	59.4 (34.4)	*F* = 0.51
Getting along with others	61.1 (48.6)	50.0 (50.0)	100 (0)	50.0 (57.7)	*F* = 0.66
Others not being friends	77.5 (41.6)	58.3 (52.0)	100 (0)	75 (50)	*F* = 0.61
Getting teased	72.5 (41.6)	58.3 (52.0)	100 (0)	62.5 (47.6)	*F* = 0.61
Unable to do same things	50.0 (43.3)	16.7 (28.9)	100 (0)	50.0 (43.3)	*F* = 5.1
Keeping up with others	65.0 (39.4)	58.3 (52.0)	100 (0)	50.0 (40.8)	*F* = 0.08
School Functioning:	70.0 (30.2)	70.8 (31.5)	75.0 (43.3)	65.6 (27.7)	*F* = 0.07
Paying attention in class	77.5 (34.3)	91.7 (14.4)	83.3 (28.9)	62.5 (47.9)	*F* = 0.74
Forgetting things	80 (23.0)	83.3 (14.4)	100 (0)	62.5 (25.0)	*F* = 0.56
Keeping up schoolwork	90.0 (21.1)	100 (0)	100 (0)	75.0 (28.9)	*F* = 0.43
Missing school- not feeling well	58.3 (40.0)	50 (50)	75.0 (35.4)	56.3 (42.7)	*F* = 0.27
Missing school- for appointments	58.3 (40.0)	50 (50)	50.0 (70.7)	68.8 (23.9)	*F* = 0.20

* $p < .05$ ** $p < .01$

Total Sample - Child Health and Functioning – Child Self-report

Only 10 CSHCN were able to complete at least one interview; the majority was cognitively unable to do so. All three settings were represented: three CSHCN were from home care setting, three from P-PEC settings, and four from LTC setting. Children's ages were three, 5–7 years old, three, 9–10 years old and four, 15–18 year olds. Most reported themselves to be in excellent or good health. Five were moderately disabled and five were severely disabled.

From the child self-report, the children's Physical Health Summary mean was 61.3 (SD 36.1). Seventy percent of the children reported problems with having hurts and pains some of the time, often, or almost always; 70 % problems participating in sports or playing; 60% walking; 60% problems running; 50% problems bathing; 50% problems doing chores or picking up toys; and 40% having low energy level.

The children's Psychosocial Health Summary included Emotional Functioning Score, Social Functioning Score, and School Functioning Score. The Emotional Functioning or mental health overall mean was 67.5 (SD 39.2). From the Emotional Functioning scale, 50% of the children reported problems being afraid or scared some of the time, often, or almost always; 50% being sad or blue; 50% trouble sleeping; 40% being angry; and 40% worrying.

The Social Functioning overall mean was 65.0 (SD 36.2). Sixty percent of the children reported problems keeping up with the others some of the time, often, or almost always; 60% doing the same things as peers; 40% getting along with others; 40% getting teased; and 30% making friends.

The School Functioning overall mean was 70.0 (SD 30.2). Sixty percent of the children reported problems missing school for doctor or hospital appointments some of the time, often, or almost always; 50% keeping up with schoolwork; 40% with paying attention in class;40% forgetting; and 20% missing school when not feeling well.

Group Comparisons - Child Health and Functioning – Child Self-report

There were no significant differences in the Total Summary Score, the Physical Health Summary Score, or the overall Psychosocial Health Summary Score across the care settings in the children's self report.

There was no significant difference in the Physical Functioning score across the care settings. Children from P-PEC setting had the least physical functioning problems in all the dimensions except running compared to the children from home care and LTC settings. Children from LTC had the greatest physical functioning problems with walking, sports or playing, doing chores, and having low energy levels compared to the children from home care and P-PEC settings. Children in home care had the greatest physical functioning problems with running, lifting something, and having hurts and pains compared to the children from P-PEC and LTC settings.

There was no significant difference in the overall Emotional Functioning score across the care settings. Children from P-PEC settings had the least emotional functioning problems in all the dimensions except worrying compared to the children from home care and LTC settings. There was a significant difference in trouble sleeping (F =5.9, p = .04) across the care settings. Children in the P-PEC settings had the highest score or the least problem sleeping compared to the children in home care. Children from home care settings had the greatest emotional problems in all the dimensions except being afraid or scared compared to the children from P-PEC and LTC settings. However, children from LTC settings had the greatest emotional problems with being afraid or scared compared to the children from home care or P-PEC settings.

There was no significant difference in the overall Social Functioning score across the care settings. Children from P-PEC setting had the least social functioning problems in all the dimensions of social functioning compared to children from home care and LTC settings. Children from home care settings had the greatest social functioning problems with others not wanting to be friends, getting teased by others, and being unable to do the same things as peers compared to the children from P-PEC and LTC settings. Children from LTC had the greatest social functioning problem with keeping up with their peers compared to children from home care or P-PEC settings.

There was no significant difference in the overall School Functioning score across the care settings. Children from P-PEC had the least school functioning problems with forgetting things and missing school due to not feeling well compared to children from home care and LTC settings. Children from LTC had the greatest school functioning problems with paying attention in class, forgetting things, and keeping up with school work compared to children from home care and P-PEC settings. However, children from home care settings had the least school function problems with paying attention in class compared to children from P-PEC and LTC settings.

The 10 child self-reports were compared to their own parent/guardian proxy report using the paired-sample t-test. There was a significant difference in the Physical Functioning dimension of bathing scores between the children (mean = 55, SD = 49.7) and the scores from the parents/guardians (mean = 22.5, SD = 41.6), $t = 2.3$, $p = .05$.

There was a significant difference in the Physical Functioning dimension of doing chores between the scores from the children (mean 60, SD 45.9) and the scores from the parents/guardians (mean 32.5, SD 40.9), $t = 2.9$, $p = .02$. The children scored themselves higher or had less physical problems than compared to the parents'/guardians' score.

Family Health and Functioning - Parent/Guardian Report

Question 2: Comparing the three care settings, were there differences in: Family health and functioning outcomes: physical health, mental health, functioning (family relationships, employment, and social participation), and family cost of care burden (out-of-pocket expenses, time spent traveling to and from doctor visits and other health care services, lost employment time, lost leisure time, time spent caring for the child at home).

Family health and functioning outcomes were measured using the PedsQL^{TM} 2.0 Family Impact Module and are presented in Table 10. Higher mean scores indicated better health related quality of life (HRQL).

Table 10. Family Report of Family Health and Functioning

Parent/Guardian Report	**Total N = 84**	**Home care n = 28 (**	**P-PEC care n =**	**LTC n =**	**Test statistic**
Total Score M (SD)	47.3 (28.0)	42.0 (18.7)	53.4 (31.9)	46.3 (31.2)	*F* = 0.49
Parent HRQL Summary Score	50.6 (26.9)	46.0 (23.6)	51.7 (28.1)	54.2 (29.2)	*F* = 1.8
Family Functioning Summary Score	47.3 (28.0)	42.0 (18.7)	53.4 (31.9)	46.3 (31.2)	*F* = 1.0
Physical Functioning	**54.8 (26.5)**	**49.1 (28.1)**	**53.9 (23.6)**	**61.6 (30.6)**	***F* = 3.2***
Tired during the day	**32.4 (32.6)**	**24.1 (30.0)**	**31.0 (30.4)**	**42.6 (35.9)**	***F* = 4.6***
Tired when wake up	38.1 (36.7)	30.4 (34.3)	40.5 (41.9)	43.5 (33.0)	*F* = 2.0
Too tired to do thing like to do	**53.6 (39.0)**	**45.5 (38.5)**	**49.1 (39.8)**	**66.7 (36.7)**	***F* = 4.7***
Get headaches	53.6 (35.9)	45.5 (35.4)	58.6 (37.4)	54.6 (34.7)	*F* = 1.2
Feel physically weak	**62.5 (37.1)**	**50.0 (37.9)**	**65.5 (37.4)**	**72.2 (33.5)**	***F* = 3.5***
Sick to stomach	**77.1 (31.3)**	**67.9 (39.6)**	**89.7 (19.5)**	**73.1 (28.2)**	***F* = 4.0***
Emotional Functioning	60.9 (27.7)	55.4 (28.6)	69.4 (25.1)	57.4 (28.2)	*F* = 1.5
Feel anxious	53.9 (34.6)	48.2 (34.6)	64.7 (28.8)	48.1 (38.6)	*F* = 1.4

Feel sad	55.4 (31.5)	50.9 (35.7)	62.9 (25.5)	51.9 (32.5)	*F* = 0.76
Feel angry	63.4 (30.4)	57.1 (27.9)	74.1 (28.7)	58.3 (32.5)	*F* = 2.0
Feel frustrated	45.8 (28.5)	40.2 (29.9)	53.4 (29.7)	43.5 (24.6)	*F* = 1.4
Feel helpless or hopeless	67.9 (33.1)	62.5 (31.5)	74.1 (32.4)	66.7 (35.4)	*F* = 0.73
Social Functioning	62.6 (31.7)	58.9 (29.0)	62.1 (34.3)	62.6 (31.7)	*F* = 1.1
Feel isolated from others	73.8 (36.4)	72.3 (34.9)	72.4 (37.4)	76.9 (37.9)	*F* = 0.46
Trouble getting support	69.0 (36.1)	78.6 (33.8)	60.3 (37.5)	68.5 (37.8)	*F* = 2.2
Hard to find time for social activities	**48.2 (40.3)**	**39.3 (38.7)**	**42.2 (43.4)**	**63.9 (34.9)**	***F* = 4.5***
Not enough energy for social activities	51.5 (39.3)	45.5 (39.7)	51.7 (41.7)	57.4 (36.6)	*F* = 1.2
Cognitive Functioning	68.0 (27.9)	64.3 (29.2)	73.7 (26.4)	65.7 (28.3)	*F* = 0.62
Hard to keep attention on things	67.3 (34.9)	60.7 (37.5)	75.0 (28.3)	65.7 (38.1)	*F* = 1.1
Hard to remember what people tell me	64.3 (35.2)	52.7 (38.1)	73.3 (29.8)	66.7 (35.4)	*F* = 2.7
Hard to remember what I just heard	**71.1 (31.4)**	**62.5 (31.5)**	**82.8 (25.1)**	**67.6 (34.5)**	***F* = 3.4***
Hard to think quickly	71.4 (28.8)	63.4 (31.5)	77.6 (23.5)	73.1 (30.2)	*F* = 2.1
Trouble remembering what I was just thinking	68.8 (32.4)	67.9 (31.1)	72.4 (33.6)	65.7 (33.4)	*F* = 0.05
Communication	70.5 (23.5)	69.6 (27.1)	74.1 (21.1)	67.6 (22.3)	*F* = 0.57
Other do not understand situation	55.1 (38.6)	55.4 (39.3)	61.2 (41.5)	48.1 (34.6)	*F* = 0.40
Hard to talk about child's health	71.1 (36.7)	71.4 (33.1)	71.6 (39.9)	70.4 (38.0)	*F* = 0.01
Hard to tell MD and RN how I feel	85.4 (27.5)	83.9 (31.3)	87.1 (27.2)	85.2 (24.3)	*F* = 0.08
Worry	32.0 (32.1)	24.6 (21.9)	41.4 (41.2)	29.6 (28.4)	*F* = 1.7
Medical treatments are working	44.9 (40.3)	40.2 (34.3)	51.7 (47.7)	42.6 (37.9)	*F* = 0.44
Side effects of meds/treatments	34.8 (40.1)	33.9 (42.6)	44.8 (43.5)	25.0 (31.8)	*F* = 0.43
How others will react to child's condition	52.4 (43.0)	50.9 (43.8)	56.0 (43.6)	50.0 (42.7)	*F* = 0.12
How child's illness affects other family members	**55.1 (43.5)**	**38.4 (42.2)**	**73.3 (40.6)**	**52.8 (41.8)**	***F* = 4.6***
About child's future	19.0 (35.1)	8.9 (21.7)	31.0 (43.1)	16.7 (34.0)	*F* = 2.7
Daily Activities	**33.0 (32.8)**	**18.3 (23.4)**	**36.6 (34.8)**	**44.4 (34.7)**	***F* = 6.9****
Family activities taking more time &	**27.1 (37.5)**	**11.6 (22.0)**	**36.2 (42.6)**	**33.3 (40.4)**	***F* = 4.2***

effort					
Difficulty finding time to finish household chores	**39.9 (41.5)**	**25.0 (36.0)**	**36.2 (38.1)**	**59.3 (43.9)**	***F* = 7.0***
Feeling too tired to finish household chores	**39.0 (39.5)**	**25.0 (33.3)**	**37.1 (37.6)**	**55.6 (42.4)**	***F* = 6.8***
Family Relationships	67.9 (33.1)	70.1 (28.3)	69.0 (36.2)	69.4 (35.1)	*F* = 0.11
Lack of communication	68.2 (37.5)	67.9 (35.9)	67.2 (42.8)	69.4 (34.2)	*F* = 0.02
Conflicts between family members	72.0 (34.8)	74.1 (31.5)	72.4 (36.8)	69.4 (36.9)	*F* = 0.06
Difficulty making decisions as a family	75.6 (30.8)	85.7 (25.8)	72.4 (30.9)	68.5 (33.7)	*F* = 2.3
Difficulty solving family problems together	74.4 (31.3)	83.0 (25.5)	73.3 (30.6)	66.7 (36.0)	*F* = 1.7
Stress or tension between family members	67.6 (36.4)	72.3 (32.9)	70.7 (36.0)	59.3 (39.9)	*F* = 0.56

* $p < .05$ ** $p < .01$

Total Sample - Family Health and Functioning - Parent/Guardian Report

The Total Summary Score included the Parent HRQL Summary Score (Physical Functioning, Emotional Functioning, Social Functioning, Cognitive Functioning scores) plus the Family Functioning Summary Score (Communication, Worry, Daily Activities, Family Relationship scores). The Total Summary Score mean was 47.3 (SD 28.0). The Parent HRQL Summary Score mean was 50.6 (SD 26.9). The Family Functioning Summary Score overall mean was 47.3 (SD 28.0).

The parents'/guardians' Physical Health Summary overall mean was 54.8 (SD 26.5). Eighty seven percent of the parents/guardians reported problems with feeling tired during the day some of the time, often, or almost always; 77% tired when they wake up; 63% too tired to do the things they like to do; 50% feel physically weak; 33% sick to their stomach; and 32% get headaches.

The parents'/guardians' Emotional Functioning overall mean was 60.9 (SD 27.7). Eighty two percent of the parents/guardians reported problems with feeling frustrated some of the time, often, or almost always; 65% feeling anxious; 63% feeling sad; 52% feeling angry; and 44% feeling helpless or hopeless.

The parents'/guardians' Social Functioning overall mean was 62.6 (SD 31.7). Sixty four percent of the parents/guardians reported problems with finding time for social activities some of the time, often, or almost always; 61% with not having enough energy for social activities; 44% with trouble getting support from others; and 35% feeling isolated from others.

The parents'/guardians' Cognitive Functioning overall mean was 68.0 (SD 27.9). Fifty one percent of parents/guardians reported problems remembering what people tell them some of the time, often, or almost always; 48% trouble remembering what they were just thinking; 44% thinking quickly; and 36% keeping their attention on things.

The Family Functioning Summary Score included Communication, Worry, Daily Activities, and Family Relationship scales; the mean was 56.56 (SD 23.9). The parents'/guardians' Communication overall mean was 70.5 (SD 23.5). Sixty percent of the parents/guardians reported problems with others not understanding family situation some of the time, often, or almost always; 40% found it hard to talk about child's health; 23% found it hard to tell doctors and nurses how they feel.

The parents'/guardians' Worry overall mean was 32.0 (SD 32.1). Eighty six percent of the parents/guardians reported problems worrying about the child's future some of the time, often, or almost always; 75% with the side effects of medications and/or treatments; 67% how medical treatments were working; 58% how others react to child’s condition; and 52% how child’s condition is affecting other family members.

The parents’/guardians’ Daily Activities overall mean was 33.0 (SD 32.8). Eighty two percent of the parents/guardians reported problems with family activities taking more time and effort some of the time, often, or almost always; 73% feeling too tired to finish household tasks; and 69% difficulty finding time to finish household tasks.

The Family Relationships overall mean was 67.9 (SD 33.1). Forty five percent of parents/guardians reported problems with lack of communication some of the time, often, or almost always; 42% difficult solving family problems together; 42% stress or tension between family members; 37% conflicts between family members; and 33% difficulty making decisions together.

Group Comparisons- Family Health and Functioning - Parent/Guardian Report

There were no significant differences in the Total Summary Score, the Parent HRQL Summary Score, and the Family Functioning Summary Score across the care settings. The parents/guardians from P-PEC settings scored the highest in the Total Summary Score and the Family Functioning Summary compared to the parents/guardians from home care and LTC settings. Parents/guardians from the LTC setting scored the highest in the Parent HRQL Summary scale compared to the parents/guardians from the home care and P-PEC settings. However, the parents/guardians from the home care setting scored the lowest on the Total Summary Score, the Parent HRQL Summary Score, and the Family Functioning Summary Score compared to the parents/guardians from the P-PEC and LTC settings.

There was a significant difference in the overall Physical Functioning scores (*F* = 3.2, *p* = .02) across the care settings. The parents/guardians from the home settings had the most problems with physical functioning compared to the parents/guardian from the LTC settings had the least problems with physical functioning. There was a significant difference in being tired during the day (*F* = 4.6, *p* = .02), being too tired to do the things they like to do (*F* = 4.7, *p* = 0.01), feeling physically weak (*F* = 3.5, *p* = .03) and of being sick to their stomachs (*F* = 4.0, *p* = .02) across the care settings. The parents/guardians from the home care settings had the greatest problems with all the dimensions in the physical functioning scale. Parents/guardians from the LTC setting had the least problems in all the dimensions except with being sick to their stomachs, where the parents/guardians in the P-PEC had the least problems.

There was no significant difference in the Emotional Functioning overall means across the care settings. Parents/guardians from the P-PEC had the least emotional functioning problems in all of the Emotional Functioning dimensions compared to parents/guardians from the home care and LTC settings. Parents/guardians from the home care and LTC had the same levels of feeling anxious compared to parents/guardians in P-PEC settings.

There was no significant difference in the Social Functioning overall means across the care settings. Parents/guardians from the LTC setting scored the highest and home care settings scored the lowest. There was a significant difference in the Social Functioning dimension of hard to find time for social activities (*F* = 4.5, *p* = .05) across the care settings. Parents/guardians from the LTC setting had the least social functioning problems compared to parents/guardians from P-PEC and home care settings.

Parents/guardians from the home care setting had the least problems getting support from others compared to parents/guardians from the P-PEC and LTC settings.

There was no significant difference in the Cognitive Functioning overall means across the care settings. Parents/guardians from the P-PEC setting had the least problems and parents/guardians from the home care setting had the greatest cognitive problems. There was a significant difference in the Cognitive Functioning dimension of hard to remember what I just heard ($F = 3.4$, $p = .04$) across the care settings. Parents/guardians from the P-PEC setting had the least problems compared to parents/guardians from the home care settings. Parents/guardians from the home care setting had the greatest problems in all of the cognitive functioning dimensions except remembering what they were just thinking compared to the other care settings.

There was no significant difference in the Communication overall means across the care settings. Parents/guardians from the P-PEC setting had the least communication problems in all of the dimensions compared to parents/guardians from the home care and LTC settings. Parents/guardians from the home care setting had the greatest problems with others not understanding their family situation and telling the doctors and nurses how they feel compared to parents/guardians from the P-PEC and LTC settings. Parents/guardians from the LTC settings had the greatest problem with talking about their child's health with others compared to parents/guardians from the home care and P-PEC settings.

There was no significant difference in the Worry overall means across the care settings. Parents/guardians from the P-PEC setting and the home care settings had the greatest problems with worry. There was a significant difference regarding how the child's illness affected other family members (*F* = 4.6, *p* = .013) across the care settings. Parents/guardians from the P-PEC setting had the least worry and home care parents/guardians had the greatest worry about how the child's illness affected other family members. Parents/guardian from the LTC setting had the greatest worry about the side effects of the medications/treatments. Both home care and LTC parents/guardians worried about how others will react to the child's condition.

There was a significant difference in the Daily Activities overall means across the care settings (*F* = 6.9, *p* = .002). Parents/guardians from the home care setting had the greatest problems with all the items of Daily Activities compared to parents/guardians from the LTC settings. There was a significant difference in the Daily Activities dimensions of family activities taking more time and effort (*F* = 4.2, *p* = .02), difficulty finding time to finish household chores (*F* = 7.0, *p* = .002), and feeling too tired to finish household chores (*F* = 6.8, *p* = .002) across the care settings. Parents/guardians from the LTC setting had the least problems with finding time to finish chores and feeling too tired to finish household chores compared to parents/guardians from home care and P-PEC settings.

There was no significant difference in Family Relationships overall means across the care settings. Parents/guardians from the home care setting had the highest overall mean compared to parents/guardians from P-PEC and LTC who scored nearly the same. Parents/guardians from the home care setting had the least problems in difficulty making decisions together as a family, difficulty solving family problems together, and stress or tension between family members, while parents/guardians from the LTC setting had the greatest difficulties in the same dimensions.

Family Cost of Care Burden

Family cost of care burden included out-of-pocket expenses, total time spent for health related appointments, lost employment time, lost leisure time, and time the family spent providing direct care for the CSHCN across the care settings.

Data on lost leisure were collected using a tool with questions similar to the National Survey of Children with Special Health Care Needs section, Impact on the Family. Parents/guardians had a difficult time responding to lost leisure time. They found it challenging to identify a baseline from which to respond since they described their lives as “always having their child.” Therefore, leisure time activities were collected and compared across the care settings and across time. The tool measured the parents’/guardians’ quiet time with others, rest and relaxation time, talking socially on the telephone, visiting others in their homes, eating out socially, fun activities with other adults only, participation in an organized group or club, participation in church or synagogue, participation in sports or exercise, participation in a hobby, reading for pleasure or surfing the web, watching TV or napping, participation in a recreational activity with the CSHCN, and any personal grooming appointments.

Time spent caring for the CSHCN was measured as direct hands on care that included feeding, bathing, dressing, grooming, toileting, mobility, administering medications, and providing treatments in hours per week. Care coordination time was measured as hours per week spent calling health care providers for appointments and consultations, ordering durable medical equipment and supplies, contacting insurance providers concerning provisions of care, and consultations for legal issues.

Total Sample – Family Cost of Care Burden

Out-of-pocket costs are presented in Table 11. The overall out-of-pocket mean expenditures for the past year was $6,080.14 (SD $11,203.32) with a range of $45 to $ 56,000.00. The overall out-of-pocket mean expenditures per month over time was $348.78 (SD $623.34) with a range of $10 to $4,600.00.

Total time spent for health related appointments: time traveling, time spent waiting, and time spent with the providers are presented in Table 11. The overall mean total time spent for health related appointments across the study period was 252.3 minutes (SD 224.7) or about four hours and 15 minutes, with a range of 15 to 1,515 minutes or a quarter hour to over 25 hours. The overall traveling time to and from appointments for routine care, specialty care, acute care, urgent care, emergency rooms and hospitals, therapy offices, or other health-related appointment across the care settings was mean 61.2 minutes (SD 59.9) with a range of 5 minutes to 753 minutes or almost 12 hours traveling time per month. Twenty-eight (35.9%) of the families had a total mean time for the health-related appointments for the CSHCN of 60 minutes or less per month; 25 (28.6%) had a mean time of 61 minutes to 104 minutes; and 25 (32.1%) had a mean time over more than 90 minutes total mean time per month.

Time waiting after signing in with the receptionist included being sent for tests, waiting for test results while in the office waiting room before being seen by the provider. The overall mean waiting time across the six months was 71.6 minutes (SD 90.3) with a range of two minutes to 270 minutes or just about 4.5 hours.

Time with provider included nurses, residents and physicians coming into the treatment room and talking with the parent/guardian. The overall mean time spent with the provider was 53.7 minutes (SD 63.7) with a range of six minutes to 249 minutes or about four hours.

Table 11. Out–of--Pocket & Time Investments

	Total **N = 84**	**Home care** **n = 28 (33%)**	**P-PEC care** **n = 29 (35%)**	**LTC** **n = 27 (32%)**	**Test statistic**
Out-of-Pocket Expenditures Per Month					
Health related expenditures M (SD)	\$348.78 (623.34)	\$381.11 (876.62)	\$248.42 (246.14)	\$458.93 (484.70)	$F = 0.26$
Time Investments Per Month in Minutes					
Total time for appointments M(SD)	252.3 (224.7)	292.5 (243.5)	174.1 (103.4)	307 (296.3)	$F = 2.2$
Travel Time: To & from Appointments	61.2 (59.9)	73.3 (82.6)	42.9 (25.3)	70.1 (52.6)	$F = 0.23$
To Routine Care	37.5 (36.2)	45.2 (47.2)	26.3 (14.6)	42.3 (37.7)	$F = 2.2$
To Specialty Care	67.6 (55.8)	69.3 (59.6)	58.5 (38.7)	77.4 (69.3)	$F = 0.71$
To Acute Care	36.8 (36.3)	43.9 (47.9)	25.4 (14.0)	42.8 (37.0)	$F = 2.1$
To Urgent Care	22.1 (13.2)	18.6 (14.4)	23.5 (12.9)	24.0 (13.9)	$F = 0.34$
To Emergency Room	35.2 (30.7)	37.6 (44.7)	35.2 (21.8)	32.3 (17.7)	$F = 0.16$
Time waiting in waiting room	71.6 (90.3)	90.0 (98.4)	41.9 (39.2)	86.5 (119.2)	$F = 2.4$
Time with provider	53.7 (63.7)	55.7 (54.1)	43.9 (55.5)	64.5 (84.7)	$F = 0.63$

*$p < 0.05$, **$p < 0.01$

Lost employment included whether or not the Parent/Guardian’s work decisions were affected by the child’s health condition. Overall, 68 (81%) of the parents/guardians reported their CSHCN health condition had affected their employment decisions during the study period. Twenty eight (33.3%) of the parents/guardians had stopped working at some time prior to the study period to care for their CSHCN full time. Of the 60 (71%) employed parents/guardians, the overall mean hours of work per week during the study was 35.8 (10.4) with a range of 7.5 to 57.5 hours (Table 12). The overall mean for missed work hours for the parents/guardians was 22.4 hours (13.1) with a range of 4 hours to 60 hours. The overall mean number of days missing work hours due to the CSHCN being sick in bed was 1.4 days (SD 3.8 days) with a range of less than a day to 28 days per month.

Table 12. Lost Employment & Family Caring Time

	Total N = 84	**Home care n = 28 (33%)**	**P-PEC care n = 29 (35%)**	**LTC n = 27 (32%)**	**Test statistic**
Lost Employment across the Care Settings					
Parent/guardian work Hours per week M(SD)	35.8 (10.4)	34.2 (9.2)	35.8 (11.9)	39.2 (10.1)	*F* = 1.2
PG missed work Hours per week	22.4 (13.1)	20.4 (12.6)	23.8 (14.6)	22.5 (12.1)	*F* = 0.30
Other family members' work hours per week	42.2 (14.5)	39.5 (16.6)	44.2 (10.4)	43.5 (15.5)	*F* = 0.82
Other family members' missed hours per week	17.4 (13.8)	24.3 (14.9)	8.0 (2.8)	14.3 (13.5)	*F* = 2.1
Family Time Caring for CSHCN					
Parent/Guardian care hours per week M(SD)	**33.0 (30.4)**	**46.9 (40.4)**	**26.3 (20.0)**	**25.2 (21.6)**	***F* = 6.8****
Other family members' care hours per week	**14.7 (13.8)**	**20.6 (17.6)**	**14.6 (10.4)**	**7.3 (6.8)**	***F* = 4.1***
Parent/Guardian care coordination hours per week	**6.6 (5.7)**	**8.8 (7.1)**	**5.2 (4.9)**	**5.5 (4.2)**	***F* = 3.8***

*$p < 0.05$, **$p < 0.01$

From the respondents' reports, 31 (36.9%) of the parents/guardians stated the CSHCN health condition had also affected another family member's employment decisions which included 5 (6%) immediate family members who stopped working prior to the study period to help care for the CSHCN. The overall mean hours of work per week for other family members during the study was 42.2 hours (SD 14.5) with a range of 8 to 75 hours. The overall mean for missed work hours for other family members was 17.4 hours (SD 13.0 hours) with a range of 2 to 45 hours.

Time spent caring for the CSHCN was direct hands on care that included feeding, bathing, dressing, grooming, and toileting, mobility, administering medications, and providing treatments. The majority 81 (96.4%) of the parents/guardians provided direct care for their CSHCN. The overall mean hours per week of direct care was 33.0 (SD = 30.4) with a range of zero to 168 hours (Table 12). Other family members such as older siblings, grandparents and/or other relatives also provided hands on care for the CSHCN. The overall mean hours of other family members' care was 14.7 hours (SD 13.8) with a range of two to 72 hours per week.

Care coordination time was measured as time spent calling health care providers for appointments and consultations, ordering durable medical equipment and supplies, contacting insurance providers concerning provisions of care, and consultations for legal issues. The overall mean hours per week of care coordination was 6.6 hours (SD 5.7) with a range of about one hour to 33 hours per week (Table 12).

The parents/guardians were asked what year they had their last vacation. "It must have been before (their CSHCN) was born" was a repeated comment. Seven (8.3%) stated they could not remember back to their last vacation. Eighteen (21.4%) reported a vacation before and in 2008; 19 (22.6%) had a vacation in 2009 or 2010; and 40 (47.6%) had a vacation between 2011 and 2013.

Group Comparisons – Family Cost of Care Burden

There was no significant difference in the out-of-pocket health-related expenditures per month across the care settings across the time points. Families from the LTC setting paid a mean of $458.93 (SD 484.70) per month, while families in the home care setting paid $381.11 (SD 876.62) per month. During the study period, the lowest monthly expenditure mean was $248.42 (SD 246.14) from the families in P-PEC.

There was no significant difference in the total time spent for health related appointments, time traveling, time spent waiting, or the time spent with the providers across the care settings. Twenty-nine (34.5%) of the families spent a mean of 30 minutes or less in total time spent for a health related appointment for the CSHCN per month. These included 15.4% from the P-PEC settings and 7.1% from LTC settings. Twenty-five (29.8%) of the families spent a mean of 76 or more minutes per month for the appointments. These included 13.0% from the LTC settings and 7.1% from P-PEC settings.

There was no significant difference in the parents'/guardians' work hours per week across the care settings across the care settings. Over half (57.6%) of parents/guardians reported working 40 or more hours per week during the study; 25.4% from the LTC settings; 18.6% from P-PEC settings and 13.6% from the home care settings.

There was no significant difference in the parent/guardian missed work hours per week across the care settings across the time points. Fourteen percent (14.3%) of the parents/guardians missed up to two days per month; 6% from the LTC settings, 4.5%

from P-PEC, and 3.5% from the home care settings. Seven (8.3%) of the parents/guardians reported missing 4 or more days of work per month during the study.

There was no significant difference in the number of other family members' work hours per week or in the number of missed work hours per week across the care settings. More than half (54.7%) of the other family members worked 40 hours or less per week; 20.8% were in home care and the P-PEC settings and 13.1% in the LTC settings. Twenty five percent (24.5%) of the other family members worked 40 or more hours per week; 9.4% from LTC and 7.5% each from home care and P-PEC settings. Forty one percent (41.2%) of the other family members missed 10 or less working hours per month; 17.6% of family members each from home care and P-PEC settings. Ten (58.9%) family members missed 30 or more hours of work per month during the study; 5 (29.4%) were from the home care settings; and 4 (23.5%) were from the LTC settings.

There was a significant difference in the mean number of direct care hours the parents/guardians provided for the CSHCN (F = 6.8, p = .002) across the care settings. The parents/guardians from the home care setting provided most hours per week compared to the parents/guardians from the LTC who provided the least hours. Twelve (14.8%) of the parents/guardians from the home care setting provided a mean of 34 or more hours of direct care per week for their CSHCN. Thirteen (16%) of the parents/guardians from LTC and 5 (6.2%) from the home care settings provided a mean of 14 or less hours of direct care per week during the study.

There was a significant difference in the mean number of care coordination hours by the parents/guardians (F = 4.1, p = .02) across the care settings across the time of the study. The parents/guardians from the home care setting provided the most care coordination hours compared to the parents/guardians from the P-PEC settings who provided the least hours. Forty-five percent of the parents/guardians provided three hours or less of care coordination per week; 22.6% of parents/guardians were from P-PEC, 14.3% from LTC, and 8.3 from home care settings. Thirty one percent (30.9%) of the parents/guardians provided seven or more hours per week with 14.8% from the home care setting. Fifty-five percent of the parents/guardians provided four or more of care coordination per week: 25% were from the home care settings, 17.9% from the LTC settings, and 11.9% from the P-PEC settings.

There was a significant difference in all of the leisure activities across the care settings except for visiting others, participating in church and reading for pleasure. In the leisure activity of having some quiet time with others, there was a significant difference across the care settings (*F* = 9.8, *p* = .005). Thirty five (41.7%) of the parents/guardians had some quiet time with others during the study. Parents/guardians (17, 20.2%) from the LTC had the most quiet time and parents/guardians from home care had the least (Table 13).

Table 13. Leisure Activities

	Total N = 84	**Home care n = 28 (33%)**	**P-PEC care n = 29 (35%)**	**LTC n = 27 (32%)**	**Test statistic**
Quiet time with others n (%)	**35 (41.7%)**	**9 (32.1%)**	**9 (31%)**	**17 (63.0%)**	***F* = 9.8****
Rest & relaxing	**36 (42.9%)**	**11 (39.3%)**	**13 (44.8%)**	**16 (59.3%)**	***F* = 4.9****
Talking on phone socially	**52 (61.9%)**	**18 (64.3%)**	**8 (27.6%)**	**21 (77.8%)**	***F* = 6.5****
Visiting others in their homes	35 (41.7%)	10 (35.7%)	12 (41.4%)	17 (63.0%)	*F* = 2.9
Eating out socially	**46 (54.8%)**	**15 (53.6%)**	**12 (41.4%)**	**19 (70.4%)**	***F* = 7.9****
Fun activities with other adults only	**40 (47.6%)**	**13 (46.4%)**	**8 (27.6%)**	**19 (70.4%)**	***F* = 5.1****
Participate in	**35 (41.7%)**	**13 (46.4%)**	**4 (13.8%)**	**18 (66.7%)**	***F* = 4.0***

organized group					
Participate in church	25 (29.8%)	12 (42.9%)	6 (20.7%)	7 (25.9%)	*F* = 1.5
Participate in exercise or sports	**21 (25%)**	**5 (17.9%)**	**5 (17.2%)**	**11 (40.7%)**	***F* = 5.2****
Participate in a hobby	**16 (19%)**	**3 (10.7%)**	**2 (6.9%)**	**11 (40.7%)**	***F* = 11.5****
Read for pleasure or surf the web	48 (57.1%)	19 (67.9%)	12 (41.4%)	17 (63.0%)	*F* = 1.5
Watch TV and/or nap	**54 (64.3%)**	**19 (67.9%)**	**15 (51.7%)**	**20 (74.1%)**	***F* = 7.3****
Participate in activity with CSHCN	**58 (69%)**	**24 (85.7%)**	**14 (48.3%)**	**20 (74.1%)**	***F* = 3.5***
Personal grooming appointments	**42 (50%)**	**12 (42.9%)**	**13 (44.8%)**	**17 (63%)**	***F* = 5.0****

*$p < 0.05$, **$p < 0.01$

For rest and relaxation (*F* = 4.9, *p* = .01) and talking on the telephone socially (*F* = 6.5, p = .003) there was a significant difference across the care settings. Thirty six (42.9%) of the parents/guardians reported some rest and relaxation. Talking on the telephone was most common with 52 (61.9%) of the parents/guardians. However, only 18 (21.4%) from the home care setting actually reported talking on the telephone socially.

There was a significant difference in eating out (*F* = 7.9, *p* = .001) and in participating in a fun activity with adults only (*F* = 5.1, *p* = .009) across the settings. Eating out at a restaurant was accomplished by 54.8% of the families, most from the LTC care setting (22.6%) and the least from P-PEC (14.6%). Forty percent of parents/guardians participated in an activity with other adults only. Forty two percent (41.7%) of the parents/guardians reported participating in an organized group or meeting at some time during the study period, most from LTC and home care.

There was a significant difference in participating in exercise or sports across the care settings across time (*F* = 5.2, *p* = .008). Parents/guardians (13.9%) from the LTC were those who exercised routinely, although most of them stated they started because of a need for physical therapy themselves.

There was a significant difference in the leisure activities of watching television or napping (*F* = 7.3, *p* = .001), participating in a recreational activity with the CSHCN (*F* = 3.5, *p* = .04), the parents/guardians having a personal grooming appointment (hair dresser or barber) (*F* = 5.0, *p* = .009) across the care settings. Over 69% of the parents/guardians reported a recreational activity with the CSHCN: 28.6% from home care; 23.8% from LTC; and 16.7% from P-PEC settings. Forty two (49.8%) of the parents/guardians reported an appointment for themselves for grooming during the study period; 20.2% from LTC; 15.4% from P-PEC; and 14.2% from home care settings.

There was no significant difference in the leisure activity of visiting others in their homes, participating in church or synagogue, having a hobby, or reading for pleasure or surfing the web across the care settings. Visiting others in their homes was carried out by 46.3% of the total families; 20.2% from LTC; 14.2% from P-PEC; and 11.9% from home care settings. Churches or synagogues played a role in 29.8% of the families with the most from the home care setting. Sixteen (18.9%) of the parents/guardians had a hobby of their own; 13.1% from LTC; 3.5% home care; and 2.3% from P-PEC settings. Over 57% of the families read for pleasure or ‘surf the web’.

Health Care Service Use

Question 3: Comparing the three health care settings, were there differences in: health care service use (routine doctor office visits (primary and specialty); acute care; urgent care; and emergency room visits; hospitalizations (frequency and length of stay);

home health nursing services; physical therapy (PT); occupational therapy (OT); speech pathology (SP); and respiratory therapy (RRT)?

Data were collected using the PedsQL^{TM}2.0 Family Information Form and questions similar to those from the NS-CSHCN survey section Access to Care: Utilization. The tool measured the encounters with each service each month. The amount of time per encounter was measured in days for hospital admissions, in hours for home health nursing services, PT, OT, SP, and RTT.

Total Sample- Health Care Service Use

Health care services used during the study period are summarized in Table 14. In the previous 12 months all of the children were seen by their primary care physician. During the study period, 62.6% of the children were seen in a routine care visit; 29.8% of the children were seen once; 23.8% were seen twice; and 9% were seen up to four times. Sixty two percent of the children were seen by a specialty care physician; 22.6% were seen by at least one; 21.4% were seen by three; and 17.9% were seen by four or more specialty care physicians. Forty-eight (57.2%) of the children were seen by their primary care provider for an acute care visit; 36.9% were seen once; 16.7% were seen twice, and 3.6% were seen three times for an acute care visit.

Table 14. Health Care Services Used

	Total N = 84	**Home care n = 28**	**P-PEC care n = 29**	**LTC n = 27**	**Test statistic**
Routine Care Visits per Month M(SD)	.68 (.64)	.62 (.64)	.65 (.69)	.76 (.60)	*F* = 2.1
Specialty Visits per Month	1.6 (2.2)	1.1 (1.4)	1.7 (2.0)	1.9 (3.0)	*F* = .36
Acute Care Visits per Month	.43 (.94)	.85 (1.4)	.35 (.49)	.08 (.40)	*F* = .92
Urgent Care Visits per Month	.03 (.16)	.04 (.20)	.04 (.20)	0	*F* = 2.1

Emergency Room Visits per month	.40 (.84)	.57 (1.0)	.31 (.66)	.33 (.78)	$F = .35$
Hospital Admissions Per month	.25 (.56)	.21 (.42)	.28 (.59)	.26 (.66)	$F = .14$
Length of Hospital Stay In days per month	11.6 (18.2)	10.7 (18.3)	7.7 (9.9)	16.6 (23.6)	$F = 1.1$
Nursing Services hours per week	43.5 (72.2)	51.2 (68.3)	52.5 (89.3)	25.8 (52.2)	$F = 1.1$
Physical Therapy Hours Per week	4.2 (10.4)	7.6 (17.3)	1.9 (2.3)	3.2 (3.1)	$F = 1.0$
Occupational Therapy Hours per week	3.7 (10.0)	6.6 (16.8)	2.0 (2.4)	2.6 (2.7)	$F = .69$
Speech Pathology Hours per week	3.3 (10.1)	6.3 (16.9)	1.4 (2.3)	2.1 (3.1)	$F = .88$
Respiratory Therapy Hours per week	2.0 (7.0)	1.1 (2.2)	3.5 (11.1)	1.3 (3.4)	$F = 2.1$

*$p < 0.05$, **$p < 0.01$

Twelve (14.3%) of the children used an urgent care after hours center; 10.7% were seen once; 1.8% were seen twice; and 1.8% were seen four times. Thirty-one (36.9%) of the children were seen in an emergency room; 17.9% were seen once; 11.9% were seen twice; and 7.1% were seen four times. Thirty-eight (45.2%) of the children were hospitalized; 32.1% were admitted once; 9.5% were admitted twice; and 3.6% were admitted three or more times.

Nursing services were provided in the home for 20 (23.8%) children. The mean number of hours per week was 43.5 (SD 72.2), with a range of 18 to 138 hours per week. Five (26.3%) of the children received 18 to 40 hours of nursing home health services; 5 (26.3%) received 41 to 64 hours; and 9 (47.4%) received 65 hours or more per week of nursing care.

Physical Therapy (PT) services were provided for 46 (54.8%) children. The mean numbers of PT hours per week was 4.2 (SD1.4) with a range of one to five hours per week. Thirteen (28.3%) of the children received up to 1.5 hours per week; 22 (47.8%) received three hours; and 11 (23.9%) received up to five hours of PT per week.

Occupational Therapy (OT) services were provided for 46 (54.8%) of the children. The mean number of OT hours per week was 3.7 (SD1.0) with a range of one to five hours per week. Fourteen (16.7%) of the children received one to two hours per week; 23 (27.3%) received three to four hours; and 9 (10.7%) received up to five hours of OT per week.

Speech Pathology (SP) services were provided for 34 (40.5%) children. The mean number of SP hours per week was 3.3 (SD 7.5) with a range of one to three hours per week. Thirteen (15.5%) of the children received one to two hours of SP therapy per week; 13 (15.5%) received three hours; and 8 (9.5%) received up to 5 hours per week.

Services from a Registered Respiratory Therapist (RTT) were provided for 19 (22.6%) children. The mean number of RTT hours was 3.7 (SD 4.0) with a range of 30 minutes to 15 hours per week. Seven (36.8%) of the children received up to four hours per week; 7 (36.8%) received up to two hours per week; and 5 (26.3%) received up to 15 hours per week.

Group Comparisons – Health Care Services Used

In comparing health services across the 3 care settings, there was no significant difference in these services. In routine care visits, 38.5% of children from the P-PEC care setting and 26% of the children from the LTC settings were seen once. Five (9.6%) children from the home care setting were seen two or three times. Twenty (38.5%) children each from home care and P-PEC settings were seen by specialty care physicians with 15.4% of the children from P-PEC seen by four or more specialty care physicians.

Twenty-three (47.9%) of the children from the P-PEC setting were seen for an acute care visit, while 29.2% of the children from home care setting were seen for an acute care visit. Eleven percent (10.7%) of the children from the P-PEC setting and 2.6% from home care had urgent care visits. Eighteen (45%) children from home care were seen in the ER while only 15% of the children from the LTC settings were seen. Of the 35 hospital admissions, 15 (42.9%) were children from the P-PEC setting; 11 (31.4%) children were from home care and 9 (25.7%) from the LTC settings.

There was no significant difference in the number of hospital admissions (frequency or length of stay) across the settings. Thirteen (15.5%) children had a hospital stay less than three days. Eight (9.5%) children had three or more days in the hospital; 4 (4.8%) were from the P-PEC setting, while only two (4%) each were from the home care LTC settings.

There was no significant difference in the number of PT, OT or speech pathology hours per week across the care settings. There was no significant difference in the number of RTT hours per week across the care settings.

Chapter 5

Discussion

Technological advances made during the past thirty years have dramatically improved survival rates for children with life-threatening conditions caused by preterm births, congenital anomalies, disease, or injury (Wise, 2012) resulting in children with special health care needs (CSHCN), those children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. There are approximately 10.2 million (13.9%) children in the United States who have special health care needs. That is, one in five households or over eight million families nationwide have at least one special needs child. This group of children living with chronic illness or disability will need continuous medical and nursing services that enable them to survive, and this group of children is growing. While a proportionally small group of children, CSHCN account for a disproportionately large portion of health care costs. The US spent $67 billion for health care for 60 million children in 2000. Only 16% of the children were CSHCN, yet they accounted for 41% of the total expenditures. These high health care costs are resulting in providers and insurers becoming more aggressive about placing these children in less costly settings. However, there has been very limited research examining health outcomes of CSHCN, their families and health care services used in the limited types of health care settings available for these children and families.

Health Care Options for CSHCN

The choices available for families needing services to care for their medically complex children continue to be limited to: a) one parent reducing or resigning employment to stay home to provide care, losing income and/or medical insurance; b) maintaining the child at home, using limited and costly home health nursing services, thereby isolating the children from peers; c) enrolling child in a medical day care program such as a prescribed pediatric extended care center (P-PEC); d) placing the child in the hospital, transitional care unit, rehabilitation, or a long-term/residential nursing facility (LTC).

The literature indicates that home care isolates the CSHCN from their peers. Long-term care separates the CSHCN from their families. The medical day care (P-PEC) provides socialization for the CSHCN and family respite. Currently, economic challenges faced by families and the health care system have resulted in a greater proportion of CSHCN living at home with their families despite the extensive medical needs characteristic of this growing population (Cohen, Berry, Camacho, Anderson, Wodchis, & Guttmann, 2012; Hatzmann, Heymans, Ferrer-i-Carbonell, van Praag, & Grootenhuis, 2008). However, there have not been any reported studies comparing the child and family health and functioning, and health care service use in the three care settings available for families with CSHCN (the home care setting, the prescribed pediatric extended care setting, or the long-term/residential care setting). This study begins to provide such data.

Characteristics of CSHCN

The sample of CSHCN in this study was similar in age and gender to the National Survey of Children with Special Health Care Needs (NS-CSHCN, 2005-2006). The national sample had a majority of mixed race, followed by non-Hispanic White, and non-Hispanic Black. The present study sample reflects the South Florida demographic make-up of the communities where the families of the children resided.

Most of the children were reported to be in good to excellent health by both parent and child report. This could be attributed to a well-managed therapeutic routine across the care settings including medication administration, prescribed treatments, and special therapies. Research shows that CSHCN are heterogeneous with a wide range of health conditions and related functional difficulties (Perrine et al., 2007; Viner-Brown & Kim, 2005).

The majority of children in this study experienced neurological issues (seizures, cerebral palsy, genetic disorders), breathing or respiratory problems (chronic lung disease, asthma, oxygen or ventilator dependent), and/or feeding/swallowing problems. Compared to those in the national sample, these types of conditions resulted in the children having higher levels of care with neurodevelopmental problems, functioning limitations, multiple medical technology devices and assistive devices, and prescription medications (Jackson, Krishnaswami, & McPheeters, 2011; Liptak, Murphy, & Council on Children with Disabilities, 2011).

There were also differences in the type of special health care needs. In the national sample, use of prescription medications was lower, health care service use was lower, emotional/ developmental /behavioral problems were about the same, limitations in activities was lower, and the use or need for therapies was lower. The higher proportions of prescription use, elevated health care service use, more functional limitations, and the use of therapies in the present study could reflect the study inclusion criteria.

Parent/Guardian Caregivers

Caring for CSHCN poses challenges for individual parent/guardian caregivers and for the family unit. Carnevale and colleagues (2006) reported that the long-term care of children with complex needs places a strain on the parents’ marriage and on the siblings. It is not uncommon to find high levels of stress in the caregivers and other family members resulting in depression, poor physical health, fatigue, social isolation, increased financial strain, and uncertainty about the future. The present study, while not examining depression in the parents, found that the parents/guardians had physical and social problems, cognitive difficulties, worry, communication, and difficulties with daily activities, findings consistent with literature.

A study by Varni and colleagues (2004) used the PedsQL Family Impact Module to compare families with children with complex chronic conditions, such as cerebral palsy or birth defects, who either lived in a long-term care convalescent hospital (CCH) or at home (REACH). Families with the children at home had a lower HRQL than those families with children in the hospital. These results are consistent with the present study.

Toly, Musil, & Carl (2012) researched family functioning in a longitudinal study of families caring for technology-dependent children at home. Family functioning remained the same across time. One notable finding was an improvement in family functioning when the child no longer required the medical technology.

In this study, a small percentage of families needed someone outside of the home who was bilingual (English and Spanish) to help understand providers' directives for care. Hamilton and colleagues (2012) demonstrated non-English speaking parents of CSHCN are at risk for higher dissatisfaction with health care services when a bilingual staff and support services were not available. Perhaps as a result, Flores & Lin, (2013) found minority children are more likely than White children to have problems getting specialty care.

Home Care for CSHCN

According to Kirk et al. (2005) home care requires tremendous financial, emotional, and time commitments and resources from the family. The medically complex child's "special" routine and health care needs must be performed by family members and incorporated into normal routines of the family including work, school, transportation, child care, and housekeeping (Drummond, Loonam, & Phillips, 2011; Elias, Murphy ,& Council on Children with Disabilities, 2012; Heaton et al., 2005; Hexem, Bosk, & Feudtner, 2011; Kuo et al., 2011). Care needed may include administering medications, oxygen therapy, changing tracheostomy tubes, suctioning airways, passing nasogastric tubes or foley catheters, administering intravenous infusions, giving injections, or providing continuous and sometimes painful therapeutic regimes (Kirk & Glendining, 2004; Viner-Brown & Kim, 2005).

In the present study, the burden of care for families in home care was heavy. They provided administration of medications (oral, G-tube, inhalants, injections, rectal, and topical forms), monitored the oxygen via nasal cannulas and tracheostomy tubes, suctioned airways, changed tracheostomy tubes, provided G-tube feeds, cleaned and changed G-tubes, inserted foley catheters, monitoring and trouble-shooting problems with the medical technology devices, maintenance and minor repairs of the assistive equipment, provided physical and occupational therapy, all the activities of daily living – bathing, grooming, dressing, feeding, toileting, and mobility, and any parenting that was cognitively-age appropriate, scheduled medical appointments, and transported the child to the appointments.

Kuo, Cohen, Agrawal, Berry, & Casey (2011) examined family reported burden of care using the NS-CSHCN 2005-2006. Burden was measured by the number of hours providing care and care coordination, number of medical care encounters, and unmet needs. In this study, the number of hours providing care and care coordination, especially in home care, and the number of medical care encounters were higher across the care settings than in the national sample. This may reflect a difference in condition severity of the CSHCN in this study due to the inclusion criteria for the CSHCN for comparison across the care settings.

According to Waters et al (2007), the child's HRQL decreases with the presences of more health problems, functional limitations and when the family experiences greater burden of care. Wittis and colleagues (2011) reported that there were greater perceived financial burdens, regardless of income, for families with children with functional limitations than those families with children without functional limitations. In this current study, the parents/guardians of children with a greater level of functional impairment were more likely to report financial difficulties, need for additional income, or cut more hours of work than parents/guardians of children with less condition severity affected by their functional limitations.

Lindley & Mark (2010) conducted a secondary analysis of the NS-CSHCN 2005-2006 and found that health care expenditures for CSHCN over $250.00 annually were associated with the family's perception of a financial burden. The perception of financial burden was not dependent on the financial resources at the family's disposal. Families that experienced reduced income from either cutting back hours of work or stopping work had a greater perceived financial burden. They would often respond that they needed additional income to cover the medical expenditures. In this study, more parents/guardians and other family members with children in home care reported missing more work time and working fewer hours per week.

Long Term Care for CSHCN

In comparison to the home care setting, there are relatively limited studies available on the health outcomes and cost of care for the pediatric patients in long-term/ residential care settings.

The report by Donahoe (2012) on adult long term care, describes the available long-term facilities for adult patients who are prolonged mechanically ventilator dependent, their associated costs of care and the gaps which limit policy makers in providing focused patient care. These venues included acute care hospitals with or without step-down or special units. For the acute care environments, payments are set by established guidelines from Medicare. Step down or special units usually receive patients in a persistent vegetative state that do not need hemodynamic monitoring and, therefore use less staff reducing the costs. Post-acute care included in-patient rehabilitation, skilled nursing facilities, and long-term acute care facilities. Medicare pays for 70% of the annual costs, which influences the development of these environments. Private insurers usually follow what Medicare's lead. Cost-effectiveness analyses are used and produce a model with parameters for best available estimates of costs and patient outcomes based on literature. However, there are no studies on the independence or HRQL for these adults or for children. The present research begins to fill that gap for CSHCN in long-term/residential settings.

In a qualitative study on group homes by Benederix & Sivberg (2007) siblings' described the experiences of having a brother or sister with autism and mental retardation and how these circumstances affected them and their relationship with their parents and friends. The siblings experienced the full range of emotions including responsibility, pity, fear, empathy and hope. One of the themes that emerged was 'hoping that the group home will be a relief for the family'. Some of the siblings expressed that hope for respite. Younger siblings thought they would be free from the frightening outbursts of the autistic behaviors. Older siblings thought more about their parents' situation caring for the child who was growing bigger and stronger. Some siblings saw the personal benefits of having their parents' attention back. Although this current study did not interview siblings, parents commented on effects of the CSHCN condition on other family members. Those most affected were family members from home care settings followed by those in LTC settings.

P-PEC Care for CSHCN

Medical day care settings such as prescribed pediatric extended care (P-PEC) centers are reported to complement home care by combining medical care along with the benefits of socialization, activities, and specialized therapies. They are staffed by registered nurses who provide the acute medical care needed by the children (Pierce et al., 1987). Despite an increasing number of children prescribed by physicians to P-PEC centers, there are minimal data reported on the effects of P-PEC care on the health and functioning of CSHCN and their families. This present research begins to fill the gap for CHSCN and their families in P-PEC care settings.

Differences in CSHCN Health and Functioning Across Settings

Child Health and Functioning--Parent/Guardian Proxy Report

There were no significant differences in the Total Summary Score, the Physical Health Summary Score, or the Psychosocial Health Summary Score across the care settings as reported by parents/guardians.

The children in P-PEC had the least physical problems overall. They were the youngest to be diagnosed with their first chronic condition, had moderate disability, and received the most special therapy hours per week. Children in LTC had the greatest physical functioning problems compared with those in the other settings. LTC children were the oldest, more were in a vegetative state, used more specialty care physicians, received more medications daily, and used more medical technology devices, assistive equipment and devices.

There was no difference in the Emotional Functioning across the care settings. There was a significant difference in trouble sleeping with the children in P-PEC having the least problem and the children in home care having the greatest problem. P-PEC care provided age-appropriate rest time or naps during the day. The routine may have been taught to the parents and then repeated at home successfully. Children in home care settings had the greatest problems with being afraid or scared and being angry. These parents use non-verbal responses from the children as a means of communication.

There was no significant difference in the Social Functioning across the settings. Children in the P-PEC had the least overall problem with social functioning. P-PEC provides activities daily that encourages socialization. In contrast, children in home care settings experienced the greatest problems with social functioning. Being in the home can isolate the children if they are medically unable to be transported to school or other social activities. Unless children come into the home, making friends with peers is difficult. Using internet and communication technology could benefit these home bound children, but the availability of the service is very limited and expensive.

There was no significant difference in the School Functioning across the care settings. Home care children received the highest overall score for school function, and paying attention in class. These children received public school homebound education or special education services within the school for CSHCN. The education was appropriate to their cognitive abilities. Parents/guardians may have lowered their expectations about the children's capacities and therefore, raised their impressions of their child's functioning.

There was a significant difference in missing school when not feeling well and missing school for doctor or hospital appointments across the care settings. Children in the P-PEC setting had the least problems in missing school when not feeling well. P-PEC services encourage the family to send the child even when not feeling well. Nurses at the P-PEC assess the child, call the parent if the condition warrants a call or a visit with their pediatrician. Either way, the child receives care, the parents continue their daily responsibility at home or work, and if necessary an update is provided to the physician.

However, the children in P-PEC setting had the most problems missing school for doctor or hospital appointments.

Child Report

There were no significant differences in the Total Summary Score, the Physical Health Summary Score, or the overall Psychosocial Health Summary Score across the care settings in the children's self-report.

The parents/guardians were asked if their child could answer yes/no questions. Only 10 responded affirmatively. When the children were asked to participate, all 10 agreed. Five of these children were moderately disabled and five were severely disabled. There was no significant difference in Physical Functioning mean score across the care settings. The children in P-PEC had the least overall physical problems. All the children in P-PEC responded as having absolutely no problems with lifting something heavy, bathing by themselves, and doing their chores. The children in home care had the greatest overall physical problems including running and lifting something heavy.

There was no difference in the overall Emotional Functioning mean score across the settings. There was a significant difference in trouble sleeping across the care settings with children in the P-PEC having the least problem sleeping compared to children in home care. Children from home care settings had the greatest emotional functioning in all the dimensions except being afraid or scared compared to the children from P-PEC and LTC settings. However, children from LTC had the greatest emotional functioning problems with being afraid or scared. The LTC setting is away from home and family but is furnished to be as home-like as possible given the hospital-like equipment necessary for the child's care.

There was no significant difference in the overall Social Functioning mean score score across the care settings. Children from P-PEC setting had the least social functioning problems in all the dimensions. Children from home care settings had the greatest social functioning problems with others not wanting to be friends, getting teased by others, and being unable to do the same things as peers compared to the children from P-PEC and LTC settings. Children from LTC had the greatest social functioning problem with keeping up with their peers compared to children from home care or P-PEC settings. P-PEC provides the most opportunities for socializing followed by LTC while home care settings are more limited.

There was no significant difference in the overall School Functioning mean score across the care settings. Children from P-PEC had the least school functioning problems with forgetting things and missing school due to not feeling well compared to children from home care and LTC settings. Children from LTC had the greatest school functioning problems with paying attention in class, forgetting things, and keeping up with school work compared to children from home care and P-PEC settings. However, children from home care settings had the least school function problems with paying attention in class compared to children from P-PEC and LTC settings.

When the child-self report was compared to the parent/guardian proxy report there was a significant difference in bathing and in doing chores between scores from the children and the scores from the parents/guardians. The children scored themselves higher or had less physical problems than compared to the parents/guardians' score. These differences between parent and child reports are similar to those of Uzark et al (2008). Parents underestimated their child's physical abilities. This may be reflective of their protective measures due to their physical functioning limitations and limited social experiences. The parents may overestimate the effects of the disease process on the child's psychosocial functioning suggesting a lower HRQL report for the child.

Differences in Family Health and Functioning Across Settings

While there were no significant differences in the Total Summary Score, the Parent HRQL Summary Score, and the Family Functioning Summary Score across the care settings, parents/guardians from P-PEC settings scored the highest in the Total Summary Score and the Family Functioning Summary compared to the parents/guardians from home care and LTC settings.

While there was no significant difference in the overall Physical Functioning score across the care settings, parents/guardians from the P-PEC care setting had the best physical functioning and parents/guardians from home care settings had the worst. Parents/guardians from home care reported a significant difference in being tired during the day, being too tired to do the things they like to do, feeling physically weak and of being sick to their stomach. This maybe a consequence of the number of direct care hours and care coordination hours the parents/guardians provided to their children. These parents/guardians may also experience the lack of sleep at night due to the noises of the monitors, or sounds of distress from the child, or the noises of the care being provided by a night shift nurse or just noises from the night nurse not related to the care of the child.

Hatzmann et al (2008) reported lower HRQL in parents caring for chronically ill children at home. Measures included physical health, sleep, pain, vitality, social and cognitive functioning, and daily activities. Findings described above from the present study are primarily consistent with the Hartzman et al., (2008). study from the Netherlands.

While there was no significant difference in the Emotional Functioning overall mean across the care settings, parents/guardians from the P-PEC had the least emotional functioning problems compared to those from the home care and LTC settings. Anxiety was higher in parents/guardians from home care and LTC. Parents/guardians from the P-PEC settings have their children in the care of healthcare professionals all day and the children return home with the parents. Home care parents/guardians are watching their children all day with or without help. LTC parents/guardians must leave the care of their child in someone else's hands and most times, away from their home community.

While there was no significant difference in the Social Functioning overall mean across the care settings, parents/guardians from LTC had the fewest problems and those in the home care settings had the most problems in functioning socially. There was a significant difference in finding time for social activities with those in home care having the greatest problems finding time to socialize, LTC the least and those parents/guardian from P-PEC in the middle. Parents/guardians from home care had the least problems getting support from others compared to those from P-PEC and LTC.

While there was no significant difference in the Cognitive Functioning overall mean across the care settings, there was a significant difference in "remembering what I just heard" across the care settings. Parents/guardian from the P-PEC setting had the least problems compared to parents/guardians from the home care settings. Parents/guardians from home care had the greatest problems in all cognitive functioning dimensions except remembering what they were just thinking compared to the others.

Parents/guardians caring for their children at home must be exact in remembering medication administration and feeding times and doses, scheduled doctor appointments and therapy times. They need to remember the specific instructions from each provider and remember to whom to report what. In this sample, many parents/guardians had a large notebook to help them remember specific details.

Parents/guardian from the P-PEC setting had the least communication problems in all of the dimensions compared to those in home care and LTC. Parents/guardians from home care had the greatest problems with others not understanding their family situation and telling the doctors and nurses how they feel compared to parents/guardians from the P-PEC and LTC settings. Those from LTC settings had the greatest problem with talking about their child's health with others compared to those from home care and P-PEC. Parents/guardians from P-PEC settings have children that may not look like they have a chronic health condition, so difficulty talking about it would seem less likely. Daily life revolves around the children especially for the parents/guardian in home care: timing daily activities with times for medications, feedings, treatments, scheduled therapies, scheduled health care appointments, and whatever the child needs that day. Some parents/guardians reported conversations with friends and family are usually about the child; "he's fine" was the usual answer. The parents/guardians don't have to go into details that may appall their friends or family. Conservations with other parents with CSHCN are usually easier to have because both of them understand the unique challenges they are facing. Parents/guardians in LTC may have feelings concerning their placement of their child in a long-term residential setting. They may not want others to form opinions about their necessary actions without knowing the whole story.

Parents/guardians from the home care settings had the greatest problems with worry. There was a significant difference regarding how the child's illness affected other family members across the care settings. Parents/guardian from the P-PEC setting had the least worry and home care parents/guardians had the greatest worry about how the child's illness affected other family members. Parents/guardian from the LTC setting had the greatest worry about the side effects of the medications/treatments. Both home care and LTC parents/guardians worried about how others will react to the child's condition. The aspect of the physical care has been taken away from the LTC settings' parents/guardians and partially from home care parents with home health nursing services. They have been the expert caregiver for these children and now they must give up complete and partial care respectively.

There was a significant difference in the Daily Activities overall mean across the care settings. Parents/guardians from the home care setting had the greatest problems with all the dimension of Daily Activities compared to those from LTC. There was a significant difference in family activities taking more time and effort, difficulty finding time to finish household chores, and feeling too tired to finish household chores across the care settings with parents/guardian from the LTC having the least problems compared to those from home care and P-PEC settings. LTC frees the parent/guardian of the physical hands on care of their child. The parents in the home care setting must remain available for the child's care. If nurses are not available for their shift, the parent must stay at home and provide the needed care.

There was no significant difference in Family Relationships overall mean across the care settings. Parents/guardians from the home care setting had the fewest problems compared to those in P-PEC and LTC. Parents/guardians from the home care setting had the least problems in difficulty making decisions together as a family, difficulty solving family problems together, and stress or tension between family members. Most single parent families were from the home care setting where negotiating decisions is generally limited to the mother.

Differences in Cost of Care Burden Across Settings

There was no significant difference in the out-of-pocket health related expenditures per month across the care settings. Out-of-pocket expenditures included health related needs the insurer did not cover. Families from the LTC setting paid the most per month, while families in P-PEC paid the lowest monthly. This amount of out-of-pocket money in each setting was unexpected. According to Bumbalo et al (2005), families with public insurance or Medicaid were more likely to spend $250.00 or less per month. Medicaid was the primary payer except for 12 (14.2%) families; 8 (9.5%) who had private insurance, 2 (2.3%) who had both public and private insurance, and 2 (2.3%) who were uninsured during the study period. The mean amount of monthly out-of-pocket expenditures exceeds the suggested $250.00 suggested by Lindley & Mark (2010) as a perceived family financial burden.

There was no significant difference in the total time spent for health related appointments: time traveling, time spent waiting or the time spent with the providers across the care settings. Some parents/guardians were able to choose their hospital and specialty care clinics. Some would drive further away in order to see the provider they chose. No studies were found examining the amount of time families devoted to health related appointments with CSHCN.

There was no significant difference in the parents'/guardians' mean number of work hours per week across the care settings; however those in home care worked the least. There were no significant differences in the parents'/guardians' mean number of missed work hours per week. There were no significant differences in the mean number another family member's work hours per week or in the mean number of missed work hours per week across the care settings.

There was a significant difference in the mean number of direct care hours the parents/guardians provided for the CSHCN and in the mean number of care coordination hours by the parents/guardians across the care settings. Parents/guardians from the LTC had the fewest number of direct care hours and the fewest number of care coordination hours per week, while parents/guardians from home care settings had the most number of direct care hours per week. There was a significant difference in the mean number of another family member's care hours. Other family members from the LTC had the fewest number of care hours per week and those from home care setting had the largest number of care hours per week.

McManus, Carle, Acevedo-Garcia, Hauser-Cram, & McCormic (2011) described caregiver burden using the number of hours per week families spent providing health care and care coordination for their CSHCN. Their findings suggested time obligations contributed more substantially to caregiver burden compared to their financial burdens.

There was a significant difference in the leisure activities of having some quiet time with others, rest and relaxation, of talking on the telephone socially, of eating out, of participating in a fun activity with adults only, of participating in exercise or sports, of watching television or napping, of participating in a recreational activity, and having a personal grooming appointment across the settings. The parents/guardians from the LTC settings participated most in all the leisure activities except participation in church, reading for pleasure, watching TV and napping, and participating in an activity with the CSHCN. These latter activities parents/guardians in home care participated most. The parents/guardians from the P-PEC settings participated the least in talking on the telephone, socially eating out socially, fun activities with other adults only, participating in an organized group, and participating in a hobby. The LTC parents/guardians reported the best overall HRQL score, the least problems with having time and energy for social activities across the settings.

Differences in Health Care Service Use Across Settings

There was no significant difference in the mean number of routine care or specialty care visits, acute care visits, urgent care visits, emergency room visits, or hospitalizations (frequency or length of stay) per month across the care settings. There were no significant differences in the mean number of PT, OT, and SP hours per week across the care settings. More hours of physical therapy were provided to the children in the P-PEC settings per week, while children in the LTC settings received the least. More children in the home care setting received the more occupational therapy hours per week and the children in the P-PEC settings received the least number of hours. More speech therapy hours per week were provided for children in the P-PEC settings with the children in the LTC settings the least.

The number of hours prescribed by the physician follows the recommendation of the therapist after a full evaluation. P-PEC settings and the LTC settings will provide a therapist according to the needs of the children. Parents/guardians in the home care settings may be given the names and numbers of the local providers to make arrangements for services in the home.

There was no significant difference in the mean number of Register RRT hours per week across the care settings. Children in the P-PEC settings had the largest number of hours and the children in the LTC settings had fewest. The RRTs monitor the children with ventilators and tracheotomies, assess respiratory status, provide breathing treatments, and conduct evaluations. There were more children with ventilators and tracheotomies in the home care settings. In the P-PEC settings and LTC settings, RRTs are available for the children in distress and routine breathing treatments. More hours were provided for children in the P-PEC setting than hours in the LTC settings.

Limitations of the Study

The study used a convenience sample. It is not known if the same findings would hold using random sampling. Data were based on the parent/guardian proxy reports and child-reports from 10 children for child health and functioning data. This was the most reliable method considering the cognitive abilities of the majority of children. A change in the study method was required using two methods of data collection (face-to-face interviews and by telephone). This was necessary to provide more flexibility for the parents/guardians that lived more than three drive hours or more away from the PI. Lastly, the study has a small sample size with a 9.5% attrition rate; however, this is an attrition rate less than other similar studies.

Implications

Over the past 30 years, the number of CSHCN has markedly increased, mainly as the results of advanced medical technology. Unfortunately, the options of care available for the families have not improved. One change that has begun as the result of Healthy People 2010 which set a goal to reduce the number of children living in congregate and institutional care settings. Many children and families may benefit. However, community-based supports need to be in place to assist the families in this challenge.

Implications for Clinical Nursing Care

There is a need to educate health care professionals on how they can help to improve service delivery mechanisms. Health care professionals must be aware and understand the challenges these parents struggle with constantly not just on that particular encounter. The providers need to understand that these parents may feel fatigued, strained, ill informed, guilty, or disempowered by the lack of adequate support from the health care system.

Future Research

- Qualitative study with parents of CSHCN and what influenced their choice of current care setting?
- Develop and test interventions to enhance support for the parents of CSHCN (information, community-based services, respite and leisure opportunities, transition process of the child to adult care including guardianship process)
- Examine the cost effectiveness of APNs as care managers for CSHCN in order to address the complexity of medical needs instead of other clinical staff or less skilled alternatives.

- Research on child health and health care disparities. Will a more diverse pediatric workforce help eliminate certain disparities, such as having a personal doctor or nurse, spending more time with the CSHCN and parent especially when language is a barrier.
- How to increase a collaborative relationships between agencies that serve CSHCN (PCP, SPC, therapies, schools, hospitals, nursing agencies, DME, transportation).

Summary

This longitudinal study describes the differences in child health and functioning, family health and functioning, and health care service use in families with children with special health care needs in three care settings: home care settings, P-PEC care settings, and the LTC settings. Children in the P-PEC settings had a highest HRQL overall including physical functioning and psychosocial functioning. They were the youngest and had the least condition severity. Parents/guardians in the home care settings had the poorest HRQL including physical functioning and psychosocial functioning: cognitive difficulties, worry, communication, and difficulties with daily activities. They had the fewest hours of employment and the most direct care hours for their children. The LTC parents/guardians had the highest HRQOL including having time and energy of a social life and employment. Out-of-pocket expenditures were highest for the LTC families. Health care service use was the same across the settings. Study results have provided a comparison of the outcomes in the available health care options for these vulnerable children and their families. These findings are important for family health care providers and those who make public health policy decisions.

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Glasgow Outcome Scale

Score	Description	
1	Death	
2	Persistent vegetative state	
3	Severely disability (Conscious but disabled)	
4	Moderate disability (Disabled but independent)	
5	Good recovery (Minor deficits)	

Total score (2-4) __

PedsQL Family Information Form™

1. *Who is completing the form?* Name: ____________________
2. What is your relationship to this child?
    - a. mother
    - b. step mother
    - c. foster mother
    - d. father
    - e. father
    - f.. foster father
    - g. grandmother
    - h. grandfather
    - i. guardian
    - j. other: ____
4. Child's date of birth: ____/____/_______
5. Child's gender: a. male
    b. female
6. Child's ethnic group or race:
    - a. Black, non-Hispanic
    - b. White, non-Hispanic
    - c. Hispanic
    - d. Asian or Pacific Islander
    - e. Native American or Alaskan Native
    - f. Other
7. Respondent's marital status:
    - a. single
    - b. married
    - c. separated
    - d. divorced
    - e. living with partner
    - f. widowed
8. Respondent's date of birth: ___/____/______
9. Respondent's highest level of education:
    - a. 6th grade or less
    - b. 7th-8th grade
    - c. 9th -12th grade
    - d. High school graduate
    - e. Some college or certification course
    - f. College graduate
    - g. Graduate or professional degree
10. Respondent's occupation or job title___________________
11. *In the past 6 months, has your child* had a chronic health condition (defined as a physical or mental health condition that has lasted or is expected to last at least 6 months, and interferes with your child's activities)?
    - a. Yes
    - b. No

11a. If yes, what is the name of your child’s chronic condition?

12. *In the past 12 months, has your child* had any overnight visits to the hospital?
  a. Yes
  b. No
12a. If yes, how many times? _____
12b. What was wrong? _______________________________
13. *In the past 12 months, has your child* had any emergency room/urgent care visits?
  a. Yes
  b. No
13a. If yes, how many times? _____
13b. What was wrong? _______________________________
14. *In the past 30 days* how many days did your child miss from school due to physical or mental health? _____
15. *In the past 30 days* how many days was your child sick in bed or too ill to play?_____
16. *In the past 30 days* how many days did your child need someone to care for her/him due to physical or mental health? _____
If you work outside of the home, please answer the following questions.
17. In the past 30 days, how many days have you missed from work due to your child’s physical or mental health? _____

In the past 30 days, has your child’s health interfered with	Never	Almost Never	Some times	Often	Almost Always
18. …your daily routine?	0	1	2	3	4
19….. your ability to concentrate?	0	1	2	3	4

PedsQL Pediatric Quality of Life Inventory^{TM}

Please tell us how much of a problem each item has been for you during the past ONE month:
There are no right or wrong answers.

Physical Functioning (problems with…)	Never	Almost never	Some-times	Often	Almost Always
Running	0	1	2	3	4
Participating in sports	0	1	2	3	4
Lifting something heavy	0	1	2	3	4
Taking a bath or shower by yourself	0	1	2	3	4
Doing chores around the house	0	1	2	3	4
Having hurts or aches	0	1	2	3	4
Low energy level	0	1	2	3	4

Please tell us how much of a problem each item has been for you during the past ONE month:

Emotional Functioning (problems with…)	Never	Almost never	Some-times	Often	Almost Always
Feeling afraid or scared	0	1	2	3	4
Feeling sad or blue	0	1	2	3	4
Feeling angry	0	1	2	3	4
Trouble sleeping	0	1	2	3	4
Worry about what will happen to you	0	1	2	3	4

Please tell us how much of a problem each item has been for you during the past ONE month:

Social Functioning (problems with…)	Never	Almost never	Some-times	Often	Almost Always
Getting along with others	0	1	2	3	4
Others not wanting to be friends	0	1	2	3	4
Getting teased by others	0	1	2	3	4
Not being able to do things that others same age can do	0	1	2	3	4
Keeping up with others	0	1	2	3	4

Please tell us how much of a problem each item has been for you during the past ONE month:

School Functioning (problems with…)	Never	Almost never	Some-times	Often	Almost Always
Paying attention in class	0	1	2	3	4
Forgetting things	0	1	2	3	4
Keeping up with school work	0	1	2	3	4
Missing school because of not feeling well	0	1	2	3	4
Missing school to go to the doctor or hospital	0	1	2	3	4

Cognitive Functioning Scale™

Please tell us how much of a problem each item has been for you during the past ONE month:

Cognitive Functioning (problems with …)	Never	Almost never	Some-times	Often	Almost Always
Difficulty keeping attention on things	0	1	2	3	4
Difficulty remembering what people tell me	0	1	2	3	4

Difficulty remembering what I just heard	0	1	2	3	4
Difficulty thinking quickly	0	1	2	3	4
Trouble remembering what I was just thinking	0	1	2	3	4
Trouble remembering more than one thing at a time	0	1	2	3	4

PedsQL Family Impact Module Parent Report^{TM}

Families of children sometimes have special concerns or difficulties because of the child's health. The following is a list of things that might be a problem for you.
Please tell us how much of a problem each one has been for you during the past ONE month:

Physical Functioning (problems with…)	Never	Almost never	Some-times	Often	Almost Always
I feel tired during the day	0	1	2	3	4
I feel tired when I wake up in the morning	0	1	2	3	4
I feel too tired to do the things I like to do	0	1	2	3	4
I get headaches	0	1	2	3	4
I feel physically weak	0	1	2	3	4
I feel sick to my stomach	0	1	2	3	4

Please tell us how much of a problem each one has been for you during the past ONE month:

Emotional Functioning (problems with…)	Never	Almost never	Some-times	Often	Almost Always
I feel anxious	0	1	2	3	4
I feel sad	0	1	2	3	4
I feel angry	0	1	2	3	4
I feel frustrated	0	1	2	3	4
I feel helpless or hopeless	0	1	2	3	4

Please tell us how much of a problem each one has been for you during the past ONE month:

Social Functioning (problems with…)	Never	Almost never	Some-times	Often	Almost Always
I feel isolated from others	0	1	2	3	4
I have trouble getting support from others	0	1	2	3	4

It is hard to find time for social activities	0	1	2	3	4
I do not have enough energy for social activities	0	1	2	3	4

PedsQL Family Impact Module Parent Report (continued)

Please tell us how much of a problem each one has been for you during the past ONE month:

Cognitive Functioning (problems with…)	Never	Almost never	Some-times	Often	Almost Always
It is hard for me to keep my attention on things	0	1	2	3	4
It is hard for me to remember what people tell me	0	1	2	3	4
It is hard for me to remember what I just said	0	1	2	3	4
It is hard for me to think quickly	0	1	2	3	4
I have trouble remembering what I was just thinking	0	1	2	3	4

Please tell us how much of a problem each one has been for you during the past ONE month:

Communication (problems with …)	Never	Almost never	Some-times	Often	Almost Always
I feel that others do not understand my family's situation	0	1	2	3	4
It is hard for me to talk about my child's health with others	0	1	2	3	4
It is hard for me to tell doctors and nurses how I feel	0	1	2	3	4

Please tell us how much of a problem each one has been for you during the past ONE month:

Worry (problems with…)	Never	Almost never	Some-times	Often	Almost Always
I worry about whether or not my child's medical treatments are working	0	1	2	3	4
I worry about the side effects of my child's medications/treatments	0	1	2	3	4
I worry about how others will react to my child's condition	0	1	2	3	4
I worry about how my child's illness is affecting other family members	0	1	2	3	4

I worry about my child's future	0	1	2	3	4

In the past ONE month, as a result of your child's health how much of a problem has your family had with…

Daily Activities (problems with…)	Never	Almost never	Some-times	Often	Almost Always
Family activities taking more time and effort	0	1	2	3	4
Difficulty finding time to finish household tasks	0	1	2	3	4
Feeling too tired to finish household tasks	0	1	2	3	4

In the past ONE month, as a result of your child's health how much of a problem has your family had with…

Family Relationships (problems with…)	Never	Almost never	Some-times	Often	Almost Always
Lack of communication between family members	0	1	2	3	4
Conflicts between family members	0	1	2	3	4
Difficulties making decisions together as a family	0	1	2	3	4
Difficulties solving family problems together	0	1	2	3	4
Stress of tension between family members	0	1	2	3	4

SLAITS NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Section 9. IMPACT ON THE FAMILY

1) The next question is about the amount of money paid during the past 12 months for your child's medical care. Please include out-of pocket payments for all types of health-related needs such as medications, special foods, adaptive clothing, durable equipment, home modifications and any kind of therapy. During the past 12 months (Time 1), past ONE month (Time 2-6) would you say that the family paid more than $500, $250-$500, less than $250, or nothing for your child's medical care?

Stated amount____________(Time 2-6)

2) Many families provide health care at home such as changing bandages, care of feeding or breathing equipment, giving medication and therapies, and providing transportation to appointments. Do you or other family members provide health care at home for your child?

Yes/no

3) How many hours per week do you or other family members spend providing this kind of care?

________ HOURS PER WEEK

4) How many hours per week do you or other family members spend arranging or coordinating your child's care? By this I mean making appointments, making sure that care providers are exchanging information and following up on your child's care needs.

________ HOURS PER WEEK

5) Have you or other family members cut down on the hours you work to care for your child?

Yes/no

6) Have you or other family members stopped working because of your child's health conditions?

Yes/no

7) When you transport your child to a doctor's appointment or other health service appointments, how much time do you spend travelling to and from the appointment?

To: _______minutes________hours

From: _____minutes________hours

8) When you arrive at the doctor's office or other health service office, how long do you usually wait till you see the doctor?

_______minutes________hours

9) How much time do you spend at the appointment?

_______minutes________hours

SLAITS NATIONAL SURVEY OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Section 4. ACCESS TO CARE: UTILIZATION

1) During the past 12 months (Time 1), past ONE month (Time 2-6), was there any time when your child needed any of the following services:

- Needed routine preventive care, such as a physical examination?
  Yes/no
- Needed care from a specialty doctor?
  Yes/no
-Needed acute care doctor visits?
  Yes/no
-Needed Urgent care visits?
  Yes/no
-Needed Emergency Room visits?
  Yes/no
-Needed to be hospitalized overnight?
  Yes/no
-How many days was your child in the hospital?
  _____days____weeks
-Was there a time your child used professional nursing care at home?
  Yes/no
If yes, how much time per week?
  ________hours per day_______hours per week
-Was there any time your child used physical therapy?
  Yes/no
If yes, how much time per week?
  ________hours per day_______hours per week
-Was there any time your child used occupational therapy?
  Yes/no
If yes, how much time per week?
  ________hours per day_______hours per week
-Was there any time your child used speech therapy?
  Yes/no
If yes, how much time per week?
  ________hours per day_______hours per week
-Was there any time your child used respiratory therapy?
  Yes/no
If yes, how much time per week?
  ________hours per day_______hours per week

VITA

Carmen Caicedo

EDUCATION	DEGREE	DATE	MAJOR
Florida International University, Miami, FL	PhD in Nursing (candidate)	In progress	Nursing
University of Miami Miami, FL	Master's of Science in Nursing (M.S.N.)	2003	Community Health
University of Miami Miami, FL	Bachelor of Science in Nursing (B.S.N.)	2000	Nursing
Jackson Memorial Hospital School of Nursing, Miami, FL	Diploma	1980	Nursing

PROFESSIONAL LICENSURE AND CERTIFICATIONS

Florida, License Number RN 1227102, Expiration Date April 30, 2015

PROFESSIONAL EXPERIENCE

Position	*Organization*	*Dates*
Candidate, PhD in Nursing	Florida International University College of Nursing & Health Sciences, Miami, FL	2007-present
Adjunct Professor	Miami Dade College School of Nursing Miami, FL	2009-present
Director of Nursing	PATCHES P-PEC, Inc. Florida City, FL	2005-2011
Adjunct Professor	Barry University School of Nursing Miami Shores, FL	2004-2009
Staff Nurse Charge, Resource Clinical Nurse III	Baptist Health Systems of South Florida Miami, FL	1984-2006

Publications

Brooten, D., Youngblut, JM., Seagrave, L., Caicedo, C., Hawthorne, D., Hidalgo, I & Roche, R. (2013) Parents' perception of health care providers actions around child ICU death: what helped, what didn't. *American Journal of Hospice and Palliative Medicine.* 30(1): 40-49. DOI: 10.1177/104990911244430.

Youngblut, J., Caicedo, C., & Brooten, D. (2013). Preschool Children with Head Injury: Comparing Injury Severity Measures and Clinical Care. (*Pediatric Nursing,* in press).

Brooten, D., Youngblut, J.M., Caicedo, C., Seagrave, L., & Charles, D. (2013). Causes of PICU and NICU children's deaths: parent recall and chart review. (In progress).

Brooten, D., Youngblut, J.M., Hannan, J., Caicedo, C., & Malkawi, F. (2013). Subsequent Pregnancies after Infant and Child Deaths and Parent Concerns. (In progress).

Recent Presentations

Caicedo, C., Youngblut, J.M., Brooten, D., Prentis, A., & Sanchez, N. (2012, September). Preschool Children Hospitalized with Head Injury: Functional Status and Type of Injury and Injury Severity. "Global Nursing Challenges for the Millennium," XIII Pan American Nursing Research Colloquium, international conference, Miami Beach, FL.

Caicedo, C. and Page, T. (2013, February) "Children with Special Health Care Needs: Health Care Services Used in Florida". Network for Knowledge for Healthcare Innovations, Southern Nursing Research Society, annual conference, Little Rock, Arkansas.

MEMBERSHIPS IN PROFESSIONAL ORGANIZATIONS

2010-present	Society of Pediatric Nurses
2009-present	Elected Member, Sigma Xi, Scientific Research Society
2007-present	Southern Nursing Research Society
1999-present	Elected Member, Sigma Theta Tau International Honor Society in Nursing
1997-present	Florida Nurses Association

PROFESSIONAL SERVICE

Service to Professional Organization

Sigma Theta Tau International Honor Society in Nursing
    1999-present Beta Tau Chapter, Member
    2011-present Pi Alpha Chapter, Secretary

Institutional Review Board

2005-2006	Baptist Hospital Research Council