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PATTERNS OF PSYCHOSOCIAL FUNCTIONING AND MENTAL HEALTH
SERVICE UTILIZATION IN CHILDREN AND ADOLESCENTS WITH
CHRONIC HEALTH CONDITIONS OR PHYSICAL DISABILITIES

by

Sara M. Hunt

A dissertation submitted in partial fulfillment
of the requirements for the degree

of

DOCTOR OF PHILOSOPHY

in

Psychology

Approved:

Renee V. Galliher, Ph.D.
Major Professor

Judith M. Holt, Ph.D.
Committee Member

Melanie M. Domenech Rodriguez, Ph.D.
Committee Member

Richard N. Roberts, Ph.D.
Committee Member

Donna Bilbertson, Ph.D.
Committee Member

Byron R. Burnham, Ed.D.
Dean of Graduate Studies

UTAH STATE UNIVERSITY
Logan, Utah

2009

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ABSTRACT

Patterns of Psychosocial Functioning and Mental Health
Service Utilization in Children and Adolescents with
Chronic Health Conditions or
Physical Disabilities

by

Sara M. Hunt, Doctor of Philosophy

Utah State University, 2009

Major Professor: Dr. Renee V. Galliher
Department: Psychology

This study was designed to further understand the psychosocial functioning of youth with chronic health conditions or physical disabilities, their need for and use of mental health services, and possible barriers to receiving needed services. Previous research has suggested these youth experience poorer psychosocial functioning compared to peers without special health care needs, and they also underutilize needed mental health services. A mixed-methods design was implemented consisting of a quantitative parent survey and a qualitative semistructured interview with young adults with special health care needs.

Children demonstrating poorer psychosocial adjustment in this study experienced more problems related to social functioning than psychopathology (e.g., depression, anxiety). Over half of the youth had accessed mental health services with the majority

utilizing community-based outpatient services. Identified barriers to accessing needed mental health services included difficulty finding professionals with experience in working with youth with special health care needs and lack of financial coverage.

(157 pages)

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I can best summarize my whole postsecondary education with a quote from the Grateful Dead, “What a long, strange trip it’s been.” To think I only went to college to get a bachelor’s degree so I could get a better job and now I have just finished a dissertation. How does that happen? It happened with a lot of encouragement and support from some important people. I will never have enough words to thank my academic advisor, Dr. Renee Galliher, for all that she has done in helping me advance through my graduate career. She has not only been an integral part of my experiences as a researcher, but she has also provided an exceptional model of a successful, professional woman. As sometimes happens between two determined (or just plain stubborn) people, we have had our moments of disagreement but our relationship always came out a little stronger in the end and she taught me valuable lessons on how to use my resolve for good and not evil. I look forward to our continued friendship and hope for possible collaborations in the future.

I also greatly appreciate the time and expertise of my committee members, Dr. Melanie Domenech Rodríguez, Dr. Donna Gilbertson, Dr. Judith Holt, and Dr. Richard Roberts. Your willingness to explore this topic with me inspires me to continue integrating my research and clinical practice regarding youth with special health care needs. I also owe a special debt of gratitude to Dr. Holt for providing monetary support to provide incentives to my participants. Of course this project would never have happened if it were not for everyone who participated in my survey or completed an interview. Their time and interest in my research were so invaluable.

I know most assuredly that I would not have gotten this far without the encouragement of my friends and family in Iowa and places beyond. Your incredible love and support have kept me going through almost 10 years of school! I only hope I can offer you the same in return in your life endeavors. Never think that you are too old or too settled to achieve big things. As Ma Kathy says, “Just do it already!”

I, of course, have to acknowledge my family of friends at Utah State University. What a wonderful experience to go from calling you classmates to colleagues to friends for life. I am pretty sure that I do not even realize right now how much I will miss our time together. You have touched my life in many ways and on many occasions. Always remember that we all take our turns in life.

Finally, I dedicate my educational achievements and continued goals in loving memory of my parents, James and Laura Mott, and my foster mother, Nancy Yoder. Your spirits are always with me and I know I have accomplished what I have because you were present at different times in my life when I needed you most. You are loved and missed until we meet again.

Sara Mae Hunt

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CHAPTER I

INTRODUCTION

With the development of numerous medical advancements in the past century, chronic health conditions and physical disabilities in children and adolescents have changed markedly. Improved treatments have changed the pattern of various illnesses and disorders, most notably by extending the lifespan of children and adolescents whose symptoms or injuries proved to be fatal in the past (Eiser, 1985). Gortmaker and Sappenfield (1984) reviewed the literature documenting prevalence estimates of chronic childhood disorders. Overall, the rates of any chronic disorder in children were estimated at 10-20% of the population. However, a variety of estimates were found depending upon the definitions of chronic disorder used, the methods of study, and the population surveyed. More recently, estimates from the 2000 U.S. Census identified approximately 6% of the population 5 to 15 years of age as having any type of disability (Waldrop & Stern, 2003). Furthermore, approximately 3% of children in this age range are identified as having a sensory, physical, or self-care related disability. Similarly, 6.5% of children under the age of 18 were classified as experiencing some degree of disability in a recent national health survey ($n = 99,513$; Newacheck & Halfon, 1998). Respiratory diseases (i.e., asthma), speech and sensory impairments, and intellectual disabilities (i.e., mental retardation) were found to be the most common causes of disability in this survey. Most recently, the 2003 National Survey of Children's Health reported 18% of children 0 to 17 were identified as having special health care needs ($n = 102,353$; Child and Adolescent Health Measurement Initiative, 2003).

Not only are there important physical and medical considerations for these individuals, children and adolescents with chronic health conditions or physical disabilities are at increased risk for experiencing psychosocial problems compared to those without chronic medical concerns. An integrated review of studies examining the relationship between chronic health conditions in children and adolescents and individual psychological functioning was conducted by Thompson and Gustafson (1996). Prevalence rates of psychological difficulties were compared across 61 studies, including epidemiological studies, primary research, and meta-analyses. Across epidemiological studies, 9-30% of children with chronic health conditions experienced behavioral or emotional problems compared to estimated rates of 7-17% of control children without chronic health conditions. Clinical studies presented outcome data indicating children with chronic health conditions were at risk for significant psychological problems 1.5 to 3.4 times that of children without chronic health conditions. One meta-analysis reported moderate effect sizes indicating higher levels of internalizing symptoms, externalizing symptoms, and overall adjustment problems in children with physical disorders compared to control group children without disabilities and normative comparison groups (.26 to .62, $p < .05$; Lavigne & Faier-Routman, 1992). Data collected in the 2003 National Survey of Children's Health showed 4% of parents of children ages 3 to 17 with no special health care needs identified their child as having moderate to severe difficulties in the areas of emotions, concentration, behavior, or poor social relationships compared to 31% of parents with children ages 3 to 17 with special health care needs (Child and Adolescent Health Measurement Initiative, 2003).

As mentioned in the discussion above, variability in results exists across the broad body of chronic illness/disability literature due to the various ways that “chronic health condition” and “disability” are defined across studies. There are numerous studies that have examined psychosocial constructs (e.g., psychological functioning, peer relationships, etc.) for specific chronic conditions and disabilities (e.g., cancer, diabetes, visual impairment), and other studies that have explored similar constructs using “noncategorical” definitions (identification based on characteristics of symptoms or impairment levels) of chronic conditions or disabilities. This inconsistency in operationalizing terms has yielded a body of literature that is difficult to integrate or summarize. Additionally, there are few studies that have used both a specific diagnostic approach and a noncategorical approach in exploring psychosocial outcomes, allowing for a comparison of the two approaches. This type of research would benefit clinical practice by guiding treatments and services. For example, should all children with cerebral palsy be expected to experience similar psychological problems and be treated with similar approaches? Or does the presence of emotional or behavioral problems vary based on the age of onset of symptoms or by the extent of physical limitations in daily life and so forth?

Psychosocial functioning is also operationalized differently across studies of children and adolescents with chronic health conditions and disabilities. Much of the research has used broad constructs of psychosocial maladjustment identifying twice the number of children with chronic conditions as maladjusted compared to children in comparison groups (Wallander, Thompson, & Alriksson-Schmidt, 2003). However, there is a paucity of research that identifies the specific types of psychological problems these

children develop. Furthermore, these studies used various measurements of functioning, including many questionnaires that are not normed on children and adolescents with chronic conditions or disabilities. A concern is raised because some of these self-report or parent-report measurements include items that associate physical symptoms such as pain or sleep difficulties with poor psychological functioning. This study addressed these shortfalls by utilizing a measurement of psychosocial functioning that is designed for use with children with chronic health conditions and generates results regarding more specific areas of psychosocial functioning.

The fact that psychosocial difficulties are often significant enough to warrant therapeutic intervention highlights the need for accessible mental health services for children and adolescents with chronic health conditions and physical disabilities and their families. Unfortunately, although research is limited, it appears that mental health services for this population are underutilized, and there are various barriers or limitations to accessing these services. A survey of disability advocates suggested that individuals with severe physical disabilities are an underserved group, in relation to both public and private mental health service providers (Pelletier, Rogers, & Thurer, 1985). Given some of the functional limitations and extensive medical treatments of chronic conditions and physical disabilities, it is reasonable to believe that accessing services may be difficult. However, little research has been conducted to explore these issues. Additional research in the area of mental health service utilization by children and adolescents with chronic health conditions and disabilities would not only provide added information about the *rates* of service utilization, it would also help to clarify the *nature* of service utilization (e.g., outpatient, inpatient, school-based), and the *reasons* why services are underutilized.

The current study was designed to further understand how specific medical diagnoses and condition characteristics (i.e., noncategorical approach) were associated with individual child psychological functioning and mental health service utilization. Previous research has established that children and adolescents with chronic health conditions or physical disabilities are at increased risk for emotional or behavioral problems. However, variability exists in how disabilities have been defined and how psychosocial functioning has been operationalized, which has produced some inconsistency in previous results. In addition, other studies have indicated that mental health services are underutilized, but patterns and limitations in accessing services need further review. A correlational study was proposed to examine how different strategies for operationalizing chronic health conditions and physical disabilities were associated with individual psychosocial functioning and mental health service utilization. Quantitative and qualitative techniques were used to describe those relationships.

CHAPTER II

REVIEW OF THE LITERATURE

Although medical and technological advancements have positively impacted the course of many chronic conditions and disabilities, there continue to be a number of stressors in the daily lives of children and adolescents with chronic health conditions or physical disabilities and their families. Medical treatments still have the potential to be lengthy and painful, which can have long-term effects on psychological functioning (Eiser, 1985). In addition, other issues related to social functioning, a daily need for caregiver support, financial considerations, and the acceptance of the presence of a chronic health condition or disability all have the potential to be distressing to children and their families. The following review of the literature begins with an examination of issues related to defining chronic conditions and disabilities. Next, associations with chronic conditions/physical disabilities will be explored for individual psychosocial functioning and mental health service utilization. Finally, questions for the current study will be presented.

Defining Chronic Condition and Disability

Reliable information on children with chronic health conditions or disabilities is needed, but inconsistencies in the way conditions and disabilities are defined have made it difficult to interpret available data (Stein, 1997). In a government study regarding the implications of disability definitions for children, Stein stated “different definitions of disability in children may substantially affect prevalence estimates and may differentially

identify children with particular characteristics” (p. 19). She suggested these implications could affect the number of children served according to which definitions are used, and may increase the risk of underidentifying children if disability is based on a single concept. Thus, it is important to understand the strengths and weaknesses of different conceptualizations of chronic health condition or disability in research.

“Chronic condition” and “disability” are often operationalized in one of two ways: (a) by specific medical diagnosis (e.g., cerebral palsy, asthma, blindness, etc.), or (b) by a noncategorical approach of classifying conditions or disabilities based on similar consequences or characteristics observed across many conditions (e.g., age of onset, duration of symptoms, limitations in daily functioning, etc.). Diagnostic-specific approaches to defining chronic condition or disability acknowledge the distinct biological processes of disorders and often result in condition-specific treatment regimens (e.g., specialists, specialty clinics, etc.; Wallander et al., 2003). Researchers have investigated specific conditions or have pooled together participants with identified conditions for data analysis to compare with control groups of children without disabilities (Lavigne & Faier-Routman, 1992). An argument against the use of diagnostic-specific definitions in research involves reliance upon samples of convenience. Studies conducted at single sites using small samples of children introduce strong possibilities of bias based upon unique demographic patterns of patients at a medical center (Lavigne & Faier-Routman). Stein (1997) also argued that a disease-specific method of identification is outdated according to current public policy that seeks to move towards broadening the eligibility criteria for children.

While most research tends to use specific medical diagnoses, there is considerable overlap in the consequences of disability across chronic physical conditions, such as the need for continuous medical treatment by various health care professionals; pain and discomfort are common, as are limitations in performing age-appropriate activities (Wallander et al., 2003). These commonalities across diagnoses have led some to suggest that the psychosocial study of children with chronic conditions would benefit from classification based on a noncategorical approach, implying that specific diagnoses should not be used (Pless & Pinkerton, 1975; Stein & Jessop, 1982). These authors have argued that it is the variability within different features or characteristics common to many diagnoses that affects outcomes rather than variability across different diagnoses, and that there is more characteristic variation within a diagnosis than between diagnoses. Noncategorical approaches focus on the characteristics of diverse health conditions, which may have more widespread application for program planning and reimbursement of services (Stein, 1997). Characteristics have been broadly identified in some research as nature of onset and course, life-threat potential, intrusiveness or pain of treatment, visibility and social stigma, stability versus crises, and secondary functional and cognitive disability (Wallander et al.). Lavigne and Faier-Routman (1992) suggested that a limitation with the noncategorical approach lies with the issue that this approach fails to indicate which characteristics should be most important, whether their effects are additive, or how they might otherwise be combined to predict risk for psychological problems.

A noncategorical theory was posited by Stein, Bauman, Westbrook, Coupey, and Ireys (1993). Stein and colleagues argued that traditional lists of diagnoses or conditions

are less reliable to determine eligibility or participation in services because (a) only the most prevalent childhood disorders are considered even though there are a vast number of conditions or disabilities, (b) consistency in diagnosing varies by physicians and across settings, (c) labels by themselves do not convey the extent or severity of symptoms, (d) children who have access to medical care are more likely to carry a diagnosis, and (e) there is the possibility for a delay in diagnosis after symptoms or consequences begin. They suggest that it is the consequences of chronic conditions that are more relevant than the diagnostic label itself. More specifically, consequences related to functional limitation compared to peers without disabilities or chronic conditions across all areas of development (e.g., physical, cognitive, socialization, etc.), dependency on aids to compensate for limitations (e.g., medications, assistive devices, special diets, etc.), and the need for care services above and beyond those typical for the child's age (e.g., specialized treatments, home or school accommodations, etc.). Stein and colleagues stated that the severity of conditions can be more clearly assessed by examining the characteristics or consequences of conditions, which may benefit screening purposes for service implementation, research, and interventions.

From this review, it is difficult to determine which is the most effective approach to identifying children and adolescents with chronic health conditions or physical disabilities. Both systems of categorizing have important pros and cons, but there is little insight as to how to accurately identify children and adolescents. Furthermore, it appears that few studies have systematically compared the two approaches. It is evident that this is a significant area of concern in this field of research and warrants acknowledgment in this study.

Chronic Condition/Disability and Individual Psychosocial Functioning

Thompson and Gustafson (1996) included a comprehensive discussion of how psychosocial outcomes of previous research have varied based on subject or study characteristics, resulting in limited understanding of psychological adjustment in children with chronic health conditions. First, the range of potential behavioral and emotional difficulties has not been comprehensively studied with many researchers focusing only on internalizing difficulties (i.e., anxiety, depression) or on self-esteem. Second, across all reviewed studies, a small number of psychological functioning assessment measures (e.g., Child Behavior Checklist [CBCL], Children's Depression Inventory) were frequently used. Use of these measures stems from some of the philosophical differences that exist in this field regarding whether adjustment, psychopathology, or impairment is the most important psychosocial construct to assess in children and adolescents with chronic health care needs (Harris, Canning, & Kelleher, 1996). Furthermore, the use of certain measures may be less appropriate because children with chronic conditions were not usually included in norm samples, and endorsement of many somatic items by children with disabilities reflects physical rather than psychological difficulties.

Finally, there is considerable variability across studies regarding the definitions of chronic conditions or disabilities. Studies have investigated the relationship between psychosocial functioning and chronic health conditions operationalized by either specific physical disorders or diseases, pooled illness groups, or a noncategorical approach. Based on these different descriptors, it is difficult to determine how psychosocial difficulties

might vary as a function of condition type. Overall, all conditions or disabilities seem to be associated with increased risk for psychosocial problems without much variation from one diagnosis to another (American Academy of Pediatrics, 1993). There is some indication though that some diagnoses or condition characteristics have higher rates of emotional or behavioral problems, such as children and adolescents with conditions that affect the central nervous system (e.g., seizure disorders), or sensory system (e.g., visual impairment), and those that have an associated long-term physical disability as compared to other chronic conditions (American Academy of Pediatrics; Lavigne & Faier-Routman, 1992; Silver, Stein, & Bauman, 1999).

As discussed above, measures used to assess psychosocial functioning in children and adolescents with chronic health needs often assess three general constructs: psychopathology, adjustment, or impairment. Child psychopathology refers to evaluating symptoms and behaviors that generally demand clinical attention from mental health professionals (Harris et al., 1996). From a review of the literature, Lavigne and Faier-Routman (1992) presented outcomes that suggested that physical disabilities affect internalizing symptoms more than externalizing symptoms, and that the difference may vary with diagnosis. Similarly, a meta-analysis by LeBovidge and colleagues (2003) found that children and adolescents with chronic arthritis are at increased risk for developing internalizing symptoms but not externalizing symptoms in comparison with controls. Using a noncategorical approach to identify children and adolescents with chronic health conditions, Silver et al. (1999) reported that poorer perceived prognosis by the caregiver was the only condition-related characteristic significantly associated with conduct problems in a sample of school-aged children.

A meta-analysis of depression among children ages 4 to 18 with chronic medical problems was conducted by Bennett (1994). Reviewed research was specific to chronic medical problems of asthma, burn injuries, cardiac disorders, cancer, cleft lip/palate, cystic fibrosis, deafness/hearing impairment, diabetes, hemophilia, inflammatory bowel, limb deficiency, liver transplant, neurologic disorders, orthopedic disorders, recurrent abdominal pain, renal disorders, and sickle cell disease. Results indicated that across diagnoses, children with chronic medical problems were at a slightly elevated risk for depressive symptoms. Furthermore, although variability in depressive symptoms was found across children with the same disorder, children with certain disorders (e.g., asthma, recurrent abdominal pain, sickle cell anemia) may be at greater risk than children with other disorders (e.g., cancer, cystic fibrosis, diabetes).

Besides psychopathology, Harris and colleagues (1996) identified adjustment (i.e., the full range of a child's behavior compared with that of other children of similar development) and impairment (i.e., diminished functioning in various behavioral domains such as peer relationships or school functioning) as other common psychosocial constructs evaluated in children and adolescents with chronic conditions or disabilities. The inability to perform daily functions at home or school independently is an issue related to various conditions and disabilities, and children and adolescents with activity-limiting conditions have been found to be at greater risk for poorer psychosocial outcomes in comparison to children without chronic conditions and children with chronic conditions that do not limit functionality (McDougall et al., 2004). For example, relying on others to engage in daily activities (i.e., dressing, feeding) or facing restrictions in typical childhood or adolescent activities (i.e., limits on driving for a teen with a seizure

disorder) provides stressors that are unique to children and adolescents with chronic health conditions (American Academy of Pediatrics, 1993).

In addition, psychosocial functioning in children and adolescents, regardless of health status, is associated with peer relationships and social adjustment. However, distinctive issues arise for children and adolescents who have chronic health conditions in this area of functioning as well. Some symptoms or condition characteristics may be susceptible to social stigma (e.g., need for adaptive equipment) or social comparison among peers (e.g., visible physical differences associated with limb deficiencies; American Academy of Pediatrics, 1993; Varni, Setoguchi, Rappaport, & Talbot, 1991). In addition, there is a body of research that indicates that perceived social support by peers is positively correlated with psychosocial functioning in children and adolescents with special health care needs (Noll et al., 1999; Varni et al.). Thus, children and adolescents who have difficulty with peer relationships and building a social support group may experience poorer psychosocial functioning.

To address some of the variability and difficulty with measuring psychosocial outcomes from previous research with this population, the Personal Adjustment and Role Skills Scale III (PARS III) was used in this study. The PARS III is a parent-report measure of children's overall psychosocial adjustment. It has been identified as a suitable measure of psychological and social functioning in youth with chronic illnesses and physical conditions because it assesses multiple domains that are not only associated with patterns of maladjustment in children without chronic conditions, but also highlights areas of functioning that are specific concerns for children with special health needs (Walker, Stein, Perrin, & Jessop, 1990). Additionally, it does not contain items about

physical symptoms that may artificially inflate maladjustment scores on other measures (Stein, Westbrook, & Silver, 1998).

The PARS III contains six subscales or domains (dependency, hostility, withdrawal, anxiety-depression, productivity, and peer relations) and also produces a Total score. These subscales can be matched to three areas of psychosocial functioning described above: psychopathology, daily adjustment, and impairment in behavior domains such as peer relations or school functioning. The subscales of anxiety-depression and hostility represent domains of psychopathology. Dependency and productivity relate to adjustment on a day-to-day basis, and the peer relations subscale and withdrawal subscale depict impairment in social behaviors.

Chronic Condition/Disability and Mental Health Service Utilization

Given the fact that children and adolescents with chronic health needs are likely to experience higher rates of psychosocial problems than peers without chronic conditions, it is reasonable to argue that children and adolescents with chronic health conditions or disabilities may experience greater need for psychological or mental health services. While most psychosocial research on children and adolescents with chronic health conditions or physical disabilities has suggested these children and their families are at greater risk for more negative outcomes, few studies have focused on the patterns of mental health service utilization by this population. Of the research that has been conducted, results indicate that accessing mental health services, which are at times operationalized under the umbrella term “social services,” can be problematic for

families (Hobbs, Perrin, & Ireys, 1985). Additional research in this area would not only help to improve mental health services to children and adolescents, but it could also help to reduce the high healthcare costs that these families acquire. It is suggested that serious medical, social, and psychological complications can be reduced for families if timely and effective diagnostic and intervention services are readily accessible, including mental health services (Hobbs et al.). To identify patterns of mental health service use, this study will explore rates of service utilization, in addition to possible barriers or limitations that hinder accessing services for children and families.

In the few studies that have examined access to mental health services in children and adolescents with chronic health conditions or physical disabilities, rates of mental health service utilization ranged from 14-38% (Cadman, Boyle, Szatmari, & Offord, 1987; Gortmaker, Walker, Weitzman, & Sobol, 1990; Witt, 2001, 2003). Furthermore, studies by Witt presented results that specified usage rates by type of mental health service (i.e., inpatient, outpatient, school counseling). In a national sample of children with disabilities ages 6 to 17 ($n = 3,700$), 14% received some mental health service in the previous 12 months. Out of children identified with a disability and poor psychosocial functioning, 3% accessed inpatient services, 10% utilized outpatient services, and 11% received some type of mental health service in an education setting. Rates of service use have also been examined by percentage of unmet mental health needs (14-60%; Boothroyd & Armstrong, 2005; Witt, 2001) or by percentage of recommended mental health services that were not obtained (51%; Pabian, Thyer, Straka, & Boyle, 2000). The 2003 National Survey of Children's Health reported 61% of children ages 1 to 17 with special health care needs who needed mental health services in the previous 12 months

received them, while 39% did not get needed services. This compares to 49% and 51%, respectively of children ages 1 to 17 with no special health care needs (Child and Adolescent Health Measurement Initiative, 2003).

In addition, little research has explored the limitations or barriers that children and adolescents with chronic conditions or disabilities and their families may face when attempting to access mental health services. Barriers identified in previous research include lack of referrals by medical personnel, insufficient services in the community, and a lack of funding for services (Pabian et al., 2000). Emphasis has been placed on the frequency of referrals to mental health services by pediatricians and primary care physicians for children and adolescents with chronic health conditions or disabilities and poor psychosocial functioning. A study by Weiland, Pless, and Roghmann (1992) investigated rates of referrals to mental health services by pediatricians, citing 52% of children with special health care needs as being ever referred to mental health services. Witt reported outcomes that suggested that children with chronic health conditions or disabilities and poor psychosocial functioning were less than half as likely to receive care in inpatient psychiatric settings and two times more likely to obtain outpatient services when both family members and physicians were involved in care coordination (2001). However, physicians may be unsure of behavioral norms in children with medical conditions, which may prevent them from making referrals (Sabbeth & Stein, 1990). Barriers to accessing mental health services also arise when parents are reluctant to acknowledge their child has mental health problems in addition to a chronic health condition (Sabbeth & Stein). Parents may experience guilt or blame associated with a belief that mental health problems could have been avoided as opposed to chronic health

conditions, which may leave them reluctant to discuss mental health concerns with physicians.

Additionally, obstacles to receiving mental health care arise from insufficient services in the community. Services may be inadequate from the stand point that very few mental health professionals receive specialized training in the area of chronic childhood conditions, and they may be inaccessible due to structural barriers that limit physical access to facilities (Sabbeth & Stein, 1990). Another salient barrier in accessing mental health services is the issue of inadequate coverage of mental health care by insurance companies. Few private mental health practitioners are willing to accept public insurance due to low fees and cumbersome paperwork (Sabbeth & Stein). For families with children with chronic health conditions or physical disabilities, high medical bills may already leave families with few funds to cover additional services.

Summary of the Literature: Implications for Evaluating Mental Health Service Utilization

Knowledge of mental health service utilization in children and adolescents with chronic health conditions or disabilities is limited by the small number of studies that have investigated rates and patterns of use in this population. In general, it is difficult to estimate the rates of service use as studies have operationalized service use in different ways. Additionally, conclusions about possible barriers to service use or accessibility of services are speculative due to the paucity of research in this area. It is also possible that outcomes varied due to inconsistent operational definitions of chronic health conditions.

Although the following conclusions should be interpreted with caution, there are outcome trends that lend themselves to further investigation.

Regarding rates of service utilization, results broadly indicate that mental health services may be underutilized in this population. Rates of unmet service needs in children and adolescents with chronic health conditions and poor psychological functioning ranged from 14-52%. However, rates of service utilization were operationalized in different ways across studies varying from percentages of unmet need or services not obtained, to percentages of used mental health services, to percentage of referrals to mental health services by pediatricians, to odds that children with chronic health conditions will use mental health services. Additionally, only one study was found that looked at service utilization by type of mental health service provided (i.e., inpatient, outpatient, counseling through school).

Because there is an identified problem with children and adolescents with chronic conditions and psychological difficulties accessing mental health services, it is important to understand the factors that keep them from doing so. Few studies have asked parents to describe the factors that prohibited them from initiating or following through with mental health services. In previous research using parent surveys, mental health services were classified under the umbrella construct of “social services.” Therefore, responses were not identified as pertaining solely to accessing mental health services.

One possible explanation for varying outcomes may be due to inconsistent definitions used to describe “chronic health condition” and “disability” across studies. Specifically, researchers use either specific medical diagnoses or a broader, noncategorical approach. The most significant way service use outcomes may covary by

definitions is by the number of children and adolescents who are initially identified as having a chronic health condition or disability. By using specific medical diagnoses, especially those that are more chronic or severe in nature, the researcher risks excluding many children and adolescents who are diagnosed with health conditions that are less critical in nature but still experience more functional limitations compared to children with no health condition. These functional limitations could also factor into barriers to receiving mental health services. None of the research reviewed for this study compared the two types of definitions on prevalence of poor psychosocial functioning, rates of service utilization, or barriers to service use.

Individual psychosocial functioning is also operationalized differently across studies with various measurements of functioning used. Similar to definitions of chronic conditions, some studies explored specific psychiatric diagnoses, while others operationalized psychosocial functioning using broader aspects (i.e., internalizing behaviors, externalizing behaviors, overall maladjustment). One criticism of research regarding psychosocial functioning in children and adolescents with chronic health conditions or disabilities is that few studies have made efforts to identify the specific types of psychosocial problems these children tend to develop (Wallander et al., 2003). Another limitation arises because measures of behavior problems or emotional problems in children and adolescents include items about physical symptoms that are potentially biased against children with chronic health conditions (Walker et al., 1990).

This study was designed to address limitations and recommendations from the previous review. In particular, a more definitive estimate of the rates of mental health service use and a more thorough inquiry into the barriers this population encounters when

trying to initiate mental health services are at the foundation of this study. It is proposed that the literature base in this area will be strengthened by exploring how definitions of chronic conditions or disabilities associate with patterns of mental health service utilization and how they compare and contrast. This study will also seek to identify what specific types of psychosocial problems are prevalent and how these concerns predict patterns of service utilization. Furthermore, this study will evaluate psychosocial functioning in children and adolescents with chronic health conditions and physical disabilities by using an instrument that does not use items pertaining to physical symptomatology. Specifically the following questions will be addressed:

1. How are children in this study described diagnostically and by condition characteristics? What are the associations between these two ways of defining chronic health condition and disability?
2. How are scores on the PARS III scales related to diagnostic categories and chronic health condition characteristics?
3. What are the rates of mental health service utilization among children and adolescents with chronic health conditions/physical disabilities? More specifically, who refers them for mental health services, what types of mental health service providers are used, in what settings are services rendered, and so forth?
4. How are diagnostic categories and chronic health condition characteristics related to patterns of mental health service use?
5. How are scores on the PARS III scales related to patterns of service utilization?
6. What are the reported barriers to accessing mental health services?

Previous research indicates parents of children with chronic health conditions report higher levels of psychiatric symptoms compared to parents of children without special health care needs, but not at clinically significant levels (Cohen, 1999). The effects of parental mental health on ratings of child psychosocial functioning have also been studied. Maternal depression and anxiety have been associated with a tendency for mothers to over-report child behavior problems (Chilcoat & Breslau, 1997; Fergusson, Lynskey, & Horwood; 1993; Najman et al. 2000). Less attention has been given, however, to how father psychological functioning may influence reports of child behavior. Given the possible associations between parental mental health and biased reports of poor child psychosocial functioning, parental depressive symptoms were also assessed. These scores were controlled in analyses to account for the effects of parental distress on parent report of child behaviors.

Finally, this study will also enhance the current body of literature by using both qualitative and quantitative approaches to address research aims. While quantitative research provides more objective, generalizable outcomes, qualitative research provides a unique insight into social phenomena from the perspective of those involved by seeking a more in-depth understanding of how they interpret the world around them (Glesne, 2006). In their review of literature regarding the use of mixed-method evaluation designs, Greene, Caracelli, and Graham (1989) posited five purposes for using both quantitative and qualitative methods. First, the aim of *triangulation* in a mixed-method design is to identify convergence between different types of data gathering (e.g., a qualitative interview and a quantitative questionnaire). Second, a *complimentary* mixed-method study serves to measure similar but different facets of a phenomenon to enhance

understanding of the event. Third, mixing methods for *development* purposes entails using results from one method to inform subsequent methods or steps in the research process (Sydenstricker-Neto, n.d.). Fourth, *initiation* can also shape future research by either challenging results from one method or offering new insight into research questions to be explored using a different method. Finally, mixed-method designs are beneficial in that they provide an *expansion* in our understanding of a phenomenon by aiming for range and breadth in comprehending various features of the phenomenon. As there is considerable variability and a lack of depth in previous research results regarding patterns of mental health service utilization by children and adolescents with chronic conditions or disabilities, it is suggested that a mixed-method design (i.e., both qualitative interviews and quantitative questionnaires) is warranted for further understanding in this area.

Information related to how children are identified and how their condition characteristics influence psychosocial functioning and mental health service use was derived primarily from parents' reports in the quantitative portion of this study. Results related to the associations between diagnosis and children's psychosocial functioning and service use also primarily came from the quantitative survey. The qualitative interviews with young adults with a chronic health condition or physical disability provided additional support for these research questions. Interviewee responses also provided additional insight, along with survey results, into the perceived barriers to accessing needed mental health services.

CHAPTER III

METHODS

Quantitative Data Collection

Participants

A sample of parents/caregivers of children and adolescents with chronic health conditions and physical or sensory disabilities ages 5 to 21 were surveyed. Parents or caregivers of children and adolescents with primary diagnoses of minor acute illnesses (e.g., colds, flu) were excluded. Recruitment materials also specified that children with a pervasive developmental disorder or intellectual disability would be excluded due to their significant relationship with psychosocial problems and the difficulties associated with assessing psychological symptoms in children with cognitive limitations (Gortmaker et al., 1990). However, children identified with either of these conditions were later included in the analyses as 30% of the sample met this exclusion criteria, and excluding these families would result in a very compromised sample size. Participants had the option to be entered into a drawing for one \$100 prize and two \$50 prizes as an incentive for participating in the study. See Appendix A for the online Consent Form and Recruitment Letter.

Various recruitment strategies were used. Participants were recruited through postings on listservs of parenting groups for parents of children and adolescents with chronic health conditions or physical and sensory disabilities. These listservs were selected from an internet search of listserv databases. Recruitment also took place through emails to various national and state disability organizations (e.g., Family Voices,

Utah Parent Center, etc.). Recruitment materials were posted on listservs to state leaders by national directors, who in turn posted to parents in the organization. In addition, an individual email was sent to each state director to follow up on initial recruitment and to answer any questions regarding the study. Fliers detailing the study were also made available to families through various medical clinics (i.e., spina bifida clinic, orthopedic clinic, etc.) in two large local children's hospitals. Fliers were in the form of postcard-sized handouts that were made available to families in the waiting room and clinic exam rooms to take home. Finally, participants were sought through referrals from personal contacts (i.e., family, friends, etc.).

A sample size of 100 parents was initially proposed for this section of the study. After seven months of data collection and multiple efforts to recruit from a range of online and in-person sources, 60 participants had initiated the survey. Ten participants were excluded due to not meeting inclusion criteria (e.g., child was too old; child had only a mental health diagnosis), resulting in a total sample size of 50. Because recruitment postings and emails had the potential to reach thousands of families, the small response rate was unexpected. It is suggested these low numbers might reflect the lack of available time parents/caregivers of this population of children have to complete a 30-minute survey due to meeting the daily needs of caring for a child with special health care needs. Additionally, families may be less inclined to participate in studies as parents/caregivers of children with physical disabilities or chronic health conditions may receive numerous requests to participate in disability research.

Table 1 provides a summary of the demographic information collected from the survey sample. Sixty-eight percent of the children were male and the average age was

Table 1

Demographic Characteristics (N = 50)

Variables	Number of cases
Sex	
Female	16
Male	34
Age	
4 - 9	15
10 - 14	20
15 - 19	15
Race	
White, non-Hispanic	44
African American	3
Asian	1
Hispanic	2
Native American	2
Other	2
Respondent's relationship to child	
Biological mother	4
Biological father	2
Stepmother	1
Adoptive mother	4
Nonparent caregiver	1
Residence	
Urban	19
Suburban	20
Rural	11
Respondent marital status	
Married	45
Divorced	2
Separated	1
Widowed	1
Mother education	
High school graduate	6
Some college	14
College graduate	21
Professional degree	9

(table continues)

Variables	Number of cases
Father education	
Less than high school degree	2
High school graduate	12
Some college	12
College graduate	11
Professional degree	12
Household income	
\$15,000 - 30,000	5
\$30,000 - 45,000	7
\$45,000 - 60,000	9
\$60,000 - 75,000	4
\$75,000 - 90,000	9
More than \$90,000	16

11.86. The racial background of children was: 88% White, 6% African American, 2% Asian, 4% Latino/Hispanic, and 2% Native American. The majority of respondents (84%) were related to the child as biological mothers.

Procedures

Parents/caregivers completed questionnaire measures online through the use of an online survey software package (PsychData). They completed a series of questionnaires regarding demographic information, identification of chronic health conditions or disabilities, child psychosocial functioning, parent depression, and patterns of mental health service utilization. Some items required parents/caregivers to respond through multiple choice or a Likert-scale rating system. Other items required participants to respond with open-ended responses. The measures took about 20-30 minutes to complete. The specific measures relevant to the current study are described below. See Appendix B for copies of all noncopyrighted measures.

Questionnaire Measures

Demographic information. The demographic section assessed medical diagnosis, race, age, gender, and socioeconomic status of children and families. Specific questions regarding diagnoses evaluated age of onset of diagnosis, duration of symptoms, prognosis of diagnosis (e.g., will improve, remain the same, will get worse, or do not know the prognosis), use of medical services, and the experiences of physical pain.

Questionnaire for Identifying Children with Chronic Conditions. The Questionnaire for Identifying Children with Chronic Conditions (QUICCC) is a parent-report measure of chronic conditions in children based on a noncategorical definition (Stein, Westbrook, & Bauman, 1997). Thirty-nine question sequences, each asking about a specific consequence of having a chronic condition, are answered to identify children with chronic conditions (e.g., [a] Does your child go to a medical doctor or specialist on a regular basis?, [b] Is this because of a medical, behavioral, or other health condition that your child still has?, [c] Has this condition been going on or is expected to go on for at least one year?). Question sequences are categorized into three condition dimensions: functional limitations (15 consequence items), compensatory dependence (i.e., the use of assistive devices or aids; 12 consequence items), and service use above that which is routine (12 consequence items). Questions generally are structured in three parts, where answer categories are “Yes,” “No,” or “Don’t Know.” Each part is asked contingent on whether the preceding part is answered “yes.” If the parent responds with “yes” to each of the three parts of a question, the consequence is considered to be present. A child is given an overall “yes-no” categorical determination of experiencing a specific limitation (i.e., functional limitation, compensatory dependence, or service use) based on the

presence of a consequence in that dimension, and is classified as having a chronic condition if the criterion is met for a least one of the three dimensions (Stein & Silver, 1999). The mean test-retest reliability over a 2-week period of the QUICCC was .73 (Stein et al.). Convergent validity of the QUICCC was established by comparing it to a checklist of childhood health conditions produced by the National Health Interview Survey (NHIS; Stein et al.). Seventy-four percent of children were classified the same way by both methods. Stein and colleagues also demonstrated construct validity through comparison of the QUICCC with the Functional Status-II(R) Measure (FS-II(R)), a measure designed to determine health status in children independent of condition or diagnoses. The QUICCC identified 87.5% of children identified as having a significant dysfunction through their scores on the FS-II(R).

An additional coding and scoring method was created for this study. Within each of the three QUICCC dimensions, the number of identified positive sequences (i.e., the answer for each question in the sequence was “yes”) were totaled to create an interval measurement. These scores helped to define the variability of occurrences within each category. For example, a child with seven identified positive sequences in the Functional Limitation dimension would be identified as having greater impairment compared to a child reporting three positive sequences in this category. This type of scoring provided more options for analyses of QUICCC responses and increased comparisons with other study outcomes. The possible range for each dimension is: 0-16 for functional limitations, 0-12 for compensatory dependence, 0-11 for service use, and 0-39 for total score. Obtained alphas for participants in this study were .88 (functional limitations), .87 (compensatory dependency), .46 (service use), and .93 (total score).

Personal Adjustment and Role Skills Scale III. The Personal Adjustment and Role Skills Scale III (PARS III) consists of 28 items that ask parents to rate the frequency of each behavior in the past 30 days as occurring “always or almost always,” “often,” “sometimes,” or “never or rarely.” Example items include: “In the past 30 days my child has spent time with friends (reverse scored)” and “In the past 30 days my child has wanted help in things he/she could have done on own.” Higher PARS III scores indicate better adjustment. The recommended cutoff point to indicate clinically significant poor psychosocial functioning is one standard deviation below the group mean (Witt, Riley, & Coiro, 2003). Internal consistency coefficients ranged from .70-.80 for the subscales and are $>.88$ for the total score (Walker et al., 1990). The PARS III is suitable for children who have a chronic condition or disability in that it does not include somatic items that might increase the child’s maladjustment score (Walker et al.). Perrin demonstrated concurrent validity in the comparison of the PARS-III with the Child Behavior Checklist (Walker et al.). High correlations were found between total scores on both measures in three samples of children (.74, .80, .80). The PARS-III has been validated for children over the age of 5 years (Stein et al., 1998). Obtained alphas for participants in this study were .85 (peer relations), .71 (dependency), .92 (hostility), .85 (productivity), .69 (anxiety/depression), .83 (withdrawal), and .87 (total score).

Center for Epidemiology Studies--Depression Scale (CES-D; Radloff, 1977). The CES-D is a 20-item 4-point Likert-type scale that assesses current depressive symptomatology in nonpsychiatric populations. Respondents indicate how often in the past week they have experienced depressive symptoms (1 = Never; 2 = 1-2 days; 3 = 3-4 days; 4 = 5-7 days). Examples of items from the CES-D include: “I felt depressed.,” “I

had crying spells,” and “I could not get going.” Radloff reported that the CES-D discriminated well between psychiatric inpatient and community samples and was significantly correlated with clinician ratings of depression severity in a clinical sample. In addition, significant positive correlations were observed between the CES-D and other self-report measures of depression and negative affect, while significant negative correlations were observed between the CES-D and measures of positive affect. The alpha for participants in this study was .91.

Mental Health Service Utilization. This study used two measures of service utilization. First, rates of service utilization were assessed through questions asking parents to report whether their child had been referred for mental health services, whether they had accessed mental health services for their child, what type of setting their child received services in, and also whether they were concerned about their child’s psychological adjustment but had not accessed services. Second, barriers to service use were assessed through a multiple-choice question asking parents to select predetermined responses that described their difficulties with accessing services, as well as offering them an “other reasons” response that provided them the opportunity to write in other limitations. Some predetermined responses were generated from previous research identifying limitations in accessing mental health or social services by youth with chronic conditions or physical disabilities (Briggs-Gowan, Horwitz, Schwab-Stone, Leventhal, & Leaf, 2000; Pabian et al., 2000; Sabbeth & Stein, 1990). Finally, an open-ended question asking parents to share their suggestions for improving mental health services for children and adolescents with chronic health conditions or disabilities was also included to further evaluate possible limitations to accessing services.

Qualitative Data Collection

Participants

It was proposed that participants in the qualitative section of this study would be recruited with the help of parent respondents of the quantitative study. With parent permission, 10 randomly selected adolescents or young adults (ages 15-21) with varying chronic conditions and disabilities whose parent/caregiver completed the quantitative survey were to be selected to complete a semistructured interview. Nine parents initially expressed interest in having their child participate in the interviews, however three of the children did not meet inclusion criteria for this portion (i.e., child was nonverbal; child was too young to participate). Parents of the six qualifying children were contacted through email and by phone, and informed consent and assent forms were emailed to parents and children to be signed and mailed back. Repeated attempts to collect consent and assent forms were unsuccessful with all six families. A few parents did not respond to phone messages or emails from the researcher, others indicated their child's schedule did not accommodate participating at that time, and some parents reported their child had current significant health needs that would restrict their ability to complete the interview.

Additional recruitment strategies were used to secure five participants for this portion of the study. Referrals for four individuals meeting inclusion criteria were received from a statewide clinic for children with special health care needs. Three of these individuals completed interviews and two additional participants were recruited from a local youth action group. Other attempts to recruit from national programs related to transition issues were unsuccessful.

Parental consent and child assent were obtained for adolescents who were under the age of 18 (see Appendix C). Informed consent was obtained by adolescents 18 years of age or older (see Appendix C). Participants were identified as appropriate for this study if they (a) used English as their primary language, (b) had a primary diagnosis of a chronic health condition or physical or sensory disability with onset in childhood or adolescence, and (c) did not have a diagnosis of mental retardation or other developmental disability. Participants were reimbursed for their participation with \$25.

Procedures

Semistructured interviews were conducted by phone in 20-30 minute sessions. Participants were contacted by phone or email to establish a date and time to complete the interview. Interview responses were recorded through audio taping and hand-written notes. Informed consent forms were sent to participants by mail prior to the telephone interview. Signed consent forms were sent to the researcher by mail before interviews were scheduled and completed. Parent signatures were required for all adolescent participants who were under 18 years of age.

Semistructured Interview

The semistructured interview consisted of four principal questions with two containing two follow-up questions. Principal questions inquired about participants' psychosocial functioning in childhood and adolescence, their need for mental health services, experiences with accessing services, and barriers or limitations to utilizing services. See Appendix D for a copy of interview questions.

CHAPTER IV

RESULTS

Quantitative Analyses

Separate analyses were performed examining: (a) associations between diagnostic categorization and condition characteristics, (b) associations between diagnostic labels and psychosocial functioning, (c) associations between condition characteristics and psychosocial functioning, (d) rates and pattern of mental health service utilization in this population, (e) associations between diagnostic labels and service use, (f) associations between condition characteristics and service use, (g) psychosocial functioning and service use, and (h) reported barriers to accessing mental health services.

Controlling for parent depression, a series of one-way ANCOVAs assessing relationships between specific medical diagnoses, condition characteristics, and psychosocial functioning were conducted. One-way ANOVAs were conducted on associations not involving psychosocial functioning. For all analyses, the alpha level used was .05 unless otherwise indicated. All statistical procedures used SPSS 15.0.

Associations Between Diagnostic Categories and Condition Characteristics

Table 2 categorizes the sample according to diagnostic label. There were no specific medical diagnoses that represented large portions of the sample. Because there were too many medical conditions reported to conduct coherent analyses at the level of individual diagnosis, conditions were condensed into relevant categories based on

Table 2

Diagnostic Categories (N = 50)

Categories	Number of cases
Muscle/skeletal system (e.g., muscular dystrophy, craniofacial deformities)	5
Organ systems (e.g., cardiovascular system, urinary system, digestive system)	7
Nervous system (e.g., cerebral palsy, seizure disorder)	8
Lymphatic/endocrine system (e.g., diabetes, immune deficiency disorders)	3
Multisystem	12
Developmental disabilities (e.g., autistic disorder, intellectual disabilities)	15

affected body systems (e.g., cardiovascular system, nervous system, digestive system; Marieb & Hoehn, 2006). Eight major body systems were identified. However, several of the systems had less than three children in their category so the conditions were further pooled into categories representing diagnoses involving similar body constructs (e.g., bones, organs, hormones). In addition, 24% of the children had more than one medical diagnosis that affected multiple systems of the body (e.g., concurrent diagnoses of diabetes and asthma) or one diagnosis involving multiple systems, such as VACTERL or VATER association, which involves possible anomalies to the vertebrae, anus, cardiac functioning, trachea, esophagus, renal functioning, and limb formation. These children were categorized as “multiple systems.”

To evaluate associations between diagnostic categories and condition characteristics, a series of one-way ANOVAS was conducted. Table 3 includes condition characteristics data from the QUICCC. Percentages, means, and standard deviations are included along with ANOVA results. Significant between-group differences were found for functional limitations, $F(5, 41) = 4.49, p < .01$, compensatory dependence, $F(5, 43) = 3.44, p = .01$, and total QUICCC scores, $F(5, 44) = 3.73, p < .01$. Scheffé post hoc tests were conducted to evaluate specific differences between groups for each QUICCC characteristic. For post hoc analyses with compensatory dependence as the dependent variable, no pairwise comparisons were significant with an alpha of .05. Marginally significant pairwise comparisons, with an alpha of .10, are listed in the table. Pairwise comparisons that yielded marginally significant differences are noted in Table 3 using the labels “a” and “b.” Groups that are significantly different are identified with different letter subscripts. Across these three QUICCC classifications, significant mean differences were consistently found between the organ systems, nervous system, and lymphatic/endocrine systems groups. In general, means for children in the nervous system group were the highest across all QUICCC classifications indicating higher rates of functional limitations, compensatory dependence, and service use. Conversely, the lymphatic/endocrine system group consistently had the lowest means across QUICCC scores with all means falling below the overall means.

Table 4 presents Cohen’s d effect sizes for all diagnostic categories and QUICCC classifications. Commonly used guidelines suggest .20 represents a small effect, .50 indicates a medium effect, and .80 indicates a large effect size. Twelve of the 15 comparisons in functional limitations were calculated to be large effect sizes. The

Table 3

Associations Between Diagnostic Categories and QUICCC Scores

QUICCC categories	All subjects (N = 50)	Muscle/ skeletal (n = 5)	Organ systems (n = 8)	Nervous system (n = 8)	Lymphatic/ endocrine (n = 3)	Multiple systems (n = 12)	Developmental disabilities (n = 15)	F	df	p
Functional limitations								4.49	5, 41	.002
Percent meeting criteria	90	100	71	100	33	100	93			
Mean	5.51	4.80	2.29	10.00	.67	5.25	6.07			
Standard deviation	4.35	3.83	2.14	4.17	1.15	4.09	3.95			
		a, b	a	b	a	a, b	a, b			
Compensatory dependence								3.44	5, 43	.011
Percent meeting criteria	98	100	100	100	100	100	93			
Mean	3.45	2.40	2.00	7.00	1.67	3.25	3.07			
Standard deviation	3.12	3.13	1.83	3.51	.58	2.93	2.67			
		a, b	a	b	a	a, b	a, b			
Service use								1.66	5, 42	.165
Percent meeting criteria	98	100	100	100	100	100	93			
Mean	5.15	4.60	3.86	5.75	5.00	5.55	5.36			
Standard deviation	1.54	2.07	2.12	1.04	1.73	.93	1.45			
		a	a	a	a	a	a			
Total								3.73	5, 44	.007
Mean	13.84	11.80	8.14	22.75	7.33	13.83	13.73			
Standard deviation	8.32	8.47	5.34	8.35	3.21	7.37	7.65			
		a, b	a	b	a	a, b	a, b			

Note. A, b denotes homogenous

Table 4

*Cohen's d Effect Sizes Pairwise Comparisons of Diagnostic Categories and QUICCC**Scores*

Diagnostic categories	Functional limitation	Compensatory dependence	Service use	Total score
1, 2	.81	.16	.35	.52
1, 3	-1.30	-1.38	-.70	- 1.30
1, 4	1.46	.32	-.21	.70
1, 5	-.11	-.28	-.59	-.26
1, 6	-.33	-.23	-.43	-.24
2, 3	-2.33	-1.79	-1.13	- 2.08
2, 4	.94	.24	-.59	.18
2, 5	-.91	-.51	-1.03	-.88
2, 6	-1.19	-.47	-.83	-.85
3, 4	3.05	2.12	.53	2.44
3, 5	1.15	1.16	.20	1.13
3, 6	.97	1.26	.31	1.13
4, 5	-1.52	-.75	-.40	- 1.14
4, 6	-1.86	-.72	-.22	- 1.09
5, 6	-.20	.06	.16	.01

Note. 1 = Muscle/skeletal systems; 2 = organ systems, 3 = nervous system, 4 = lymphatic/endocrine systems, 5 = multiple systems, and 6 = developmental disabilities.

strongest effect sizes were found between the organ systems, nervous system, and lymphatic/endocrine system means. For compensatory dependence, only 5 of the 15 pairwise comparisons produced large effect sizes. These effect sizes indicated means for nervous system were very different from the other five categories. In addition, there were three medium effect sizes and five small effect sizes. Three large effect sizes were found for service use, as well as four medium effect sizes and seven small effect sizes. Finally, there were nine large effect sizes for between-group means on total

QUICCC scores. Means for the children in the nervous system group were again powerfully different in this QUICCC classification from the other five groups.

Thus, in summary, with regard to identifying children by diagnostic category or condition characteristics, all of the children in this study were identified as having a chronic health condition according to the scoring guidelines of the QUICCC regardless of their medical diagnosis. However, there were significant between-diagnostic group differences on the QUICCC, especially on functional limitations and total QUICCC scores. Pairwise comparisons also indicated notable differences between diagnostic groups on compensatory dependence.

Differences among diagnostic categories were also assessed across items from the demographic questionnaire assessing condition characteristics. Table 5 presents the percentage of children in each diagnostic category by level of condition characteristic. Chi square analyses to test the significance of the association between diagnostic categories and the categorical condition characteristics were not possible because the assumption of expected values of at least five in each cell was not met. The majority (83%) of the children with multiple body systems affected displayed symptoms at birth while approximately half of the children in the other categories were symptomatic at birth. The other group that differed on this characteristic was the lymphatic/endocrine system group in that over half of these children did not display symptoms until they were older than 3 years of age. Similarly, while most of the groups were diagnosed at less than 1 year of age, the majority of children in the lymphatic/endocrine system group and muscle/skeletal group were not diagnosed until after 1 year of age.

Table 5

Associations Between Diagnostic Categories and Condition Characteristics from Demographics

Condition characteristic	Percentages							F	df	p
	All subjects	1	2	3	4	5	6			
Age of symptom onset										
At birth	50	40	43	50	0	83	40			
Less than 1 year	24	0	29	50	33	9	47			
1 - 3 years	16	40	14	0	0	0	13			
Older than 3 years	10	20	14	0	67	8	0			
Age at diagnosis										
At birth	25	20	43	13	0	40	20			
Less than 1 year	23	0	14	50	0	30	20			
1 - 3 years	25	40	29	25	0	0	40			
Older than 3 years	27	40	14	12	100	30	20			
Child's prognosis										
Improve	12	20	14	0	0	8	20			
Remain the same	46	20	14	75	67	50	47			
Worsen	14	20	43	25	0	8	0			
Don't know	26	40	29	0	33	34	27			
Frequency of medical visit										
At least once/month	40	40	14	25	33	58	47			
3 - 4 times/year	42	60	86	63	33	17	27			
1 - 2 times/year	18	0	0	12	34	25	26			

(table continues)

Condition characteristic	Percentages							<i>F</i>	<i>df</i>	<i>p</i>
	All subjects	1	2	3	4	5	6			
Mean pain scores (<i>SD</i>) range 1 - 10										
Pain of symptom	4.29 (2.54)	5.60 (3.51)	5.43 (2.15)	3.50 (1.41)	4.00 (3.00)	4.63 (2.66)	3.53 (2.64)	1.02	5, 43	.42
Pain of treatment	4.35 (2.32)	5.80 (1.30)	4.71 (2.63)	4.88 (2.64)	2.67 (.58)	4.91 (2.12)	3.33 (2.32)	1.62	5, 43	.18

The prognoses of the majority of children suggested that their conditions will either remain the same or improve. However, 72% of parents of children with diagnoses affecting an organ system reported their child's condition will either worsen or they were unsure of their child's prognosis.

Children in the muscle/skeletal systems and organ systems categories visited medical professionals more frequently than the other groups with at least 3 or 4 visits per year. While 78% of the total sample had been hospitalized, children in the multiple systems group had the highest rate of hospitalizations at 92%, and children in the lymphatic/endocrine systems group and the developmental disabilities group had the lowest rates at 67% for each. However, the nervous system group had the highest frequency of children hospitalized with 50% hospitalized more than five times.

Additionally, the means and standard deviations of pain levels related to diagnosis symptoms and treatments are also displayed. Pain scores for most of the children were close to the overall means. ANOVAs conducted for pain scores were not significant for between-group differences.

Observations can also be made from Table 5 regarding the variability within each diagnostic category. As would be expected, responses for children in the multiple systems category were some of the most diverse across age at diagnosis, prognosis, frequency of medical visits, and number of hospitalizations. There was also variety in the responses for children in the muscle/skeletal systems and organ systems groups as well. Results for both of these groups were most varied across age of symptom onset, age of diagnosis, and prognosis.

Two condition characteristic variables from the demographic questionnaire were not included in these analyses because of the lack of variability in responses. Eighty-four percent of parents reported their children were diagnosed by a medical specialist, and 16% identified their primary care provider as diagnosing their child. Additionally, 92% of parents said they expect their child's diagnosis to last the rest of their child's life.

Associations Among Diagnostic Categories and Psychosocial Functioning

Table 6 presents results from a series of one-way ANCOVAs comparing the diagnostic group means on the PARS III while controlling for parent depression scores from the CES-D. Means and standard deviations are also included for each of the PARS III subscales. Significant between-group differences were found for productivity, $F(5, 41) = 5.20, p = .001$. Marginally significant differences were found for peer relations, $F(5, 41) = 2.04, p = .093$, and total score, $F(5, 41) = 2.02, p = .095$. Bonferroni post hoc tests were conducted to evaluate specific differences between groups for each PARS III scale. For post hoc analyses with peer relations and total score as the dependent variable respectively, no pairwise comparisons were significant with an alpha of .05. Marginally significant pairwise comparisons, with an alpha of .10, are listed in the table and are cautiously interpreted due to the small sizes of each group and compromised power. The muscle/skeletal systems and developmental disabilities groups were significantly different on the productivity scale. On the peer relations scale, significant differences were found for the organ systems and developmental disabilities groups, while the organ systems and nervous system groups demonstrated significant mean differences on the

Table 6

Associations Between Diagnostic Categories and PARS III Scores

PARS III categories (possible range)	All subjects (N = 50)	Muscle/s keletal (n = 5)	Organ systems (n = 8)	Nervous system (n = 8)	Lymphatic/ endocrine (n = 3)	Multiple systems (n = 12)	Developmental disabilities (n = 15)	F	df	p
Peer relations * (4 - 16)								2.04	5, 41	.093
Mean	8.56	8.80	11.43	7.50	8.00	9.18	7.29			
Standard deviation	3.13	4.76	3.26	1.85	1.00	3.46	2.27			
		a, b	a	a, b	a, b	a, b	b			
Dependency (4 - 16)								.346	5, 40	.882
Mean	11.36	12.20	12.14	10.86	11.67	11.00	11.14			
Standard deviation	2.51	2.49	2.04	2.73	3.06	2.65	2.71			
		a	a	a	a	a	a			
Hostility (6 - 24)								.493	5, 41	.779
Mean	17.81	17.60	20.00	17.88	15.00	16.55	18.36			
Standard deviation	4.55	5.37	3.96	3.98	8.19	5.13	3.67			
		a	a	a	a	a	a			
Productivity (4 - 16)								5.20	5, 41	.001
Mean	8.98	12.00	11.57	8.88	9.00	8.00	7.43			
Standard deviation	2.74	2.83	3.10	1.96	4.36	1.73	1.55			
		b	a, b	a, b	a, b	a, b	a			
Anxiety/depression (6 - 24)								.571	5, 40	.722
Mean	19.41	19.40	20.57	19.29	16.33	19.82	19.57			
Standard deviation	3.04	1.95	2.88	3.64	1.53	2.99	3.37			
		a	a	a	a	a	a			
Withdrawal (4 - 16)								1.15	4, 40	.353
Mean	13.85	14.40	15.29	12.86	13.67	14.00	13.36			
Standard deviation	2.19	1.82	1.25	2.61	3.21	2.19	2.17			
		a	a	a	a	a	a			

(table continues)

PARS III categories (possible range)	All subjects (<i>N</i> = 50)	Muscle/s keletal (<i>n</i> = 5)	Organ systems (<i>n</i> = 8)	Nervous system (<i>n</i> = 8)	Lymphatic/ endocrine (<i>n</i> = 3)	Multiple systems (<i>n</i> = 12)	Developmental disabilities (<i>n</i> = 15)	<i>F</i>	<i>df</i>	<i>p</i>
Total* (28 - 112)								2.02	5, 41	.095
Mean	79.25	84.40	91.00	72.75	73.67	78.36	77.14			
Standard deviation	12.88	12.58	11.20	16.48	14.36	10.49	10.35			
		a, b	a	b	a, b	a, b	a, b			

Note. a, b denotes homogenous groups.

* Listed pairwise comparisons significant with alpha = .10.

total score scale. In general, means for children in the organ systems group were consistently higher than the total subjects' means indicating better adjustment in psychosocial functioning than the other groups. Conversely, means for children in the nervous system group were below the total subjects' means on all PARS III subscales except for hostility. This suggests parents of children in this diagnostic group reported poorer psychosocial functioning for their children compared to others.

Table 7 reports Cohen's *d* effect sizes for all pairwise comparisons for means listed in Table 6. Three out of 15 comparisons produced large effect sizes for peer relations. There were also four medium effect sizes and six small effect sizes. The largest effect sizes were observed for differences between the organ systems group and the other groups. There were no large effect sizes in comparisons for dependency or hostility. However, 8 out of 15 comparisons produced large effect sizes for productivity involving means of several of the diagnostic groups. Within anxiety/depression, there were five large effect sizes, and the lymphatic/endocrine systems group demonstrated the largest differences with all of the other groups. Two out of 15 comparisons produced large effect sizes for the withdrawal subscale and there were three medium effect sizes. The mean for the organ systems group demonstrated the largest differences from other groups. Finally, 4 out of 15 comparisons produced large effect sizes for total PARS III scores and there were five medium effect sizes. The organ systems group mean again demonstrated large effect size differences, while the muscle/skeletal systems group mean demonstrated the medium effect sizes.

Table 7

*Cohen's d Effect Sizes Pairwise Comparisons of Diagnostic Categories and PARS III**Scores*

Diagnostic categories	Peer relations	Dependency	Hostility	Productivity	Anxiety/depression	Withdrawal	Total score
1, 2	-.65	.03	-.51	.14	-.48	-.57	-.55
1, 3	.36	.51	-.06	1.28	.04	.68	.79
1, 4	.23	.19	.38	.86	1.75	.28	.79
1, 5	-.09	.47	.20	1.71	-.17	.20	.52
1, 6	.40	.41	-.17	2.00	-.06	.52	.63
2, 3	1.48	.53	.53	1.04	.39	1.19	1.30
2, 4	1.42	.18	.78	.68	1.84	.67	1.35
2, 5	.67	.48	.75	1.42	.26	.72	1.16
2, 6	1.47	.42	.43	1.69	.32	1.09	1.29
3, 4	-.34	-.28	.45	-.04	1.06	-.28	-.06
3, 5	-.61	-.05	.29	.48	-.16	-.47	-.41
3, 6	.10	.10	-.13	.82	-.08	-.21	-.32
4, 5	-.46	.23	-.23	.30	-1.47	-.12	-.37
4, 6	.40	.18	-.53	.48	-1.24	.11	-.28
5, 6	.65	-.05	-.41	.35	.08	.29	.12

Note. 1 = muscle/skeletal systems; 2 = organ systems, 3 = nervous system, 4 = lymphatic/endocrine systems, 5 = multiple systems, and 6 = developmental disabilities.

Associations Among Condition Characteristics and Psychosocial Functioning

Table 8 contains partial correlations between PARS III subscales and QUICCC scores and items from the demographic questionnaire that assess condition characteristics. The correlations control for caregiver depression scores from the CES-D. Of the correlations among QUICCC conditions and PARS III scales, correlations were strongest for Peer Relations and Withdrawal. Higher rates of functional limitations, compensatory dependence, and service use were correlated with poorer functioning in peer relations. In addition, higher rates of functional limitations and service use were

Table 8

Associations Between Condition Characteristics and PARS III Scores

Diagnostic categories	Peer relations	Dependency	Hostility	Productivity	Anxiety/ depression	Withdrawal	Total score
QUICCC scales							
Function limitations	-.431**	-.031	.275	-.134	.257	-.316*	-.043
/cinoebstirt deoebdebece	-.345*	.138	.193	-.012	.225	-.248	.026
Service use	-.420**	-.249	.148	-.302*	.011	-.303*	-.262
Total score	-.433**	-.009	.245	-.129	.223	-.315*	-.060
Age of symptoms	-.024	.021	-.322*	.287	-.235	.224	-.070
Age of diagnosis	-.090	-.397**	-.094	-.066	-.425**	-.029	.304*
Pain of symptoms	.091	-.193	-.157	.113	-.17	-.092	-.123
Pain of treatments	.072	-.210	-.081	.058	.002	.046	.036

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

related with being more withdrawn. A significant relationship was also found between service use on the QUICCC and productivity on the PARS III indicating increased service use is associated with decreased productivity.

With the exception of age of diagnosis, there were few significant relationships between condition characteristics from the demographic information form and QUICCC and PARS III scores. An interesting pattern developed for age of diagnosis in that diagnosis at a younger age was correlated with increased independence, fewer symptoms of anxiety or depression, and less withdrawal. One other significant correlation formed between age of symptom onset and hostility. Again, children with an earlier onset of symptoms demonstrated a positive outcome in the form of displaying less hostility.

Tables 9, 10, and 11 present results from a series of one-way ANCOVAs comparing the between-group means on condition characteristics from the demographic form (prognosis, frequency of medical visits, and hospitalizations related to medical conditions) on the PARS III, while controlling for parent depression scores from the CES-D. Means and standard deviations for each condition characteristic are also included for each of the PARS III subscales.

There were no significant between-group differences for child's prognosis (Table 9) and hospitalizations (Table 11) on the PARS III. However, in Table 10, significant between-group differences were found for frequency of medical visits on productivity, $F(2, 44) = 4.60, p = .02$. Marginally significant differences were found on the withdrawal subscale, $F(2, 43) = 2.81, p = .07$. Bonferroni post hoc tests were conducted to evaluate specific differences between groups for each PARS III scale. For post hoc analyses with

Table 9

Associations Between Prognosis and PARS III Scores

PARS III categorie (possible range)s	All subjects (N = 47)	Prognosis will improve (n = 6)	Prognosis remain same (n = 21)	Prognosis will worsen (n = 7)	Prognosis unknown (n = 13)	F	df	p
Peer relations (4 - 16)						1.41	3, 42	.254
Mean	8.51	9.83	9.10	8.00	7.23			
Standard deviation	3.15	4.92	2.90	2.52	2.71			
		a	a	a	a			
Dependency (4 - 16)						1.26	3, 41	.302
Mean	11.39	12.00	11.90	11.57	10.23			
Standard deviation	2.53	1.26	2.51	2.15	3.00			
		a	a	a	a			
Hostility (6 - 24)						1.09	3, 42	.365
Mean	17.85	19.50	16.57	18.86	18.62			
Standard deviation	4.59	2.07	5.30	3.76	4.43			
		a	a	a	a			
Productivity (4 - 16)						.505	3, 42	.681
Mean	9.00	9.83	8.81	9.86	8.46			
Standard deviation	2.77	3.19	2.32	2.91	3.28			
		a	a	a	a			
Anxiety/depression (6 - 24)						.351	3, 41	.789
Mean	19.48	19.17	19.50	20.57	19.00			
Standard deviation	3.07	1.94	3.20	3.05	3.44			
		a	a	a	a			
Withdrawal (4 - 16)						.183	3, 41	.908
Mean	13.85	13.33	13.95	14.00	13.85			
Standard deviation	2.21	3.08	2.33	1.73	2.03			
		a	a	a	a			
Total (28 - 112)						.419	3, 42	.740
Mean	79.23	83.67	78.00	82.57	77.38			
Standard deviation	13.02	14.11	15.05	10.53	10.54			
		a	a	a	a			

Note. a, b denotes homogeneous groups.

Table 10

Associations Between Frequency of Medical Visits and PARS III Scores

PARS III categories (possible range)	All subjects (N = 48)	Medical visits monthly (n = 19)	Medical visits 3-4 year (n = 21)	Medical visits 1-2 year (n = 8)	F	df	p
Peer relations (4 - 16)					2.13	2, 44	.131
Mean	8.56	8.32	9.19	7.50			
Standard deviation	3.13	3.43	2.99	2.73			
		a	a	a			
Dependency (4 - 16)					1.91	2, 43	.152
Mean	11.36	10.53	12.05	11.63			
Standard deviation	2.51	3.03	2.06	1.77			
		a	a	a			
Hostility (6 - 24)					.955	1, 44	.392
Mean	17.81	16.79	18.00	19.75			
Standard deviation	4.55	4.35	5.12	2.82			
		a	a	a			
Productivity (4 - 16)					4.60	2, 44	.015
Mean	8.98	8.26	10.10	7.75			
Standard deviation	2.74	2.26	3.06	1.91			
		a, b	a	b			
Anxiety/depression (6 - 24)					.805	2, 43	.454
Mean	19.51	18.94	20.00	19.63			
Standard deviation	3.04	3.41	2.87	2.67			
		a	a	a			
Withdrawal* (4 - 16)					2.81	2, 43	.071
Mean	13.85	14.21	13.95	12.75			
Standard deviation	2.19	1.90	2.31	2.43			
		a	a, b	b			

(table continues)

PARS III categories (possible range)	All subjects (N = 48)	Medical visits monthly (n = 19)	Medical visits 3-4 year (n = 21)	Medical visits 1-2 year (n = 8)	F	df	p
Total (28 - 112)					1.28	2, 44	.287
Mean	79.25	76.95	81.43	79.00			
Standard deviation	12.88	11.71	15.36	7.62			
		a	a	a			

Note. a, b denotes homogenous groups.

*Listed pairwise comparisons significant with alpha = .10.

Table 11

Association Between Hospitalizations and PARS III Scores

PARS III categories (possible range)	All subjects (N = 47)	Hospitalized (n = 39)	No hospitalizations (n = 11)	F	df	p
Peer relations (4 - 16)				2.09	1, 45	.155
Mean	8.51	8.86	7.55			
Standard deviation	3.11	3.28	2.46			
Dependency (4 - 16)				.137	1, 44	.713
Mean	11.34	11.28	11.64			
Standard deviation	2.60	2.70	1.86			
Hostility (6 - 24)				.016	1, 45	.901
Mean	17.76	17.81	17.81			
Standard deviation	4.66	4.58	4.64			
Productivity (4 - 16)				.027	1, 45	.869
Mean	9.00	9.00	8.91			
Standard deviation	2.82	2.82	2.02			
Anxiety/depression (6 - 24)				.748	1, 44	.392
Mean	19.57	19.69	18.91			
Standard deviation	3.11	3.02	3.18			
Withdrawal (4 - 16)				.762	1, 44	.388
Mean	13.89	13.97	13.45			
Standard deviation	2.20	2.12	2.46			
Total (28 to 112)				.226	1, 45	.637
Mean	79.22	79.54	78.27			
Standard deviation	13.01	13.65	10.36			

withdrawal as the dependent variable, no pairwise comparisons were significant with an alpha of .05. Marginally significant pairwise comparisons, with an alpha of .10, are listed in the table and are interpreted due to the small sizes of each group and compromised power. The means for children who have medical visits three to four times a year and children who have visits one to two times a year stood out as being significantly different from the other groups on productivity. Additionally, between-group mean differences were

significant on the withdrawal subscale for children in the monthly visits group and children with visits one to two times a year.

Effect sizes were also calculated for the pairwise comparisons in Tables 9, 10, and 11. Cohen's *d* effect sizes are presented in Table 12. There were no large effect sizes for comparisons amongst the prognosis groups on any of the PARS III scales as well as between the "hospitalized" and "no hospitalization" groups. A large effect size was found between a comparison of the means for "monthly medical visits" and visits occurring "one to two times a year" on the hostility subscale. The only other large effect size for frequency of medical visits was found on the productivity subscale between the "three to four times a year" group and the "one to two times a year" group.

Rates and Patterns of Mental Health Service Use

Table 13 presents information related to the rates and patterns of mental health service use by all of the children. Half of the parents (51%) reported their child has been referred for mental health services at some point in time. Half of the referrals were made by a medical provider (e.g., primary care provider, specialist), while another 30% of referrals came from the parent/caregiver or other family member. Other referrals were equally distributed between social service agencies, medical homes/care coordinators, and school personnel. Approximately 62% of the children reported on in this study have accessed mental health services at some point, while 20% of those children have used services in the past year. The most common reasons given for accessing mental health services were for testing (e.g., neuropsychological testing; learning disabilities, depression, and behavior problems (e.g., anger, noncompliance). Multiple parents

Table 12

Cohen's d Pairwise Comparison Effect Sizes for Demographic Condition Characteristics and PARS III Scores

Condition characteristics	Peer relations	Dependency	Hostility	Productivity	Anxiety/depression	Withdrawal	Total
Prognosis							
1, 2 ^a	.18	.05	.73	.37	-.12	-.23	.39
1, 3	.47	.24	.21	-.01	-.55	-.27	.09
1, 4	.65	.77	.25	.42	.06	-.20	.51
2, 3	.40	.14	-.50	-.40	-.34	-.02	-.35
2, 4	.67	.60	-.42	.12	.15	.05	.05
3, 4	.29	.51	.06	.45	.48	.08	.49
Frequency of Medical Visits							
1,2 ^b	-.27	-.59	-.25	-.68	-.34	.12	-.33
1, 3	.26	-.44	-.81	.24	-.23	.67	-.21
2, 3	.59	.22	-.42	.92	.13	.51	.20
Number of Hospitalizations							
1, 2 ^c	.45	-.16	-	.04	.25	.23	.10

Note. a: 1 = Prognosis improve; 2 = Prognosis stay same; 3 = Prognosis worsen; 4 = Don't know prognosis; b: 1 = Monthly med visits; 2 = 3 to 4 visits/year; 3 = 1 to 2 visits/year; c: 1 = Hospitalized; 2 = No hospitalizations.

indicated their child received counseling for issues related to their medical diagnoses.

Examples given included failure to adhere to medical treatments, fear of injections, and IVs, and acceptance of their disability or condition.

Ninety-three percent of the services accessed in the past year were rendered in an outpatient or school setting. Similarly, 92% of services ever accessed were in the same settings with outpatient services accounting for almost half of those. Only three parents reported that their child had ever been hospitalized for psychiatric concerns. Each has had only one hospitalization for this reason and the reported length of stay was on average 10 days.

Table 13

Patterns of Mental Health Service Utilization (N = 47)

Variables	Number of cases
Ever referred for services	
Yes	24
No	23
Source of referral	
Primary care provider/Specialist	12
Service agency or school	5
Family member	3
Self	4
Ever accessed services	
Yes	29
No	18
Type of services used in past 12 months	
Inpatient psychiatric or substance abuse	2
Outpatient counseling services	16
Services in a school setting	10
Type of services ever used	
Inpatient psychiatric or substance abuse	3
Outpatient counseling services	21
Services in a school setting	12
Type of outpatient professional	
Psychologist	20
Psychiatrist	6
Social worker	5
School personnel (e.g., counselor, psychologist)	5
Outpatient setting	
Private practice	13
Hospital	4
Community mental health	10
School	6
Number of outpatient sessions	
Less than 10	8
10 to 20	6
20+	2

Additional information was gathered regarding outpatient mental health services. The majority of services were provided by a psychologist (56%) with the rest of services being equally distributed between psychiatrists, social workers, and school personnel (i.e., school counselor, school psychologist). Thirty-nine percent of services were administered in a private practice setting with another 30% of services being accessed at community mental health centers. The other 31% of outpatient services were received almost equally through schools and hospitals.

Twelve parents indicated their child is currently in counseling. The typical number of sessions received was less than 10. Nine parents reported their child had only attended one mental health appointment. Three reported there were no additional appointments scheduled by the mental health professional and two accessed services one time only for testing. Other reasons given for attending a single session included lack of finances and transportation to get to appointments.

With regards to psychotropic medications, only nine parents reported their children take medication on a regular basis for mental health issues. Six of those children are prescribed medication by a psychiatrist and the other three received prescriptions from their primary care providers.

Eleven parents also reported they have current mental health concerns for their children and they were asked to describe those concerns. Of those who responded, a variety of issues were presented from externalizing concerns (e.g., behavior problems, attention-deficit/hyperactivity disorder), to social adjustment difficulties, to depression, and lack of adherence to required medical treatments.

*Associations Among Diagnostic Categories
and Service Use*

Table 14 describes patterns of mental health service use by diagnostic category. Percentages indicate the number of children in each diagnostic category who met criteria for service use outcomes. Almost half of the children in each category have been referred for mental health services except for children in the developmental disabilities category (33%). Also notable are children in the lymphatic/endocrine systems category, who were all referred for services. Regarding rates of children who have ever accessed services, all the children again in the lymphatic/endocrine systems group met this criterion, while the rate increased for children in the developmental disabilities group to 53%. The muscle/skeletal systems group had the lowest rates of referrals and use of mental health services at 50% each. In the past 12 months, only children in the multiple systems group and developmental disabilities group required inpatient psychiatric services. Within the other categories, children who received mental health services in the past year did so mainly in outpatient counseling settings. However, children in the organ systems group utilized more mental health services in a school setting than outpatient setting (43% compared to 14%).

Percentages were also calculated for services that have ever been utilized. In addition to children in the multiple systems group and developmental disabilities group, 33% of children in the lymphatic/endocrine systems group have also been hospitalized for psychiatric concerns. Similar to patterns of use in the past year, the majority of children across the groups that required counseling services did so in an outpatient community setting versus in the schools.

Table 14

Associations Between Diagnostic Categories and Service Use

Variables	Percentages					
	1	2	3	4	5	6
Ever referred for services						
Yes	40	57	50	100	50	33
No	60	43	50	0	42	53
Ever accessed services						
Yes	40	57	63	100	58	53
No	60	43	37	0	33	33
Type of services used in past 12 months						
Inpatient psychiatric or substance abuse	0	0	0	0	8	7
Outpatient counseling services	40	14	25	100	25	33
Services in a school setting	0	43	25	0	17	20
Type of services ever used						
Inpatient psychiatric or substance abuse	0	0	0	33	8	7
Outpatient counseling services	40	43	50	67	58	33
Services in a school setting	0	29	25	0	33	27
Type of outpatient professional						
Psychologist	0	43	50	100	50	13
Psychiatrist	40	0	12	0	8	13
Social worker	0	0	12	33	8	13
School personnel (e.g., counselor)	0	14	12	0	8	7
Outpatient setting						
Private practice	0	43	25	33	33	13
Hospital	40	0	0	0	17	0
Community mental health	0	0	25	67	17	20
School	0	29	0	0	17	13
Number of outpatient sessions						
Less than 10	40	0	25	33	17	20
10 to 20	0	43	25	33	33	0
20+	0	14	0	34	0	0

Note. 1 = muscle/skeletal systems; 2 = organ systems; 3 = nervous system; 4 = lymphatic/endocrine systems; 5 = multiple systems; and 6 = developmental disabilities. Some columns do not equal 100% due to missing data.

Outpatient services were further examined by the type of mental health professional seen, the location where services were rendered, and the number of sessions completed. Children in the muscle/skeletal systems group who accessed outpatient services did so only with a psychiatrist. Parents in the other groups reported their children

saw a variety of professionals to meet their mental health needs. While the majority of these children saw a psychologist, percentages for children in the developmental disabilities group were almost evenly distributed across psychologists, psychiatrists, social workers, and school personnel.

There was more diversity between groups with regards to where they accessed outpatient services. While children in the muscle/skeletal systems group only accessed psychiatry services in hospitals, children in the organ systems group were reported to have received services in private practice and school settings. Additionally, parents indicated children in the nervous system and lymphatic/endocrine systems groups saw mental health professionals in both private practice and community mental health settings. The multiple systems and developmental disabilities groups were more likely to seek services in multiple settings.

With regards to the number of outpatient sessions received, only children in the organ systems and lymphatic/endocrine systems were reported to have received more than 20 counseling sessions. A portion of children in each of the nervous system and multiple systems group received less than 10 services, while the other children in these groups attended 10 to 20 sessions. Finally, all of the muscle/skeletal systems group and developmental disabilities group were identified as receiving less than 10 sessions.

Associations Among Condition Characteristics and Service Use

To examine the relationships between condition characteristics and mental health service use, analyses were conducted using QUICCC scores and the service use outcome

assessing whether children had ever accessed services. This item was determined to be a primary and general indicator of service use. Table 15 includes percentages of children meeting each of the QUICCC classifications who have accessed mental health services or never used services in addition to QUICCC means and standard deviations for each QUICCC-service use pairing. Independent-samples *t* tests were conducted to compare the means for the two mental health service use groups for each of the QUICCC classifications. Only one *t* test was significant. For service use, children who accessed mental health services ($M = 5.55, SD = 1.48$) reported higher use of services related to their medical diagnoses than children who did not access mental health services, $M = 4.61, SD = 1.46, t(45) = 2.13, p = .04, d = .64$.

Condition characteristic items from the demographic questionnaire were also compared to responses on the service use item assessing whether children in this study have ever accessed mental health services. Percentages in Table 16 represent the number of children in the two service use groups according to their age of symptom onset, age at diagnosis, prognosis, frequency of medical visits, and whether they have been hospitalized or not for their medical diagnosis. Means and standard deviations for pain of symptoms and pain of treatments for both service use groups are presented at the bottom of the table. Independent-samples *t* tests were conducted to compare the means for each pain item. No significant differences were found between means on either pain outcome.

Children who have accessed mental health services demonstrated a greater range in age of symptom onset compared to children who have not accessed services. Over half of children who have used services did not display symptoms until after the first year of

Table 15

Associations Between QUICCC Scores and Service Use

QUICCC categories	Have accessed services (n = 29)	Never accessed services (n = 18)	t	df	p	d
Functional limitations			-.67	45	.506	-.20
Percent meeting criteria	56	40				
Mean	5.28	6.17				
Standard deviation	4.49	4.31				
Compensatory dependence			-.26	45	.793	-.08
Percent meeting criteria	60	35				
Mean	3.41	3.67				
Standard deviation	2.96	3.55				
Service use			2.13	45	.039	.64
Percent meeting criteria	60	38				
Mean	5.55	4.61				
Standard deviation	1.48	1.46				
Total			-.08	45	.936	-.02
Mean	14.24	14.44				
Standard deviation	8.09	8.95				

life, compared to 61% of children who have never used services were symptomatic at birth. A similar pattern occurred with age at diagnosis. Sixty-four percent of children who have accessed mental health services did not receive their medical diagnoses until after one year of age, while 67% of children in the never used services group were diagnosed at birth or before their first birthdays.

Table 16

*Associations Between Condition Characteristics from Demographic Form and Service**Use*

Condition characteristic	Have ever accessed services %	Never accessed services %
Age of symptom onset		
At birth	4	61
Less than one year	2	33
1 to 3 years	1	6
Older than 3	1	0
Age at diagnosis		
At birth	21	33
Less than one year	15	34
1 to 3 years	21	33
Older than 3	43	0
Child's prognosis		
Improve	10	17
Remain the same	38	50
Worsen	14	17
Don't know	38	11
Frequency of medical visit		
At least once/month	48	28
3 to 4 times/year	38	50
1 to 2 times/year	14	22
Hospitalized		
Yes	72	89
No	28	11
Mean pain scores (<i>SD</i>)		
Range 1 to 10		
Pain of symptoms	4.41 (2.64)	4.39 (2.40)
Pain of treatments	4.38 (2.37)	4.44 (2.31)

Notable differences were also found with regards to prognosis. While 67% of parents with children who have never used mental health services reported their child's diagnosis will remain the same or improve, over half (52%) of children who have used services were identified as worsening medically or parents did not know their child's diagnosis. Thirty-eight percent of parents who have accessed services for their child did not know their child's diagnosis compared to only 11% in the other group.

Children identified as having used mental health services also had more frequent medical visits (48% have monthly appointments compared to 28% in the other group). However, the majority of those who have accessed mental health services (72%) and those who have not accessed services (89%) reported hospitalizations due to their medical conditions.

Associations Between Psychosocial Functioning Indicators and Service Use

Controlling for parent depression, associations between PARS III scores and patterns of mental health service were assessed through a series of one-way ANCOVAs. The questionnaire item detailing whether children had ever accessed services or not was once again designated as the service use outcome for analyses. Table 17 includes PARS III means and standard deviations for each service group as well as Cohen's *d* effect sizes for comparisons between means for each service group on the PARS III subscales.

As expected, children who have accessed mental health services had lower means than children in the other group across all PARS III scales indicating poorer psychosocial functioning compared to children who have not accessed services.

Significant between Table 17

PARS III Scores and Service Use

PARS III categories (possible range)	Have ever accessed services	Never accessed services	<i>F</i>	<i>df</i>	<i>p</i>	<i>d</i>
Peer relations (4 to 16)			8.58	1, 44	.005	-1.01
Mean	7.41	10.39				
Standard deviation	2.44	3.40				
Dependency (4 to 16)			3.04	1, 43	.088	-.62
Mean	10.79	12.24				
Standard deviation	2.72	1.92				
Hostility (6 to 24)			.483	1, 44	.491	-.40
Mean	17.14	18.89				
Standard deviation	5.03	3.68				
Productivity (4 to 16)			1.26	1, 44	.267	-.43
Mean	8.48	9.67				
Standard deviation	2.63	2.87				
Anxiety/Depression (6 to 24)			2.03	1, 43	.161	-.61
Mean	18.79	20.53				
Standard deviation	3.20	2.42				
Withdrawal (4 to 16)			.466	1, 43	.498	-.43
Mean	13.48	14.41				
Standard deviation	2.18	2.18				
Total (28 to 112)			1.96	1, 44	.168	-.59
Mean	76.03	83.89				
Standard deviation	9.83	15.92				

group differences were found on the peer relations scale, $F(1, 44) = 8.58, p < .01$, $d = -1.01$. Marginally significant difference was found between groups on the dependency scale, $F(1, 43) = 3.08, p = .09, d = -.62$.

In order to determine the percentage of unmet mental health needs, individuals with PARS-III scores in the clinical cutoff range were selected as a subsample of children with identified mental health needs. Table 18 shows the number of those with

Table 18

Clinical Range of PARS III Scores and Unmet Mental Health Service Needs

PARS III Categories (N = Met clinical cutoff)	Ever referred for services	Never referred for services ^a	Have ever accessed services	Never accessed services ^a	Have current mental health concerns	No current mental health concerns ^a
Peer relations (N = 8)	3	5	6	2	1	6
Dependency (N = 10)	9	1	9	1	4	5
Hostility (N = 7)	6	1	6	1	1	6
Productivity (N = 7)	5	2	5	2	4	3
Anxiety/depression (N = 8)	6	2	7	1	4	4
Withdrawal (N = 14)	6	8	9	5	5	8
Total (N = 5)	3	2	3	2	1	4

^aColumns represent unmet service needs.

lower PARS-III scores who have never been referred for mental health services, have never accessed services, and who were identified by their parents as having a current mental health concern. The majority of these children have been referred for mental health services. However, 5 children demonstrating difficulties with peer relations have not been referred compared to 3 that have, and 8 children who are in the clinical range for withdrawal scores have not been referred for services compared to 6 that have.

The majority of children PARS III scores in the clinical range have also accessed mental health services. However, almost 36% of withdrawn children have not used

services. Surprisingly high numbers (50-86%) of parents reported no current mental health concerns for these children. Productivity was the only category that had more parents who expressed mental health concerns than parents who did not report concerns.

Reported Barriers to Accessing Services

To examine the barriers to accessing mental health services, frequencies and percentages were calculated for each predetermined response selected from the mental health service utilization questionnaire. Frequencies and percentages are also presented for themes that developed in the “Other” response category. Similar analyses were applied to the open-ended question asking parents to provide their suggestions for improving mental health services for their child.

Parents identified difficulty with finding mental health professionals trained in working with youth with disabilities or chronic health conditions as the major barrier to accessing needed services. One parent commented, “I don’t even know where to begin in terms of finding a professional who could relate to a nonverbal, severely DD youth.” A lack of finances and no insurance coverage were also identified as common barriers. Another group of barriers related to functioning of the child and family (i.e., child’s health, lack of childcare for siblings, and difficulty scheduling appointments due to schedule constraints).

Along the same line, parents were asked to provide suggestions for ways to improve accessing mental health services. Twenty-seven parents responded to this open-ended question. After coding the responses for themes, six common themes emerged (see Table 19). Similar to the barriers above, a majority of suggestions related to mental

Table 19

*Barriers to Mental Health Service Utilization and Suggestions to Improve Services**(N = 47)*

Responses	Number of cases
Barriers	
Lack of finances	6
No insurance coverage for services	6
Difficulty finding professionals	12
No referral made	4
Did not understand what services were needed	4
Placed on wait list	2
Health concerns	4
No child care for siblings	1
Lack of time	2
Suggestions for improvements	
Educate MH professionals about disabilities/health conditions	13
Increased collaboration between MH professionals and other professionals and families	8
Educate families on mental health issues and services	11
Improve provision of services (e.g., flexible hours, parent support support groups, earlier intervention)	9
Insurance parity for mental health services	6
Educate school personnel about disabilities/health conditions and mental health issues	3

health professionals, specifically educating them about medical conditions and issues surrounding having a disability or chronic health condition. Some of the comments related to this issue included:

I am unaware of any mental health providers in our area that have experience with working with children with chronic health conditions. I would love to find one for my son.

More available personnel who are familiar with chronic illness and its affect on children/teens.

More professionals who are educated and trained in psychological issues for children who have chronic health problems.

Another theme emerged as several parents also commented on educating families about how their child's health condition might affect their psychological functioning.

One parent recommended teaching, "Awareness of acquired mental health concerns with onset of adolescence. Help parents identify symptoms and implement possible strategies at home." Another stated, "Make parents see that mental health issues for disabled children may not be obvious." One parent also commented on when to talk to parents about mental health issues, "More awareness earlier in his life. We probably could have avoided a lot of problems had we had counseling for his health and how our family would change due to the diabetes and his own reaction and depression."

Two themes also evolved related to expanding mental health services and increasing collaboration between medical professionals, parents, and mental health professionals. Suggestions for widening the scope of services included making office hours more flexible, informing the community about what mental health services are available for youth with special health care needs, and providing childcare for siblings. A few parents also commented on offering support groups for parents:

Having a child with disabilities is very stressful. I have heard the statistic that 80% of special needs families get divorced due to stress and financial strain. Some sort of counseling for the parents around this and coping with the diagnosis.

With regards to collaboration, several parents recommended primary care providers make more referrals to mental health professionals. Multiple parents suggested requiring mental health services be included in the child's medical treatment. One parent

stated, “It should be required that pediatricians practice with child psychologists.” Other parents provided these suggestions:

I feel that mental health care should be included as treatment for chronic health conditions because almost every child I have had contact with who has a chronic health condition (i.e., diabetes) seems to change (for the worse) after a honeymoon period with the disease.

Periodic series of sessions with a mental health provider. As kids grow older, identifying their mental health and its association with their physical disabilities may assist in avoiding the “I am crazy” feeling that may come with physical disabilities.

Collaboration was also discussed in the context of involving parents more in gathering information about their child and acknowledging their right to advocate for needed services.

Another theme that emerged indicated a desire for improved insurance coverage for mental health services. More specifically, parents wanted to have mental health services covered at the same rate as general medical services. Finally, a less frequently endorsed theme related to educating school personnel about not only mental health issues, but also concerns related to having a disability or chronic health condition.

Qualitative Analyses

Interviews were transcribed and coded for analyses. Responses were coded according to four principal areas of interest: (a) childhood and adolescent psychosocial functioning, (b) need for mental health services, (c) experience with mental health services, and (d) suggestions to improve meeting the mental health needs of children and adolescents with chronic health conditions or physical disabilities. Each principal area

was then analyzed for themes or patterns in responses. Table 20 provides an overview of the 5 participants whose responses are reflected in this study. All names have been changed to maintain privacy. The following section will explore each theme separately.

Childhood and Adolescent Psychosocial Functioning

The three themes that emerged from the responses to the principal question regarding psychosocial functioning map on to the constructs measured with the PARS III: psychopathology, adjustment, and impairment. The participants shared various experiences with symptomatology that ranged from mild psychological distress to receiving a diagnosis of major depression. Additionally, they each identified struggling with adjusting to differences in their daily functioning compared to that of peers without disabilities, and some reported impairments in relationships with peers and family and school functioning. Because of their importance to mental health, each of these psychosocial constructs will be explored in-depth.

Psychopathology. Depression or sadness and anger or frustration were most commonly reported by the 5 participants. Most of the participants indicated experiencing mild symptoms of psychological distress; however, Tom described having more severe depressive symptoms as described throughout this section.

Kelsey identified feeling “normal” up until the time when she lost her eyesight:

I mean the only time I can really think that I ever was depressed or upset or mad was when I did lose my vision at 14. And I was pretty depressed for awhile. It was about three months that I was pretty bad but about three months was the worse. I didn't want to do anything, I just wanted to lay in bed and forget the world.

Table 20

Participant Profiles (N = 5)

Informant	Age	Diagnosis	Background
Kelsey	19	Blind	Lost her vision at 14 due to a reaction to acne medication.
Jack	21	Seizure disorder	Had a stroke at birth which stunted the growth of his right arm.
Tom	19	Cerebral palsy	Diagnosed at one year of age and has had numerous surgeries. He is also blind in one eye.
Ethan	18	Retinitis pigmentosa; legally blind	Progressive loss of vision since the age of 2. His sister also has the same diagnosis.
Matthew	15	Cerebral palsy	Diagnosed at birth and has had multiple surgeries.

In contrast, Jack's experiences with a lifelong disability indicate years of emotional distress:

Well I had a lot of sadness and stuff because I got teased a lot during like elementary, junior high, and high school and stuff. So I got sad a lot, that was it, and I got a little bit angry because I got teased a lot. They teased me because of the way I looked basically because I have, like my arm is different from other people, my right arm and stuff. So like my hand looks like a kid's, like a child's arm.

Tom reported the most severe psychopathology including past suicidal ideation.

He was diagnosed with depression last year and identified not only feeling distress

related to the circumstances of his physical conditions, but also the difficulty of his parents' divorce when he was 11:

My parents got divorced and then I've had lots of surgeries in my life, been in and out of hospitals. Before the divorce I didn't deal with it, I just shut everybody out. And I just didn't talk about it and I still don't talk about it, I just shut everybody out. The surgeries just get me down anytime because I have to learn how to rewalk every time I have surgery usually, and like that gets frustrating. And, I mean being blind in one eye, you know I only have one eye, and then being shorter than others...I'm frustrated with life. So the physical aspect of it, like my size and everything it can maybe make me think of things mentally and that's probably brought me down.

Ethan's and Matthew's frustrations were related more to social comparisons and experiences. Ethan said:

Mainly my biggest problem was not being able to participate in some sports like basketball and such, sports like that. And like also watching my friends being able to drive and me not able to. That's really only the issues I had.

Although Ethan's vision loss has occurred gradually since childhood, he did not report any significant emotional distress related to this stating:

I had been told all along that my vision was going to get worse so I didn't really get any expectations of being able to do certain things and so I didn't get my hopes up and therefore I didn't get tore down or whatever. I just basically have the mindset that I've known that it's [blindness] going to happen so when it comes it probably won't really surprise me because I've known all my life that it's getting to that point.

Matthew initially discussed just feeling confused by others reactions to his noticeable physical differences:

I hadn't really thought about it but like random people will just come up to me and ask me what's wrong, and that doesn't really frustrate me, it's just kind of weird. But I've been so used to it that I'll just tell them. It's not like a problem to me. I wasn't really mad because they have a right to know but just like, I don't know, just kind of confused.

Matthew then described feeling “scared to death” when discussing the many surgeries he has faced throughout his life. He also noted feelings of depression were “really strong” right after the procedures but they would subside after he got used to “not being able to do as many things as you could.”

Adjustment. Adjustment related to psychosocial functioning refers to the individual’s adaptation to events across various developmental areas, such as physically, cognitively, socially, and so forth. The inability to perform daily functions at home or school independently (e.g., accessing the playground area) is an issue related to various conditions and disabilities as discovered through the responses of the five participants. They highlighted not only how their medical condition affected their day-to-day routines, but also how their emotional distress compounded their difficulties in functioning.

Kelsey was diagnosed in 7th grade and recalled missing the last three to four months of the school year and then returning at the beginning of 8th grade:

It was hard because I was really shy when it first happened. I didn’t want to ever be around people and you know really do anything and I was scared to go back to school and scared to learn all the new things I needed to.

Jack also discussed how his physical disability and feelings of sadness influenced attending school:

It really affected it because um the more and more every time I went to school, the more and more I just didn’t want to go anymore. And like I didn’t want to do any of the activities with the kids because all I’d do is get teased. It got to the point that my senior year I finished at home. Like the guy dropped off packets to me so I could finish, so I could get my high school diploma and stuff, but I finished at home.

Jack also said he felt “more free” at home because he was no longer being teased on a regular basis.

Tom's depression has had a strong effect on his daily life:

It all depended on the day but some days it was pretty bad, like low like I didn't care about life or anything. And I didn't get out of the house; I just sat home and didn't go anywhere. I isolated myself. And then since school got out, I've isolated myself more over the...at first I did. I didn't go out, I didn't go anywhere...I just stayed home for the first part of the summer.

However, he has become more adjusted to the surgeries and various medical procedures he regularly receives. Tom described not feeling "phased" by the surgeries and accepting that they are "just part of my life now."

Ethan and Matthew both talked about the functional limitations they face on a daily basis and how assistive devices and accommodations help them adjust. Ethan uses special adaptations to his computer to help him read the screen, some of his text books are in Braille, and he has received accommodations in his college classes including a "reader and a scribe." He also uses a cane to navigate when in crowds. Ethan discussed feeling frustrated at times by not being able to do some things independently:

Occasionally it will happen where there's something you want to do but you can't because you can't see what's going on or you need someone to help you do it or something and it makes you feel inadequate once in awhile, but it doesn't happen too often.

Matthew uses a walker and expressed appreciation that his high school has an elevator he can use. Although he also described feeling as if he did not belong or was "out of place" when he was younger and could not do some of the activities that peers were doing, Matthew shared a new perspective:

Like they can do what they want to do and I just find other ways to do it. When I was younger it used to bother me but now I don't really care. I can put it that simple because there's like, like I weight lift a lot. That's one of my favorite hobbies and I can out lift most of my friends. But the reason driving is so big

though is because my friends have told me, “You’re never going to be able to drive. Face that fact.” That upsets me because I’m going to prove them wrong.

Impairment. Psychosocial functioning in children and adolescents, regardless of health status, encompasses peer relationships and social adjustment. However, distinctive issues arise for children and adolescents who have chronic health conditions in this area of functioning as well. The 5 participants each shared their view of how their medical diagnoses and psychological functioning influenced the quality of peer relationships and family relationships.

Kelsey experienced a significant change in her relationship with friends after being diagnosed:

I noticed with a lot of my friends it was hard because I never wanted to go out and do stuff. I was always--it was hard for them to see me going through what I was going through and they wanted to help so bad but there was nothing that they could do.

Jack reported having the most negative interactions with peers. As mentioned earlier, the teasing he received through elementary and into high school resulted in Jack finishing his senior year at home. Although he reported having some close friendships in elementary school, the support he felt from them was not lasting:

I had a pretty good group of friends. They more or less helped me because like they knew what was happening to me and so they would help me like get my mind off the teasing. They would even help me in school, they would um help me fight them, like tell them to back off and stuff. But then I kind of lost contact with them in high school because they made new friends and stuff.

Tom and Ethan shared positive experiences with peers and establishing friendships. Tom described his group of friends as his “solid rock” who “kept me going.” Ethan felt a sense of normalcy in his friendships indicating that his friends would not

only assist him physically but they also teased him with “stuff that friends normally do.”

All of the participants also reflected on how their medical conditions have affected their family relationships and interactions. Kelsey felt her family grew stronger and closer as a result of her diagnosis, via their attempts to support her through her vision loss. She also noted the emotional distress placed on her family:

But at the same time I have family who are on depression pills from what I went through. It was hard but they've stuck by me. I mean my mom will still say, “I never ever should have taken you to that doctor,” you know and they always blame it on themselves and they think it's their fault but it's not--no one could have stopped it.

Jack stated his seizure disorder has affected his family in that he felt his mother attended to him more than his siblings. He laughed, however, when he recalled how his older sister would defend him in elementary school by “beating up” children who were teasing him. He also shared that he and his sister did not reveal to their mother that Jack was being teased until he was much older. Jack reflected:

When I got mad or sad you know, like I got depressed, and so everyone asked me what is wrong and stuff, and it just kind of affected my family a little bit because, um, sometimes I would lash out at them and I didn't mean to. It was kind of hard because then it would bring up sadness every time I brought it [teasing] up so I tried to bury it underneath. I didn't tell my mom what happened to me in elementary school until I got older and she was shocked.

Jack also reported his family made the decision to withdraw him from high school when they realized the emotional toll the teasing was taking on him. He expressed that he has experienced less depression since being out of school because he has spent the majority of his time with his family. Jack said, “They treat me normal and that makes me feel a whole lot better. So I feel like maybe I am worth something than not so.”

Earlier, Tom and Matthew both shared similar feelings of fear related to the surgeries they have had as part of the treatment for cerebral palsy. They also witnessed similar emotions in their parents. Tom shared:

I mean like every time I had to have surgery, it took its toll on my parents about me having surgery physically and emotionally. I've had a few scares like death almost during surgeries. So every time it's kind of scary when I have to go under and whether I'll come up or not.

The families of Ethan and Matthew have provided support and encouragement that both felt have challenged them to exceed their limitations. As Matthew described, "My family, just like there are certain things that my family knows I can do and if like I don't do it, they get frustrated."

Need for Mental Health Services

The participants were each asked if they had ever talked to a counselor or therapist in childhood or adolescence. Only Kelsey and Tom reported accessing mental health services. Their experiences will be discussed in the next section. As Jack, Ethan, and Matthew had never utilized mental health services, they were asked who they reached out to when they experienced emotional distress related to their diagnoses. In addition, they were each asked how it might have helped to formally talk with a counselor or therapist. Their responses were organized into three themes exploring the significance of family support, friend support, and therapeutic support.

Family. Once he felt comfortable telling his family about the teasing, Jack described his family as being "supportive" and reassuring which "comforted" him. He

also noted that he chose not to share his difficulties with his friends. Matthew also indicated he used family as his main outlet for talking about his frustrations.

Friends. Ethan presented a different source of support. He benefited from not only talking with his sister, but he also identified peers as being a significant source of help:

I had a few friends that like they were also visually impaired and I'd talk to them once in awhile. I'd just talk it through with them but mainly it was my sister [who also shares the same diagnosis]. I had a lot of older friends that were also my sister's friends and they were a little older so I kind of looked up to them and they gave me advice and helped me a lot.

Therapy. With regards to how counseling could have helped them, there were mixed responses from Jack, Ethan, and Matthew. Jack felt it could have helped him deal with his anger and depression related to the teasing. However, he expressed some doubt that it would have been enough:

But with just how much I got teased, I don't know, it probably could have helped but couldn't have helped. I didn't really talk to a [school] counselor that much because they didn't really, like they wanted to help but they couldn't help. Plus I felt like if I went to a counselor and they tried to stop it, then they would tease me all the more.

Ethan also expressed doubt about the benefits of counseling as he felt that his frustrations were never that severe to require professional help.

Matthew identified talking to a counselor or therapist would have been beneficial during the time surrounding his surgeries to deal with some of the fear and depression that accompanied them. He said some of his anxiety before surgery was eased by having the doctors explain the procedures and he offered this suggestion for after surgery:

Probably like after, like through the rehab or recovery. I haven't really talked to one but I figure like you're always kind of depressed because you're in so much

pain and you don't know what's going on. You don't know what the next step is going to be so I figure it would help you if talked to somebody.

Experiences with Mental Health Services

As stated earlier, only Kelsey and Tom reported using mental health services in their youth. They both identified attending outpatient counseling through private providers in their respective communities. While Tom actively requested help with his depression, Kelsey was advised to attend counseling at the request of school personnel although she did not indicate experiencing emotional or behavioral difficulties at that time. Their experiences are described in more detail below.

Kelsey. When she was first diagnosed, Kelsey did not want counseling as she preferred to “deal with it myself” and also described feeling overwhelmed at the time by the change in her vision. She was referred for counseling in her junior year of high school by the transition specialist that was working with her. Kelsey said, “They didn't want me to like one day hit an all-time low and get mad about it and hate the world and not know what to do and it's helped.”

Kelsey attended sessions for a year and a half with a provider in her community. She reported it was initially hard to open up about what happened to her but from counseling and the support of her family and friends she has come to view her vision loss differently:

I think the counseling helped and I just think realizing that this is the way my life is going to be so I need to suck it up and just be happy that I'm just blind and not anything else.

Tom. Tom was referred last year by his primary medical provider to a therapist in

a social services office sponsored by his church. He said he initiated a conversation with his doctor about his feelings of sadness, being isolated, and having thoughts of suicide.

Tom attended therapy for 5 months and reported he did not find it to be helpful:

It was not really helpful because like I said, I didn't like to talk about it so I bottled up. I mean he listened but I didn't really open up so then I felt like I wasted his time for awhile.

He also said he did not recall his therapist ever discussing Tom's cerebral palsy or how it affected his life. Tom is currently prescribed an antidepressant by his doctor and noted that he would return to counseling if needed. However in the mean time, he reported he has recently talked to a church leader who he described is "easier to open up to."

Suggestions for Meeting Mental Health Needs

Each of the participants were asked to provide suggestions as to how to better meet the mental health needs of children and adolescents with chronic health conditions or physical disabilities. Responses to this question were varied and as there were few common responses, each suggestion was identified as an individual theme.

Listen. One suggestion was given by all of the participants, which was simply stated: Listen. They each suggested families allow their child to be open to express their emotions and talk about their difficulties. Kelsey stated, "I think emotion is a big part of the mourning process. I mean you need to get mad and sad in order to heal from something so traumatic."

Counseling and education. Only Kelsey identified counseling as an option and stated these youth should be referred for counseling "whether they want to or not." Tom also suggested educating not only families but teachers and peers on how to best support

the child who may be struggling with difficult emotions or behaviors.

Shared experiences. Ethan and Matthew expressed the benefits of talking with others who share the same diagnosis or experiences. Ethan said:

I would tell them that even though sometimes it seems like it's just going to tear you down and be negative, there's a lot of people out there that have gone through the same things and done the same things as them and still been very successful. And so it really is possible to make a big change and do something really great if, if you want it bad enough.

Self-advocacy. Matthew also suggested encouraging youth with chronic health conditions or physical disabilities to challenge their limitations and advocate for their abilities:

My dad has always told me, "Don't quit. Let them tell you what they want to tell you. Just do what you want to do and don't let anyone stop you." Because see it's how people cope with it. See like I've learned that this is the way I am and if people can't deal with it, then it's their fault. Because I've learned I'm different...oh well.

While there were many similarities amongst these five individuals, there were important differences in their responses to distressing events related to their diagnoses as well as their suggestions for improving mental health services. Overall, their narratives provide unique insight as to how these youth describe their experiences with psychosocial functioning and their perceptions of the need for mental health services.

CHAPTER V

DISCUSSION

This study was designed to further understand the psychosocial functioning of children and adolescents with chronic health conditions or physical disabilities, their need for and use of mental health services, and possible barriers to receiving needed services. Previous research has suggested these youth experience poorer psychosocial functioning compared to peers without disabilities or chronic health conditions and they also underutilize needed mental health services. A mixed-methods design was implemented consisting of a quantitative parent survey and a qualitative semi-structured interview with young adults with special health care needs.

Parent responses regarding their child's psychosocial functioning and mental health service use were examined from two approaches defining "disability" and "chronic health condition." The first involved categorizing children reported on in this study by their medical diagnosis, and the second consisted of classifying these children by a non-categorical approach based on the characteristics of their conditions. Analyses examined psychosocial and service use outcomes according to the two definition styles.

When identified by medical diagnosis, the children in this study were divided into six groups based on body systems and constructs affected by their diagnosis (i.e., muscle/skeletal systems, organ systems, nervous system, lymphatic/endocrine systems, multiple systems, and developmental disabilities). Significant differences between the groups were identified on several condition characteristics.

There were fewer differences between diagnostic groups with regards to scores of psychosocial functioning on the PARS III. However, there were several significant relationships when condition characteristics were compared on PARS III scores. While all of the participants in the interviews reported mild symptoms of depression or anger, only one individual identified receiving a diagnosis of depression. Some of them also shared negative experiences with peer relations as well as impairments in their daily functioning due to emotional distress.

With regard to patterns of mental health service utilization, the majority of children reported on had been referred to and accessed mental health services. Children were more likely to use outpatient counseling services in private practices or community mental health centers. The majority of children were referred for counseling by a medical professional and they typically received fewer than 10 sessions. Conversely, only 2 out of the 5 participants interviewed had accessed mental health services.

Patterns of mental health service use were fairly similar across diagnostic groups, and with the exception of one group, more than half of children had accessed services. Condition characteristics from the QUICCC and demographic questionnaire were also compared with regards to patterns of service use. Children who accessed other services (e.g., physical therapy, speech therapy) accessed mental health services more than children who had fewer service needs. In addition, children who developed physical symptoms and were diagnosed past 1 year of age were more likely to have accessed mental health services compared to those who were symptomatic and diagnosed at birth.

Differences in psychosocial functioning were also examined between children who had accessed mental health services and those who had not. In general, means on the PARS III were lower for children who had accessed mental health services compared to those who had not. The rate of unmet mental health needs was also calculated and with a few exceptions, the majority of children with scores in the clinical range on the PARS III had been referred for services or had accessed services.

Participants also reported on the barriers to accessing mental health services as well as provided suggestions to improve services. A major theme in both responses indicated a difficulty in finding mental health professionals who are knowledgeable in working with children with special health care needs. In addition, parents identified an inability to cover mental health services due to a lack of finances and insurance coverage as both a barrier and suggestion for improving services. Another important theme within the suggestions was the request for educating parents about the possible mental health concerns their children may experience. Participant responses from the interviews also indicated a concern with the effectiveness of mental health services in addition to suggesting families be informed of ways to help their child cope with emotional distress related to their diagnoses. The following discussion outlines implications and limitations of this study.

Diagnostic Categories and Chronic Conditions

A goal of this study was to systematically compare two common approaches to defining chronic health condition and disability, and to consider their implications in

conducting research. The children reported on in the parent survey were first identified by their medical diagnosis, which proved to be complicated as there were not only small numbers of numerous diagnoses, but also a large minority (24%) of the sample consisted of children with multiple medical diagnoses. This is similar to results from previous research, which has estimated 20-30% of children with chronic health conditions have two or more diagnoses (McDougall et al., 2004; Newacheck & Taylor, 1992).

All of the children in this study were identified as having a chronic health condition according to QUICCC scores. Additionally, except for children in the Organ Systems group, Lymphatic/Endocrine Systems group, and the Developmental Disabilities group, all of the children in the medical diagnoses groups met QUICCC criteria on all of the three classifications. However, there was missing data in the Developmental Disabilities group on the QUICCC, which accounts for the lower percentages on some of the QUICCC classifications. Stein and colleagues (1997) reported that 74% of children from a community based survey ($N = 1265$) were classified similarly by both the QUICCC and the National Health Interview Survey childhood condition checklist that contained specific medical diagnoses and illnesses.

Using the additional QUICCC coding and scoring system created for this study, a more in-depth look at the differences between the diagnostic groups on condition characteristics was possible. There was little variability between the groups with regards to service use. However, rates of functional limitations and compensatory dependence were significantly higher for children in the nervous system group compared to significantly lower rates in children in the organ systems and lymphatic/endocrine

systems groups. These differences are consistent with the individual diagnoses that make up each of these groups. Most of the children in the nervous system group were identified as being diagnosed with cerebral palsy, which is a disorder that affects an individual's ability to move and to maintain balance and posture (National Institute of Neurological Disorders and Stroke, 2008). The nature of this disorder lends itself to decreased functioning and increased use of assistive devices compared to children in the organ systems (e.g., asthma, kidney disease) and lymphatic/endocrine systems (e.g., diabetes) groups who maintain higher rates of mobility and less dependency on assistive devices.

Results from associations between diagnostic groups and condition characteristics from the demographic questionnaire also produced noteworthy differences between groups. As might be expected, children with multiple body systems affected displayed symptoms much earlier in life and 70% were diagnosed before 1 year of age. It is posited that because multiple body systems were involved, signs of complications would be more severe, pervasive, and noticeable earlier in life compared to other individual diagnoses. Conversely, the majorities of children in the muscle/skeletal systems and lymphatic/endocrine systems groups demonstrated symptoms and were diagnosed later in childhood. Children in these groups had conditions (e.g., muscular dystrophy, diabetes) that do not present clinically until after the first year of life (Centers for Disease Control and Prevention, 2005, 2006).

While the majority of parents identified their child's prognosis as improving, remaining the same, or worsening, rates of parents who did not know their child's prognosis ranged from 27-40% across the diagnostic groups. This was an unexpected

finding and seemed relatively high given that nearly all of the parents knew their child's specific diagnosis. However, this may represent some of the variability that occurs within diagnoses as well as the variability between diagnoses in each of the groups.

The majority of children across groups were reported to have at least three to four medical visits a year with children in the muscle/skeletal systems and organ systems group reporting more frequent visits than the other groups. Children in the nervous system group also had more frequent medical visits in a year; however 50% of these children had more than five hospitalizations. It is not uncommon for children with cerebral palsy to undergo multiple surgeries to reduce contractures or to reduce spasticity (March of Dimes, 2008). The two participants in the interview portion who are diagnosed with cerebral palsy both reported undergoing numerous surgeries throughout childhood related to these symptoms.

One argument against using diagnoses to define chronic health conditions or disabilities is due to the variability within conditions. While variability was expected in the multiple systems group, results in other diagnostic groups were varied as well. Parents in the muscle/skeletal systems group differed in the reports of their child's prognosis. Reports regarding age of symptom onset, age of diagnosis, and prognosis varied across children in the organ systems group as well. This is most likely a result of the different diagnoses that make up each of these groups. For example, diagnoses range from kidney disease to asthma in the organ systems group. However, in general, there were consistent patterns of condition characteristics within most of the diagnostic groups. In addition, it is argued that the technique used for grouping children in this study by

body system and body constructs was appropriate as evidenced by the multiple differences found between groups according to condition characteristics and fewer differences within each group.

Diagnostic Categories and Psychosocial Functioning

Differences among diagnostic groups were assessed with regard to scores for psychosocial functioning from the PARS III. The PARS III was designed to use specifically with youth with special health care needs as it does not include items assessing physical symptoms that might confound scores in this population. The recommended and commonly used cutoff to indicate poor psychosocial adjustment on the PARS III is one standard deviation below the group mean. The total score group mean for this study was 79.25 ($SD = 12.88$) with a cutoff score of 66.37. Ten percent of the children reported on in this study were identified as having poor psychosocial adjustment. PARS III means from previous research using community and clinical samples of children with special health care needs ranged from 86.6 ($SD = 11.9$) to 89.5 ($SD = 17.0$), and one study reported 11.5% of children with chronic conditions or disabilities were identified as having poor psychosocial functioning on the PARS III (Walker et al., 1990; Witt, 2003). Additionally, Walker and colleagues reported PARS III group means from three samples of children without special health care needs ranged from 87.1 to 94.2. These reported means seem to correlate with previous research indicating better psychosocial adjustment in children without special health care needs compared to those with chronic health conditions or physical disabilities.

Results from this study indicated a few significant differences between diagnostic groups in general on psychosocial functioning. Only children in the organ systems group had above group means on all of the PARS III subscales indicating better overall psychosocial functioning compared to the other groups. Their total scale mean score of 91.00 ($SD = 11.20$) is comparable to the mean scores reported above of children without special health care needs. Conversely, children in the nervous system group had the most below group means which suggests they had the poorest overall psychosocial functioning. These results reflect similar findings in previous studies that indicated few differences in psychosocial functioning between diagnoses that do not involve the brain, but higher rates of behavior problems and poorer social functioning in children with diagnoses involving the nervous system (e.g., cerebral palsy, seizure disorders; Wallander et al., 2003; Weiland et al., 1992). Furthermore, levels of intellectual functioning have been shown to make independent contributions to psychosocial adjustment across conditions (Wallander et al.). This lends support to considering children with developmental disabilities individually from children with diagnoses of chronic health conditions or physical disabilities only.

PARS III scores can also be considered in the context of the three specific areas of psychosocial functioning discussed earlier: psychopathology (anxiety/depression scale, hostility scale), daily adjustment (dependency scale, productivity scale), and social impairment (peer relations scale, withdrawal scale). Although there were no significant between-group differences on the anxiety/depression scale and hostility scale, children in the lymphatic/endocrine systems group had the lowest means on both scales. However, it

is important to note that there were only 3 children in this group. A meta-analysis exploring depression in children with chronic conditions reported that this population as a whole may be at a slightly elevated risk for depression, but most are not clinically depressed (Bennett, 1994).

With regards to daily adjustment on the PARS III, scores were similar between the groups on dependency but there were significant differences on the productivity scale. Children in the muscle/skeletal systems group demonstrated the highest level of productivity followed by the organ systems group. Productivity was significantly lowest for children in the developmental disabilities group. Items on the productivity scale assess a child's ability to stay on task, level of motivation, as well as their ability to overcome difficulties with the task. These tasks require a level of cognitive ability that children with developmental disabilities may not meet.

Significant differences were also found between groups with regards to social impairment. Children in the organ systems group were reported to have more positive experiences with peer relations than the other groups, while children in the developmental disabilities had the most difficulty with peer relations. On the withdrawal scale, children in the organ systems group again had higher means indicating a higher level of positive peer engagement compared to children in the nervous system group who demonstrated more withdrawn behavior. The nervous system group also displayed additional social impairment with lower means on the peer relations scale as well. A review of the literature from Thompson and Gustafson (1996) demonstrated children with conditions affecting the brain scored much lower on the social competence scale of

the CBCL compared to children with diagnoses not affecting the brain, and they were also reported to be more socially isolated. In addition to causing mobility issues and visible differences, cerebral palsy, and other neurological disorders can also affect speech making communication difficult (Pirila et al., 2007). A combination of these symptoms may lead children with nervous system diagnoses to have more problems forming peer relationships as they may experience social stigma because their symptoms are highly visible in addition to an inability to effectively communicate with others.

Condition Characteristics and Psychosocial Functioning

QUICCC scores using the new coding and scoring system, along with condition characteristics from the demographic questionnaire, were compared with PARS III scores. PARS III subscale scores will once again be discussed according to the three specific constructs of psychosocial functioning. With regard to psychopathology, few significant relationships were found between overall condition characteristics and the anxiety/depression and hostility subscales. Late age of symptom onset was significantly correlated with increased hostility, and later age of diagnosis was significantly correlated with increased symptoms of anxiety and depression. These results may reflect the disruption in overall functioning and adjustment that may come with acquired chronic conditions or disabilities later in life. Conversely, children who are diagnosed at birth or in infancy might display better psychosocial adjustment because they and their families accept and adjust to the diagnosis as a part of the child's life. However, previous research has provided mixed results regarding age of onset and its effect on psychosocial

functioning with recommendations that age of onset be studied in a longitudinal assessment that covers key periods of development (e.g., school entry, transition to middle school; Perrin, 2002; Thompson & Gustafson, 1996; Wallander et al., 2003).

Patterns of psychopathology on the PARS III correlated with the reports of the interview participants. There was minimal variability in the report of type of psychological symptoms and severity of symptoms amongst the interviewees except for Tom. While he discussed experiencing more severe symptoms of depression (e.g., withdrawal, suicidal ideation), he attributed his distress to a combination of his cerebral palsy and his parents' divorce in childhood. Like Tom, Kelsey also received counseling services but she did not identify herself as having a clinical level of emotional distress, and she indicated the counseling served as more of a preventative action than a needed therapeutic intervention. In addition, while Kelsey was the only interviewee to acquire her diagnosis past early childhood, her report of depressive symptoms did not seem to differ from the other participants.

Similar to the comparisons of diagnostic categories with psychosocial functioning above, significant relationships were found for daily adjustment on the dependency and productivity scales. Children with a later age of diagnosis demonstrated significantly higher rates of dependency. It is suggested that children diagnosed early on in life have likely accessed treatments and services that would increase their independence throughout their development compared to children diagnosed later on in life who may have to learn a new set of skills related to self-sufficiency. With regards to productivity, children who used more services demonstrated lower levels of productivity. A child

receiving physical therapy or nursing services may not have the physical abilities to complete tasks. In addition, a significant difference between groups with regards to frequency of medical visits was also found for productivity. Children with visits three to four times a year demonstrated significantly more productivity than children who attended medical appointments one to two times a year. More frequent medical visits may serve as prevention from conditions worsening, but also to promote adherence to treatments that increase productivity and functioning (Walders & Drotar, 1999).

Issues related to daily adjustment were also identified by the interview participants. Both Ethan and Matthew discussed feeling frustrated that they were not able to perform some of the activities and tasks that peers engaged in. This seems to indicate an awareness of not being as productive compared to others their age that did not have a chronic health condition or physical disability. Ethan also commented on dependency issues. As his vision has continued to decline, Ethan has had to rely more on the use of assistive devices and the help of others, which also produced feelings of frustration.

Kelsey and Jack both reported disruptions in their daily functioning related to attending school as a result of emotional distress associated with their medical diagnoses. Kelsey's vision loss required her to miss almost 4 months of school in junior high. When she returned, she described feeling anxious with not only being around others, but also with adjusting to being in the classroom again and adapting to learning in a new way. Jack's ability to be productive in school and complete requirements for his high school diploma was disrupted by the frequent teasing he received from others related to his physical

condition. The teasing was so extreme and impacted Jack so strongly that he made the decision with his family to complete his senior year at home.

Significant relationships were once again found for social impairments on the peer relations and withdrawal scales. All three of the QUICCC condition classifications were significantly correlated with peer relations. Children with greater functional limitations, increased compensatory dependence, and higher rates of service use had poorer peer relations. Furthermore, children with greater functional limitations and increased service use were also identified as being more withdrawn. Several factors may explain these relationships. Decreased functioning may make it difficult to physically engage with peers and join in similar activities. There is some consistent support from the empirical literature for diminished functionality correlating with increased emotional and behavioral problems (Lavigne & Faier-Routman, 1993; Thompson & Gustafson, 1996; Witt et al., 2003); however, the functional limitation scale from the QUICCC was only significantly correlated with social impairment and not psychopathology. It is possible that social impairments may serve as a mediator between increased functional limitations and psychological distress.

Reliance on devices or technology may indicate problems with communication (e.g., hearing, speech). Children may also feel self-conscious about their reliance on devices and peers without special health care needs may be confused or frightened by the devices. However, some research indicates that visibility of a condition was associated with better interpersonal relations (Pless & Nolan, 1991). It is hypothesized that the degree of visibility influences the likelihood that a child accepts himself as having a

chronic condition or disability. Depending on the number of services accessed, this could be quite time consuming and require youth with special health care needs to be absent from school and other social functions. Results from previous research estimate children with special health care needs miss from 9 to 16 days of school a year compared to an average of 5 days for children without special health care needs (Thompson & Gustafson, 1996).

Other than Jack's experiences, the other interviewees reported positive experiences with peer relationships. Kelsey, Tom, Ethan, and Matthew all portrayed their friends as being supportive and accommodating of their medical diagnoses. They also indicated they felt a sense of normalcy in their friendships from shared interests to typical teasing that occurs between close friends. Most of the participants also reported having supportive and caring family relationships even though they were aware of the stress their diagnoses placed on family members. Kelsey talked about her parents' blaming themselves for her vision loss because they took her to the doctor and got her the prescription that caused her condition. Tom and Matthew also talked about the fear their parents displayed each time they underwent their surgeries. Although few studies have explored the relationship between peer relations and psychosocial adjustment in this population, there is some indication that perceived social support from both family and peers was associated with better adjustment than those with social support from only one source (Wallander & Varni, 1989). With regards to family relationships, a number of studies indicated family cohesion made a significant contribution to social functioning in youth with special health care needs (Thompson & Gustafson, 1996).

Another significant relationship indicated children with more frequent medical visits were less withdrawn than children with medical appointments one or two times per year. Although there were no significant between-group differences on the PARS III between children who had been hospitalized versus never hospitalized, children who had been hospitalized had higher means on the peer relations and withdrawal subscales. Previous research has focused mainly on the relationship between condition characteristics and psychological functioning and less on peer relationships or social adjustment (Thompson & Gustafson, 1996). Although more frequent medical visits might also require a child to be away from peers and hinder social relationships, it is not clear how hospitalizations may lead to more positive peer relations compared to never being hospitalized. It is posited that children who are hospitalized might receive positive attention from peers and increased empathy regarding their condition. In addition, it may be possible that some medical complications may be overlooked in the children who have never been hospitalized causing them to be less engaged due to pain or sickness. However, a study comparing children with moderate to severe asthma with matched controls on peer relationship adjustment revealed participants who experienced more hospitalizations were less preferred as playmates and were perceived to be more sensitive and isolated (Graetz & Shute, 1995). Although in general, participants with asthma demonstrated peer relationships that were equivalent to those of their peers.

Patterns of Mental Health Service Utilization

Rates of referrals (51%) and use of mental health services (62% quantitative

portion, 40% qualitative portion) in this study were higher than in previous studies of mental health service utilization by children and adolescents with chronic health conditions or physical disabilities (11-38%; Cadman et al., 1987; Gortmaker et al., 1990; Krauss & Wells, 2000; Witt, 2003). Although this may also be a result of the definitions used in this study, this could reflect an increase in awareness over the past 20 years of the psychological needs of youth in this population. Furthermore, this could also indicate a higher need for mental health services due to increased psychosocial maladjustment in children and adolescents with special health care needs.

Only one previous study was found that explored how children and adolescents with chronic health conditions and physical disabilities used mental health services (Witt, 2001). In a national sample of children identified with a disability ($N = 3,700$), 3% accessed inpatient services, 10% utilized outpatient services, and 11% received some type of mental health service in an education setting. A similar pattern emerged in this study with the majority of mental health services being accessed in an outpatient or school setting compared to inpatient hospitalization. However, unlike results reported by Witt, more children in this study accessed counseling services in private practices and community mental health centers than school settings. Witt (2003) reported children with disabilities with poor psychosocial adjustment were more likely to use mental health services in schools if they were older (15-17 years), male, and were covered by public insurance.

This study also inquired about the number of counseling sessions children had received. The majority of children attended less than 10 counseling sessions and only two

children had attended more than 20 sessions. Kelsey and Tom varied greatly in the number of counseling sessions they attended. While Kelsey received counseling for approximately 18 months, Tom only attended sessions for 5 months. They both saw mental health professionals in their communities but they were referred in different ways. Through his primary care provider, Tom was referred for counseling after he initiated a conversation with his doctor about his depression. Kelsey was referred through school personnel (i.e., transition specialist) at their suggestion about 4 years after her diagnosis to address any residual difficulties Kelsey was having related to her sudden vision loss.

Diagnostic Categories and Service Use

Parent responses indicated almost half of the children in each diagnostic group had been referred for mental health services. While only 33% of children with Developmental Disabilities had been referred for services, 53% had actually used mental health services. This discrepancy could be explained in that half of these children accessed services in a school setting, which could include required testing as part of an individual education plan (IEP). Several parents identified psychological testing as a mental health service they accessed for their child.

The majority of parents reported their child received a referral to mental health services from their primary care provider or medical specialist. As part of the study conducted by Witt (2001, 2003) regarding the use of mental health services by children with disabilities, parents/caregivers were asked to identify who coordinates their child's overall medical care as well as who coordinates social services and personal care

services. Half of the children had a medical professional involved in coordination of care, 35% had no one who was coordinating services, and 14% had a family member coordinating services without the help of a medical professional. Children with care coordination involving a health professional had greater odds for accessing mental health service while coordination by a family member alone demonstrated no advantage over no one coordinating services. This highlights the importance of the involvement of medical professionals in recognizing the need for mental health services in youth in this population and making appropriate referrals.

Children in the muscle/skeletal systems group had the lowest rates of referrals (40%) and use of mental health services (40%), while children in the lymphatic/endocrine had the highest rates (100% for referrals and service use). Children in this category also had the lowest means on anxiety/depression and hostility on the PARS III indicating more psychopathology than the other groups. However, there are only three children in this category and they each have a different medical diagnosis that makes it difficult to make suggestions about the nature of these results. It is noteworthy that parents of two out of these three children reported they accessed mental health services because of concerns related to their child's medical diagnosis (e.g., nonadherence to treatment; "dealing with medical condition").

Few variations in service use were found between the diagnostic groups. The majority accessed outpatient services with either a psychologist or psychiatrist, and most accessed counseling in the community versus in the schools. However, children in the developmental disabilities group were reported to utilize outpatient services from a

variety of professionals and in multiple settings. With regards to number of counseling sessions received, although children in the organ systems group were found to have the highest level of psychosocial functioning, they attended the most counseling sessions. Fifty-seven percent of this group accessed mental health services and 75% of these children received 10 to 20 counseling services, and 25% attended more than 20 sessions. This may indicate that when children in this group demonstrated poor psychosocial functioning, they recognized the need for services and utilized them effectively.

Condition Characteristics and Service Use

As described above, there is some indication from previous research that decreased functioning was associated with increased psychosocial difficulty. Although higher scores for functional limitations on the QUICCC were found in children who had accessed mental health services, means were not significantly different between children who had accessed services versus children who had not. Only means on service use were significantly different on the QUICCC with children who had accessed mental health services reporting higher rates of using other services (e.g., physical therapy, nursing services).

Condition characteristics from the demographic questionnaire were also compared with service use. Results showed that children with later age of onset for symptoms and diagnoses were more likely to have accessed mental health services compared to children who demonstrated symptoms and were diagnosed at birth. As mentioned above, there were significant correlations between late onset of symptoms and

later diagnoses with higher anxiety/depression and hostility. Because previous results have not been clear on the relationship between age of onset of symptoms and diagnoses, findings from this study suggest that it is important to explore this connection in more depth.

Future research should also explore the connection between frequency of medical visits and mental health service use. Results from this study showed children who had more frequent medical visits were more likely to have used mental health services, which is similar to the finding above that children who use more services in general have accessed mental health services at a higher rate than children with fewer service needs. This may indicate more medical professionals are referring youth with special health care needs to mental health services when needed. Another explanation for this trend may be that more frequent medical treatment has some effect on the psychosocial adjustment of these youth.

Psychosocial Functioning and Service Use

Means on the PARS III were compared between children who had accessed mental health services and those who had not. Significant between group differences were found on the peer relations scale and dependency scale. In general, children who had accessed mental health services had lower functioning on all of the scales compared to children who had never used services.

The percentage of children in this study with an unmet mental health need was also calculated. While the majority of children in the clinical range on the PARS III

subscales had been referred for mental health services, children in the clinical range on the peer relations scale and withdrawal scale were more likely to have never been referred for services. Conversely, the majority of children in both of these categories had actually used mental health services similar to children in the clinical range on the other PARS III scales. In a national sample of youth with disabilities that measured psychosocial adjustment using the PARS III, almost 40% of children identified in the clinical range on the total score reported using some type of mental health service (Witt, 2001). In this study, 60% of children in the clinical range on the total score were identified as having accessed mental health services.

In addition to completing the PARS III about their child, parents in this study were also asked whether they had any current mental health concerns. The majority of parents with children in the clinical range on the peer relations, dependency, hostility, withdrawal, or total score scales reported no current mental health concerns. This was a somewhat surprising finding. Previous research has estimated rates of unmet mental health service needs range from 14-60% (Boothroyd & Armstrong, 2005; Pabian et al., 2000; Witt, 2001) while they were 40-60% in this study.

When combined with other results described above, children in this study demonstrated significant difficulty with social impairment compared to psychopathology. Daily adjustment (i.e., productivity and dependency) was also found to be more of a source of poor functioning than psychopathology. A general statement could be made that the way chronic conditions and disabilities affect psychosocial adjustment has more to do with social functioning (i.e., social impairment and daily adjustment) than at the

individual level of functioning (i.e., psychopathology). It is argued that responses in this study suggest that daily adjustment involves social comparison and a recognition that the child is functioning differently than peers. As stated previously, there is a paucity of research related to the social adjustment and functioning of children and adolescents with chronic health conditions and physical disabilities, and especially with regards to how it relates to the child's overall psychosocial functioning.

Barriers to Service Use

Responses from the parent survey were combined with participant responses from the interviews to identify reported barriers to accessing mental health services for a child or adolescent with a chronic health condition or physical disability. Barriers experienced by children and families in this study were similar to others described in previous research (Krauss & Wells, 2000; Pabian et al., 2000). Krauss and Wells surveyed 2,220 families in the United States with children with special health care needs. Almost half of the families of children with a mental health need reported having difficulty accessing mental health services due to problems finding providers with needed skills and experience, difficulty getting referrals and making appointments for services, and a lack of coordination of care between the mental health professional and other care providers.

One of the most frequently reported barriers in this survey was difficulty finding a mental health professional who had experience working with children with special health care needs. The other most frequently identified barrier was a lack of finances or insurance to cover needed services. Although parents were not asked about their health

plans in this study, Krauss and Wells (2000) reported parents of children with special health care needs who had concurrent mental health concerns were significantly less satisfied with their child's main health plan than were parents of children without mental health concerns. Parents in that study also reported a high rate of problems with accessing needed services, specifically mental health services and home health services, with their health plans.

Parents in this study also identified barriers with the initial set up of services. More specifically, they reported challenges related to referrals not being made, not understanding what type of mental health services to access, or they were placed on a wait list for services. Results from a study by Witt (2001, 2003) were presented earlier that suggested when medical professionals are involved in coordination of care and services for youth with disabilities, they are more likely to access needed mental health services compared to when families coordinate care on their own or there is a lack of care coordination all together. Similar findings by Briggs-Gowan and colleagues (2000) indicated children meeting criteria for a psychiatric disorder were three times as likely to see a mental health professional if their parent/caregiver discussed concerns about the child's psychological well-being with their pediatrician.

Although fewer parents endorsed these items, a theme emerged related to family functioning serving as a barrier to using services. Parents indicated they did not have time to begin mental health services for their child or their child was not in good enough health at the time for them to access services. Child care for siblings was also identified as a problem in getting needed services for their child with special health care needs.

This is similar to suggested family barriers to accessing mental health services as outlined by Sabbeth and Stein (1990). They indicated families may find it difficult to find time or money to take their child with a special health care need to yet another appointment in addition to the effort that goes into securing child care for siblings for each of the numerous appointments that child may already have.

Six themes emerged from suggestions for improving mental health services. Half of the parents who responded to this question recommended educating and training mental health professionals to increase their knowledge and skills related to working with youth who have special health care needs. Many of the interview participants expressed an uncertainty regarding how therapy or counseling could help with emotional distress related to their diagnoses. Reasons ranged from assessing their symptoms to not be severe to a feeling that counseling would not meet all of their needs especially with regards to improving peer relations. However, Kelsey strongly endorsed mental health services for all children with special health care needs “whether they want to or not.” Matthew also recognized a need for counseling for youth undergoing surgeries and numerous medical treatments to address feelings of anxiety and depression related to the procedures.

Sabbeth and Stein (1990) identified possible barriers to receiving services from the mental health professional’s point of view. They stated there are few therapists/counselors who have the needed skills to communicate with children who have hearing, visual, or language disorders. Furthermore, only a small percent of mental health professionals have specialized training in working with youth with special health care

needs. The authors also reported opinions vary amongst mental health professionals about how much they should know about a child's particular diagnosis. Some feel they should learn about each particular disorder and its treatments while others report effectiveness in working with the child's mental health issues with less focus on the physical condition of the child. However, Tom's therapist never addressed his medical condition and Tom did not find his experience with mental health services to be effective in treating his depression. As the experiences and skills of mental health professionals have received much attention in this study, future research on the training and perceptions of working with youth with special health care needs by mental health providers is warranted to address this significant barrier and improve service delivery.

Nearly half of the parents also promoted a theme of educating parents about mental health issues related to their child with a chronic health condition or physical disability. All of the interviewees recommended families be aware of their child's need to express their emotions and to be open to hear about their child's challenges related to their conditions. This seems especially effective as many of the interview participants reported they largely relied on their families for support and to share their difficulties. Recommendations from the American Academy of Pediatrics Committee on Children with Disabilities (1999) suggest that parents be empowered to be proactive in care coordination for their child by informing them of their child's condition and educating them on accessing needed services. Multiple sources could be used to provide education to caregivers about psychosocial difficulties that may accompany their child's health condition, especially with regard to social functioning. Medical providers, mental health

professionals, school personnel, social service agencies, and other providers who have frequent contact with these children and their families would be important informants to help parents and caregivers be more aware of their child's mental health.

A third less frequently endorsed theme was to educate school personnel about both disability and health concerns as well as mental health issues. From the interviews, Tom suggested school personnel be educated about how to offer support and how to empathize with youth who have chronic health conditions or physical disabilities. Research exploring how school counselors meet the needs of students with disabilities indicated that some school counselors view counseling students in this population to be a "duplication of service" (Frye, 2005). This idea suggests that students with disabilities who are receiving special education services would be getting double services if they are involved in counseling with the school counselor. Frye recommended school personnel receive in-service training to promote the idea that the school counselor's responsibility is to all students, and that additional research be conducted that examines the existing beliefs and attitudes of school staff about their perceived roles in meeting the personal and social needs of youth with disabilities.

Two other themes seemed to be similar in that they provide suggestions for improving how services are provided. Ideas ranged from expanding office hours to providing parent support groups in addition to individual services for children. Parents also asked for better collaboration between mental health professionals and other providers (e.g., medical, school) as well as the families themselves. A few recommended mental health services be automatically included in their child's medical treatment. Few

studies have explored the efficacy of integration of psychological interventions with health care for children with special health care needs and their families. However, of those completed, results showed a reduction in medical care utilization and costs associated with health care, improved health outcomes, and increased treatment compliance (Walders et al., 1999).

Finally, coverage of services was also raised as a suggestion. Parents requested mental health services be covered by insurance companies at the same rate as their child's medical services. Walders and colleagues (1999) presented findings from previous research that describes the negative consequences of separating reimbursement for mental health services from physical health care services. Some of the consequences identified included children and families may limit use of more proactive, preventative services for psychological problems related to the child's medical diagnosis; limited comprehensive care that assists children with maximizing their functioning and quality of life; and increases barriers already faced by these children and their family in accessing mental health services. An editorial by Druss (2006) identified three suggested goals for establishing mental health parity: (a) protect individuals against financial loss when they need mental health care, (b) reduce the stigma related to mental disorders and legitimize treatments, and (c) to improve access to and quality of mental health services. Aside from these six main themes, two other suggestions from the interviewees are worth mentioning. Ethan and Matthew both shared how they benefited from talking with others who had shared experiences with their diagnoses or similar medical experiences. Ethan talked about a mentoring group that he had recently joined where adults with vision loss

who are 21 and older are paired with youth with similar conditions to offer support and encouragement. A search of the literature reveals some previous research on parents supporting or mentoring other parents with children with disabilities, but no studies were found exploring the effects of mentoring or peer support for youth with special health care needs.

Matthew also promoted challenging youth with special health care needs to overcome perceived limitations. He discussed how his family has taught him that others may doubt his abilities but he should advocate for his skills and capabilities and not let people set limits for him. A meta-analysis of the empirical literature by Test, Fowler, and Brewer (2005) demonstrated that teaching self-advocacy skills to individuals with varying disabilities and ages has had a positive impact on their knowledge of self, communication, knowledge of rights, and leadership. One study that has examined peer relationships in children with physical disabilities found that a child's assertiveness and self-advocacy facilitated peer relationships (Coe, 1996). Furthermore, at the high school level, youth with disabilities who advocated for themselves and adapted to activities to support inclusion appeared to make noticeable differences in their acceptance from peers.

Limitations

There are limitations in the generalizability of results to the overall population of youth with special health care needs. As has been a problem with previous studies, how to identify and categorize these children and adolescents for the purpose of conducting research was a difficulty in this study as well. Although there was relatively limited

within group variation, each diagnostic category was made up of multiple diagnoses and conditions rather than consisting of large numbers of a single diagnosis. An additional concern stems from relying on parent/caregiver reports of child diagnosis. Responses may lack uniformity in that some respondents may have provided all of their child's medical diagnoses, while others may have entered only their child's primary diagnosis and did not identify other medical concerns. This can also attribute to ambiguity in defining groups.

However, by grouping the numerous diagnoses by body system or body construct involved, there was some evidence that this system identified true differences in conditions between each diagnostic group. More significant differences between groups were found though when analyzing the sample according to condition characteristics rather than diagnostic categories. It seems that generalizability would be stronger if chronic health conditions and physical disabilities were considered by their shared characteristics but with an understanding of how each diagnosis uniquely contributes to that characteristic. For example, there was a strong indication of social impairment and poor peer relationships when psychosocial functioning was explored by diagnostic categories as well as condition characteristics. However, it is plausible that social impairment could be explained differently in a child with a developmental disability (i.e., lack of social reciprocity) versus a child with muscular dystrophy (i.e., impairment in mobility).

Another limitation that affects the generalizability of these results relates to the small sample size and demographic makeup of the quantitative portion. Fifty

parents/caregivers is a very small percentage of the families in this country with youth with special health care needs. Furthermore, there is limited representation of youth from lower socioeconomic status as well as youth from ethnic minority groups. Findings from this study may be best applied to the functioning of middle to upper class families of youth with chronic health conditions or physical disabilities who are computer literate and may be actively involved in advocacy and seeking supports for their child.

Even though the sample size was small and medical diagnoses were quite varied, there were some consistent patterns in the findings that also correlated with previous research (e.g., children with neurological disorders displayed poor psychosocial functioning; a need for further research on the relationship between peer relations and psychological functioning). Similarly, there were only five participants in the qualitative portion of this study which limits generalizing their experiences to the larger population of youth with chronic health conditions or physical disabilities. There were some consistencies in the narrative accounts between interviewees, but it is unlikely that data saturation was achieved due to the small number of interviews.

Issues with methodology are also recognized as a limitation. While recruitment strategies had the potential to reach a large population of parents and caregivers, very few responded and participated. It was thought that an online survey would be an opportune method of gathering parent/caregiver responses as participants could take the survey at times when it was most convenient for them and they could do so on any computer, whether at work, home, and so forth. Participants also had the ability to stop at any point,

save their responses up to that point, and log back in at another time to complete the rest of the survey.

Although online survey research is still a very young and evolving technique, some identified advantages to this strategy include access to individuals in distant locations and the ability to reach participants who are difficult to contact (Wright, 2005). The low number of participants in this study may reflect the disadvantages of sampling from an online community (e.g., forums, listservs) including the fact that participation in online communities may be sporadic (Wright). While some members may regularly check and participate in discussions, others may do so intermittently and therefore may miss postings about research opportunities. Incidentally, the response rate of online surveys in the early stage of Internet research was its strength; however, as more and more researchers are targeting a wider range of Internet users, response rate has become more of a problem (Ye, 2007). Another common concern raised with online surveying is the issue with self-selection bias in that some individuals in online communities are more likely to complete online surveys than others (Wright; Ye). There is some indication respondents more likely to respond to Web surveys are relatively more homogenous than randomly selected respondents which again questions the generalizability of results (Ye).

While several studies have explored parent participation in the education and medical care of their child with special health care needs, there does not appear to be any studies that have explored rates and patterns of parent participation in research. There may be specific characteristics of this group of parents/caregivers that limited their participation in this study as well as their child's participation in the interview portion. It

is suggested that lack of time may be a similar problem to participation in research as it was for accessing mental health services. As a significant amount of the caregiver's time may go to meeting the daily health care needs of their child with a chronic health condition or physical disability, there may be less time to spend on activities that are not a necessity of meeting the child's needs. In addition, parents may have chosen not to participate as a result of stigma associated with psychological issues and mental health services or caregivers' reluctance to acknowledge their child has psychosocial problems. Sabbeth and Stein suggested parents/caregivers of children with chronic conditions may view mental health issues as "yet another thing wrong" or as being avoidable and therefore may not acknowledge them (p. 74, 1990).

A common limitation cited in research involving the psychosocial functioning of youth with special health care needs is the lack of longitudinal data. Parents may have underreported or overreported poor psychosocial functioning in their child based on whether their child had demonstrated any recent emotional or behavioral difficulty. Interviewing parents and the youth themselves over time may provide a more accurate estimate of the frequency of poor psychosocial functioning, as well as better explain the relationships between conditions and psychosocial adjustment.

Implications for Practice and Research

Several interesting outcomes were observed in this study regarding the patterns of mental health service use by youth with chronic health conditions or physical disabilities. Results may help inform clinicians of better treatment practices for youth with special

health care needs. Mental health professionals are encouraged to educate themselves about a medical diagnosis in a broad manner but it is also important to understand how condition characteristics vary within diagnoses and may have an individual effect on psychosocial adjustment. It is also recommended professionals and families pay special attention to the child's social adjustment as this construct seemed to be most related to poor psychosocial functioning. In addition, educating parents/caregivers and medical professionals about the possible mental health needs of these youth could lead to increased referrals for mental health services as well as focus attention on reducing barriers to accessing needed services.

Suggestions for conducting research with youth with special health care needs and their families are also offered with regards to methodology procedures. As discussed earlier, a limitation of this study was the small sample size given the potential to recruit participants from a large population by way of listservs. Other recruitment strategies that take into consideration accessing families through common points of service delivery may prove more successful. For example, a larger sample of children and adolescents with chronic health conditions and physical disabilities could be reached through recruitment in educational or medical systems. Additionally, a larger, more diverse sample may also be garnered through collaboration with colleagues in other institutions across the country. Finally, parents/caregivers may feel more comfortable and invested in the research project if they are involved in designing the study through participatory action research.

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APPENDICES

Appendix A:
Consent Form and Recruitment Letter
for Quantitative Study

Date Created: December 8, 2006
Utah State University IRB Approved 12/11/2006
Approval terminates 12/10/2007
Protocol Number: 1697



WEB SURVEY INFORMED CONSENT/ASSENT FORM

Mental Health Service Utilization in Children and Adolescents with Chronic Health Conditions and Physical Disabilities

Introduction/Purpose: Sara Hunt, a doctoral student in the Department of Psychology at Utah State University, and Dr. Renee Galliher are in charge of this research study. We would like you to be in the study because we want to know about the experiences of children and adolescents with chronic health conditions or physical disabilities with using mental health services in childhood and adolescence. About 100 parents of children with chronic health conditions or physical disabilities will complete this research study.

Procedures: Your part in this study will be a 20 to 30 minute online survey. You will be asked a series of questions asking about your child's medical diagnosis, in addition to a series of questions asking about your child's psychological well-being. You will also complete questions related to your own psychological well-being. Finally, other questions will be presented that ask you to describe your child's experiences with mental health services. Your responses will be collected into a database and scored by members of our research team.

Risks: There is some risk of feeling uncomfortable in this study. Some individuals may not want to share personal information about their children with the researchers. You can choose not to answer survey questions that relate to personal or difficult issues.

Benefits: We hope that you will find this study to be interesting and informative. Your information will help us learn more about use of mental health services by children and adolescents with chronic health conditions or physical or sensory disabilities. It will help us understand how often children use these services and what barriers might keep them from accessing services.

Explanation and Offer to Answer Questions: If you have any questions, please contact Sara Hunt at (435) 797-1986 or at sarahunt@cc.usu.edu. You can also ask the Primary Investigator, Professor Renee Galliher, at (435) 797-3391.

Payment: When you finish this research, you will have the option to submit your name and email address for a drawing to be held in April 2007 for one prize of \$100 or two \$50 prizes. Upon completing the final question of this survey, you will be taken to a new webpage where you can enter this information. Clicking the "Submit" button at the bottom of the page will enter your information into the drawing. Your name and contact information will be stored in a separate data base and your survey answers will not be linked to your name in any way.

INFORMED CONSENT/ASSENT FORM

Mental Health Service Utilization in Children and Adolescents with Chronic Health Conditions and Physical Disabilities

Voluntary Nature of Participation and Right to Withdraw without Consequences: Being in this research study is entirely your choice. You can refuse to be involved or stop at any time without penalty.

Confidentiality: Consistent with federal and state rules, your information and answers will be kept private. Only Sara Hunt, Dr. Galliher, and research assistants will be able to see the data. All information will be kept in a secured database. Your answers will only have an ID number and not your name. Additionally, because your IP address will be invisible, it will be impossible to identify your computer. Your name will **not** be used in any report about this research and your specific answers will not be shared with anyone else. If you choose to submit your name and email address online for the cash drawing, the information will be stored in a separate database and will not be linked to any of your survey answers. Data from this study may be used for three years by our research team before it is destroyed. When the research has been completed, a newsletter with the general results will be sent to you if you would like.

IRB Approval Statement: The Institutional Review Board for the protection of human subjects at Utah State University has approved this research project. If you have any questions regarding IRB approval of this study, you can contact the IRB administrator, True Rubal-Fox at (435)797-1821.

Copy of Consent: Please print a copy of this informed consent for your files.

Investigator Statement: I certify that the research study has been presented to the participant by me or my research staff. The individual has been given the opportunity to ask questions about the nature and purpose, the possible risks and benefits associated with participation in the study.

Signature of PI and Student Researcher:

Renee V. Galliher, Ph.D., Principal Investigator _____
Sara Hunt, Student Researcher

Participant Consent:

If you have read and understand the above statements, please click on the “CONTINUE” button below to indicate your consent to participate in this study.

Thank you very much for your participation! Your assistance is truly appreciated

RECRUITMENT LETTER

Utah State University IRB Approved 12/11/2006

Approval terminates 12/10/2007

Protocol Number: 1697

Hello! My name is Sara Hunt and I am a doctoral student at Utah State University. I would be grateful for your participation in a research study designed to explore the experiences that children and adolescents with chronic health conditions or physical disabilities have with mental health services. The goals of this research are to inform medical providers and mental health professionals, as well as offer suggestions for improved mental health services for children with chronic health conditions. If you have a child with a chronic health condition or physical disability between the ages of 5 and 21, who does not have a diagnosis of Mental Retardation, Autistic Disorder, or Asperger's Disorder, please consider participating in my study.

Your participation would involve completing an online survey about your child's medical diagnosis and their experiences with mental health services. This should take about 30 minutes of your time. All survey responses will be confidential but you may choose to submit your name and email address to be entered in a drawing for one \$100 prize and two \$50 prizes to be given away in July 2007. If you have any questions about the research, please do not hesitate to contact me, Sara Hunt, (435) 797-1986 or at sarahunt@cc.usu.edu. You may also contact my faculty advisor, Renee V. Galliher, Ph.D. at (435) 797-3391 or Renee.Galliher@usu.edu.

The survey may be found at:

<https://www.psychdata.com/s.asp?SID=120169>

Appendix B:
Measures

7. *Father education*

- Less than high school graduate
 High school graduate
 Some college
 College graduate
 Professional degree

8. *Household income:*

- Less than \$15,000
 \$15,000 – 30,000
 \$30,000 – 45,000
 \$45,000 – 60,000
 \$60,000 – 75,000
 \$75,000 – 90,000
 More than \$90,000

9. *How would you describe where you live?*

- Urban (city)
 Suburban (subdivision)
 Rural (country)

10. *What is(are) your child's diagnosis(es)?*

11. *Who diagnosed your child?*

- Primary care physician
 Medical specialist (e.g., cardiologist, neurologist, etc.)
 School personnel
 Emergency room physician
 Other: _____

12. *At what age did your child begin to show symptoms of his/her diagnosis(es)?* _____13. *At what age was your child formally diagnosed with his/her diagnosis(es)?* _____14. *What is your child's prognosis?*

- Child's symptoms will improve
 Child's symptoms will remain the same
 Child's symptoms will worsen
 Do not know child's prognosis

15. *I expect my child's diagnosis(es) to last for:*

- Less than 3 months
 3 to 6 months
 6 to 12 months
 More than 1 year
 Rest of his/her life

16. *How often does your child visit a medical professional (e.g., family physician, specialist, etc.) as a result of his/her diagnosis(es)?*

- Daily
 Weekly
 Monthly
 3 to 4 times a year
 Every 6 months
 Once a year
 Less than once per year

17. *Has your child been hospitalized for his/her diagnosis(es)?* _____

If yes, how many times? _____

18. *How would you rate the overall severity of pain or discomfort experienced by your child due to **symptoms** related to his/her diagnosis(es)?*

1	2	3	4	5	6	7	8	9	10
None				Moderate					Severe

19. *How would your rate the overall severity of pain or discomfort experienced by your child due to **treatments** related to his/her diagnosis(es)?*

1	2	3	4	5	6	7	8	9	10
None				Moderate					Severe

CES-D

INSTRUCTIONS FOR QUESTIONS: Below is a list of the ways you might have felt or behaved. Please indicate how often you have felt or behaved this way during the past week. Use the following scale to respond to each item.

1 = Never; 2 = 1 -2 days; 3 = 3 – 4 days; 4 = 5 -7 days

During the past week:

1. I was bothered by things that usually don't bother me.
2. I did not feel like eating; my appetite was poor.
3. I felt that I could not shake off the blues even with the help of my family and friends.
4. I felt that I was just as good as other people.
5. I had trouble keeping my mind on what I was doing.
6. I felt depressed.
7. I felt that everything I did was an effort.
8. I felt hopeful about the future.
9. I thought my life had been a failure.
10. I felt fearful.
11. My sleep was restless.
12. I was happy.
13. I talked less than usual.
14. I felt lonely.
15. People were unfriendly.
16. I enjoyed life.
17. I had crying spells.
18. I felt sad.
19. I felt that people disliked me.
20. I could not get "going."

Mental Health Service Utilization

1. *Has your child ever been referred for mental health services (e.g., counseling or psychological testing)?*

_____ Yes _____ No

2. *If yes, who referred you and your child to mental health services?*

_____ Primary care physician

_____ Specialist doctor

_____ Care coordinator or medical home

_____ Social service agency

_____ School personnel

_____ Family member

_____ Friend

_____ Self

_____ Other: _____

3. *Have you ever accessed mental health services for your child?*

_____ Yes _____ No

If no, please skip to question #10.

If yes, for what reason(s)?

4. *In the past 12 months, what type of mental health services has your child utilized?*

_____ Inpatient psychiatric or substance abuse care

_____ Outpatient counseling services

_____ Mental health services provided through a school setting

_____ None

_____ Other (Please describe):

5. *What type of mental health services has your child **ever** received?*

_____ Inpatient psychiatric or substance abuse care

_____ Outpatient counseling services

_____ Mental health services provided through a school setting

_____ Other: _____

6. *If your child required hospitalization for psychiatric problems, how long was his/her hospital stay? _____*

How many hospitalizations has your child required for psychiatric problems?

7. *If your child received counseling in an outpatient setting, did he/she see a:*

____ Psychologist

____ Psychiatrist

____ Social worker

____ School counselor/school psychologist

____ Other: _____

And did your child receive these services in a:

____ Private office

____ Hospital

____ Community mental health center or clinic

____ Through a provider of various services (e.g., social services, home health care, etc.)

____ School

____ Other: _____

8. *How many counseling sessions has your child attended?*

____ One session only

____ Less than 5 sessions

____ 5 to 10 sessions

____ 10 to 15 sessions

____ 15 to 20 sessions

____ More than 20 sessions

____ Sessions are still occurring

9. *If your child has attended only one counseling session, what were the reasons for not continuing sessions?*

____ Lack of finances

____ No insurance coverage for needed mental health services

____ Therapist/counselor did not schedule additional sessions

____ Could not access services because of physical structure of clinic/office

____ Child's health problems would not allow him/her to see a mental health professional again

____ Other reasons (please specify):

10. *Does your child take regularly prescribed medication for a mental health concern?*

Yes No

If yes, who prescribes this medication?

Primary physician

Specialist doctor

Psychiatrist

Other: _____

11. *Do you have current mental health concerns (e.g., depression, aggression, anxiety, etc.) regarding your child but have not accessed mental health services?*

Yes No

If yes, what are they?

12. *If you have had difficulties with accessing mental health services, which of these best describes the reasons for that:*

Lack of finances

No insurance coverage for needed mental health services

Difficulty finding mental health professional in your community

Lack of referral for services

Did not understand what services were needed

Placed on a wait list

Could not access services because of physical structure of clinic/office

Child's health problems would not allow him/her to see a mental health professional

Other reasons (please specify):

13. *What are your suggestions for improving mental health care for children and adolescents with chronic health conditions or disabilities?*

Appendix C:

Consent Form for Qualitative Study



Parental Permission for Interview and Youth Assent Mental Health Service Utilization in Children and Adolescents with Chronic Health Conditions and Physical Disabilities

Dear Parent: This document explains what we are asking your child to do in helping us with this research study.

Introduction/Purpose: Sara Hunt, a doctoral student in the Department of Psychology at Utah State University, and Dr. Renee Galliher are in charge of this research study. We would like you to be in the study because we want to know about the experiences of teenagers your age with chronic health conditions or physical disabilities with using mental health services. About 10 individuals will be in this research study.

Procedures: Your part in this study will be a 20 to 30 minute interview. The interview will be conducted over the phone. Prior to the phone interview, you will be asked to provide the address of your location during the interview. This contact information will be used only to contact you in the event of a disconnection or emergency and will be destroyed immediately following the interview. You will be asked a short series of questions asking about any emotional or behavioral problems you have experienced as a child or teenager, your contact with mental health services as a result of these problems, and difficulties you had with accessing mental health services. Your responses will be audio taped and coded by members of our research team.

Risks: There is some risk of feeling uncomfortable in this study. Some teenagers may not want to share personal information with the researchers. We will do everything we can to make you more comfortable. You can choose not to discuss personal or difficult issues or answer questions in the interview process.

The law does require researchers to report certain information (e.g., threat of harm to self or others, abuse of a minor by an adult) to the authorities.

Benefits: We hope that you will find this study to be interesting and fun. Your information will help us learn more about use of mental health services by children and adolescents with chronic health conditions or physical or sensory disabilities. It will help us understand how often children use these services and what barriers might keep them from accessing services.

Parental Permission for Interview and Youth Assent
Mental Health Service Utilization in Children and Adolescents with Chronic
Health Conditions and Physical Disabilities

Explanation and Offer to Answer Questions: _____
has explained this study to you and answered your questions. If you have more questions, you can also ask the Primary Investigator, Professor Renee Galliher at (435) 797-3391.

Payment: When you finish this research, you will be paid \$50. Your participation does not involve any costs.

Voluntary Nature of Participation and Right to Withdraw without Consequences: Being in this research study is entirely your choice. You can refuse to be involved or stop at any time without penalty.

Confidentiality: Consistent with federal and state rules, your audiotape and answers will be kept private. Only Sara Hunt, Dr. Galliher, and research assistants will be able to see the data. All information will be kept in locked filing cabinets in a locked room. Your answers and audiotapes will only have an ID number and not your name. Furthermore, any identifying information will be removed from the interview transcript and we will use pseudonyms (a false name) in any report describing the interviews. Your name will **not** be used in any report about this research and your specific answers will not be shared with anyone else. Data from this study, including the audiotape, may be used for three years by our research team before it is destroyed. When the research has been completed, a newsletter with the general results will be sent to you if you would like.

IRB Approval Statement: The Institutional Review Board for the protection of human subjects at Utah State University has approved this research project. If you have any questions regarding IRB approval of this study, you can contact the IRB administrator, True Rubal-Fox at (435)797-1821.

Copy of Consent: Please print a copy of this informed consent for your files. Sign one copy and return it to the primary investigator, Renee Galliher, by fax at (435) 797-1448, or by mail to Renee Galliher, Department of Psychology, 2810 Old Main Hill, Utah State University, Logan, UT 84322.

Parental Permission for Interview and Youth Assent
Mental Health Service Utilization in Children and Adolescents with Chronic
Health Conditions and Physical Disabilities

Investigator Statement: I certify that the research study has been presented to the participant by me or my research staff. The individual has been given the opportunity to ask questions about the nature and purpose, the possible risks and benefits associated with participation in the study.

Signature of PI and Student Researcher:

Renee V. Galliher, Ph.D., Principal Investigator Sara Hunt, Student Researcher

Youth Assent:

I understand that my parent(s)/guardian is/are aware of this research and have given permission for me to participate. I understand that it is up to me to participate even if my parents say yes. If I do not want to be in this study, I don't have to. No one will be upset if I don't want to participate or if I change my mind later and want to stop. I can ask questions that I have about this study now or later. By signing below, I agree to participate.

Signature of Participant

Date

Print Name

Parent/Guardian Permission:

I have read the above description of the study and I give permission for my teenager to participate.

Parent/Guardian Signature

Date

Print Name

Appendix D:
Semistructured Interview

Semistructured Interview

ID Number: _____

Age of participant: _____

Gender: _____

Diagnosis: _____

1. Sometimes teenagers talk about having problems as a child or teenager with difficult feelings like sadness, fear, anger, or other emotions. They also may have experienced times of problem behavior like acting out or getting into a lot of trouble. What type of difficulties have you had similar to these experiences?

- How did they affect your day to day life?
- How did they affect your friendships or relationships with others?

2. Who do/did you usually talk to about these problems?

3. If you received counseling or other mental health services, what type of services did you receive?

- What did you think about _____ (fill in with service they provide)?
- How might it have helped to talk to a therapist or counselor?

4. What is the best way to help children and teenagers with emotional or behavior problems?

CURRICULUM VITAE

Sara M. Hunt

1674 Bayview Avenue #306
 Toronto, ON M4G 3C3
 Canada
 (647) 350-7497
 sara.hunt@aggiemail.usu.edu

EDUCATION:

- Ph.D. Clinical/Counseling/School Psychology (APA accredited)
 (expected 2009) Utah State University, Logan, UT
 Dissertation: *Patterns of psychosocial functioning and mental health service utilization in children and adolescents with chronic health conditions or physical disabilities.*
 Chair: Renee V. Galliher, Ph.D.
- M.S. Counseling Psychology
 December, 2005 Utah State University, Logan, UT
 Thesis: *Associations between parent-daughter relationships, individual female adolescent psychological functioning, and female adolescent self-defeating behaviors.*
 Chair: Renee V. Galliher, Ph.D.
- B.A. Psychology
 May, 2003 University of Iowa, Iowa City, IA
 Thesis: *An ecological perspective on infants' emotionality.*
 Chair: Grazyna Kochanska, Ph.D.
- A.A. Arts and Sciences
 May, 2001 Indian Hills Community College, Ottumwa, IA

CLINICAL EXPERIENCE:

- 9/08 - Present Predoctoral Intern (Clinical Psychology)
Bloorview Kids Rehab, Toronto, Ontario, Canada
 Complete three major rotations in a children's rehabilitation hospital. Assess and consult on individual and team evaluations, and provide therapeutic intervention at individual, family, and group levels. Children present with diverse psychiatric concerns (e.g., Autistic Disorder, Developmental Delay, anxiety) with

concurrent health concerns (e.g., acquired brain injury, spina bifida). Involved in ongoing research related to use of mental health services in youth with special health care needs.
Supervisors: Doug Schmidt, Ph.D., Janice Hansen, Ph.D.

7/07 - 7/08

Behavior Specialist (Clinical Assistantship)

*Up-To-3 Early Intervention Program
Utah State University, Logan, UT.*

Assessed, formulated, and implemented behavioral interventions with parents of children between the ages of birth to three. Children presented with diverse concerns (e.g., sleep problems, externalizing behavior problems, feeding problems, learning problems) and sessions were conducted at home with caregivers. Worked within an interdisciplinary team consisting of nurses, physical therapists, occupational therapists, social workers, teachers, nutritionists, speech therapists, and parents.
Supervisors: Gretchen G. Peacock, Ph.D., Sue Olsen, M.Ed.
Hours: Total hours 212, Direct Service hours 113

6/06 - 6/07

Student Therapist (Clinical Assistantship)

Center for Persons with Disabilities at Utah State University, Clinical Services Division, Logan, UT.

Performed psychoeducational assessments for children and adolescents. Also performed psychological and intellectual assessments for adult clients participating in the Vocational Rehabilitation program. Regularly administered and interpreted the following assessment measures: WISC-IV, WAIS-III, WPPSI-III, WMS, and WJ-III(Ach). Other responsibilities included conducting clinical interviews, writing psychological reports, participating in weekly multidisciplinary staffings, and providing some supervision to practicum students.

Supervisor: Robert Cook, Ph.D.

Hours: Total hours 921, Direct Service hours 233

6/06 - 6/07

Student Therapist (Pediatric Practicum)

Budge Pediatric Clinic at Logan Regional Hospital, Logan, UT.

Collaborated with eight referring pediatricians to provide individual and family therapy for child and adolescent patients in a primary care pediatric clinic setting. Provided behavior management and cognitive-behavioral interventions for disruptive behavior disorders, anxiety, and depression.

Supervisor: Gretchen G. Peacock, Ph.D.

Hours: Total hours 465, Direct service hours 273

- 9/05 - 6/06 Student Therapist (Clinical Practicum)
Avalon Hills Residential Eating Disorders Facility, Petersboro, UT.
 Served as secondary therapist for adolescent girls (ages 13 to 17) and young women (18 to 25) with various diagnosed eating disorders. Conducted individual, family, and group sessions with clients in a residential treatment setting.
 Supervisor: Jennifer Tolman, Ph.D.
 Hours: Total hours 425, Direct service hours 307
- 8/04 - 8/05 Student Therapist (Child Clinical Practicum)
Utah State University Psychology Community Clinic, Logan, UT.
 Provided child, adolescent, and family therapy. Conducted psychological assessments including administration, scoring, interpretation, and report writing. Provided behavior management and cognitive-behavioral interventions for disruptive behavior disorders, anxiety, and depression.
 Supervisor: Gretchen G. Peacock, Ph.D.
 Hours: Total hours 380, Direct service hours 196
- 1/04 - 8/04 Student Therapist (Adult Counseling Practicum)
Utah State University Psychology Community Clinic, Logan, UT.
 Provided individual psychotherapy to adults. Conducted comprehensive diagnostic evaluations, including writing full-length integrative reports. Worked with various presenting problems including depression, anxiety, and schizoaffective disorder.
 Supervisor: Susan Crowley, Ph.D.
 Hours: Total hours 160, Total direct service hours 53

RESEARCH EXPERIENCE:

- 9/04 - 5/06 Graduate Research Assistant
Early Intervention Research Institute, Utah State University, Logan, UT.
Utah Doors Project & KidsLink Project.
 Utah Doors Project: designed user manuals for a web-based social service interagency application program, assisted in testing of program, prepared presentations, and assisted with grant writing.
 KidsLink Project: interviewed providers of services to children ages birth to 8 in Utah, constructed data base, performed data entry, and reviewed literature on school readiness.
 Supervisors: Adrienne Akers, M.S., R.P.T., and Terry Russo, M.S., M.B.A.

- 9/02 - 6/03 Undergraduate Research Assistant
Family Studies Lab, University of Iowa, Iowa City, IA.
 Longitudinal study of the internalization of moral standards in young children. Assisted in data collection; coded and entered data.
 Supervisor: Grazyna Kochanska, Ph.D.
- 1/02 - 5/03 Undergraduate Research Assistant
Center for Marriage and Family Development, University of Iowa, Iowa City, IA.
 Longitudinal study to predict and prevent aggression in marriages. Developed and conducted semi-structured interviews with newly married couples.
 Supervisor: Erika Lawrence, Ph.D.

TEACHING EXPERIENCE:

Guest Lectures:

- 03/08, 02/07,
12/05 Guest Lecturer SPED 6500 – Interdisciplinary Workshop
Center for Persons with Disabilities, Utah State University, Logan, UT.
 Presentation on mental illness for an interdisciplinary course on disability issues.
- 7/06 Guest Lecturer PSY 3210 – Abnormal Psychology
Dept. of Psychology, Utah State University, Logan, UT.
 Taught a lecture on eating disorders for an undergraduate course on abnormal psychology.
- 4/06, 4/05 Guest Lecturer PSY 1010 – General Psychology
Dept. of Psychology, Utah State University, Logan, UT.
 Conducted a lab on schizophrenia for an undergraduate course on general psychology.
- 7/05 Guest Lecturer PSY 4230 – Psychology of Gender
Dept. of Psychology, Utah State University, Logan, UT.
 Taught a lecture on genetic differences of gender for an undergraduate course on the psychology of gender.
- 7/05 Guest Lecturer PSY 1010 – General Psychology
Dept. of Psychology, Utah State University, Logan, UT.
 Taught two lectures on mental disorders for an undergraduate course on general psychology.

Teaching Assistant:

8/03 - 5/04 Teaching Assistant PSY 6530 - Developmental Psychology
Dept. of Psychology, Utah State University, Logan, UT.
 Graded weekly written assignments and exams and dealt with student concerns for a graduate course in developmental psychology.
 Supervisor: Camille J. Odell, M.S.

ADDITIONAL TRAINING:

9/07 - Present Utah Regional Leadership Education in Neurodevelopmental
Disabilities (URLEND)
University of Utah School of Medicine, Salt Lake City, UT and
Center for Persons with Disabilities at Utah State University,
Logan, UT.
 Attend didactic seminars with trainees and faculty from various disciplines (e.g., pediatrics, social work, genetic counseling, business administration); participate in interdisciplinary clinics serving children, youth, and families with special health care needs; and complete leadership project related to working with children with special health care needs. Increase knowledge and skills regarding taking a collaborative interdisciplinary approach to providing services to youth with special health care needs and their families.
 Supervisor: Gretchen G. Peacock, Ph.D.

8/04 - 4/05 Interdisciplinary Team Training
Special Education Department, Utah State University, Logan, UT.
 Received training in an interdisciplinary approach to issues concerning persons with disabilities. Conducted research regarding disability issues and completed 200 clinical hours through volunteer service.
 Received certification in Interdisciplinary Training.
 Supervisor: Barb Fiechtl, M.S.

PUBLICATIONS:

Lawrence, E., Pederson, A., Barry, R. A., Brock, R. L., Langer, A., Fazio, E., **Hunt, S.**, Madsen, L., & Dzankovic, S. (2008). Objective ratings of relationship skills across the multiple domains as predictors of marital satisfaction trajectories. *Journal of Social and Personal Relationships*, 25, 445-466.

PRESENTATIONS:

Hunt, S. M. & Galliher, R. V. (2009, March). *Psychosocial functioning in children and adolescents with chronic health conditions or physical disabilities*. Submitted to the Biennial Meeting of the Society for Research on Child Development, Denver, CO.

Hunt, S. M. & Galliher, R. V. (2008, November). *Patterns of mental health service utilization in youth with chronic health conditions or physical disabilities*. Poster accepted at the Association of University Centers on Disabilities Annual Meeting and Conference, Washington D.C.

Hunt, S. M. & Galliher, R. V. (2006, March). *Parent-daughter relationships, individual adolescent internalizing symptoms, and female adolescent self-defeating behaviors*. Poster presented at the Biennial Meeting of the Society for Research on Adolescence, San Francisco, CA.

Glover, J., **Hunt, S.**, & Galliher, R.V. (2005, April). *Adolescent couple members' views of coercive and aggressive behaviors in romantic relationships*. Poster presented at the Biennial Meeting of the Society for Research in Child Development, Atlanta, GA.

Hatch, D.L., **Hunt, S.**, & Galliher, R.V. (2005, April). *Attitudinal and psychological factors associated with sexual intercourse in adolescent romantic couples*. Poster presented at the Biennial Meeting of the Society for Research in Child Development, Atlanta, GA.

Hunt, S., Jones, M. D., & Galliher, R. V. (2004, April). *Borderline personality characteristics and romantic relationship functioning among college students: Modeling pathways to aggression*. Poster presented at the Biennial Meeting of the Society for Research on Human Development, Park City, UT.

LEADERSHIP EXPERIENCE:

8/05 - 5/06

Student Representative

Psychology Department, Utah State University, Logan, UT
Elected by peers. Brought student issues to monthly faculty meetings, managed student participation in graduate admissions process, and organized department social events.

OTHER PROFESSIONAL EXPERIENCE:

- 6/02 - 7/03 Psychiatric Nursing Assistant
University of Iowa Hospitals and Clinics, Iowa City, IA.
 Provided direct care to children and adolescents on a child inpatient psychiatric unit. Responsible for monitoring and charting patient welfare and behavior. Occasionally served on adult psychiatric inpatient units.
 Supervisor: Catherine Willoughby, M.S., R.N.
- 3/98 - 3/01 Volunteer Advocate
Court Appointed Special Advocates, Ottumwa, IA.
 Provided court advocacy for children in need of assistance. Monitored and reported on adjudicated children to the juvenile court system.
 Supervisor: April Goodman
- 4/97 - 6/01 County Relief Director
Mahaska County Community Services, Oskaloosa, IA.
 Directed and provided county funds to assist low-income people with general living and medical expenses. Assisted the County Mental Health Coordinator in determining county funding for services for children and adults with mental retardation, developmental disabilities, or chronic mental illness.
 Supervisor: Joleen Arnold, L.S.W.

AWARDS AND HONORS:

- 2006 Graduate Student Senate Travel Award, Utah State University
 2006 Department of Psychology Student Travel Award, Utah State University
 2002 Upper Classmen Scholarship, University of Iowa
 2002 Iowa Community College Academic Scholarship, University of Iowa, 2 semesters
 2002 Golden Key International Honour Society
 2002 Iowa Community College Transfer Scholarship, University of Iowa, 2 semesters
 2000 State of Iowa Governor's Volunteer Award
 1999 Foundation Scholarship, Indian Hills Community College

REFERENCES:

- Renee V. Galliher, Ph.D. Department of Psychology, 2810 Old Main Hill
 Utah State University, Logan, UT 84322-2810
 (435) 797-3391
 renee.galliher@usu.edu

Gretchen G. Peacock, Ph.D. Department of Psychology, 2810 Old Main Hill,
Utah State University, Logan, UT 84322-2810
(435) 797-0721
gretchen.peacock@usu.edu

Robert Cook, Ph.D. Clinical Services, 6813 Old Main Hill,
Utah State University, Logan, UT 84322-6813
(435) 797-3822
robertc@cpd2.usu.edu