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## Communication Between Home And School For Parents Of Children With Chronic Illness

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# COMMUNICATION BETWEEN HOME AND SCHOOL FOR PARENTS OF CHILDREN WITH CHRONIC ILLNESS

KERI EDWARDS

242 Pages

A child with chronic illness has a physical or behavioral condition that affects the child's daily functioning, lasts longer than three months, and requires medical intervention such as medication, hospitalizations, and/or home care (Newacheck, McManus, & Fox, 2001). Chronic illness interferes with all areas of development, including physical, social, emotional, and cognitive development, and a growing number of children with chronic illnesses are attending school. Effective communication between parents and educators is essential so that accurate information about the nature and extent of the impact of chronic illness on children's learning experiences and schooling can be shared and appropriate supports and instruction can be provided. In order to better understand communication between parents of children with chronic illness and educators, the experiences of parents communicating with their children's educators were investigated. Specifically, investigation focused on how parents prefer to communicate with teachers and other school staff, parental academic and social expectations for their children, and what educational supports parents believe should be available for their children. Key findings relate to communication, physical development, social and emotional development, behavior, cognitive development, and advocacy. Communication findings represent concerns related to teacher knowledge, skills, and attitudes, as well as the amount and valence of communication. Physical development findings related to the environment, pain and

symptom management, supports for participation, staff knowledge and ability once again, and physical structure. Social and emotional development findings related to peer relationships, peer supportiveness, accuracy of information, and self-esteem. Behavioral findings focused on not making assumptions about that health was the cause of behaviors, being aware of long-term impact, and independence versus over-protectiveness towards a child with a chronic illness. Cognitive development findings related the of the chronic illness to teacher or school preparedness for having the child with chronic illness in the class. Finally, advocacy findings indicated the need to promote awareness and education and to increase preparation. Further research is recommended to understand the relationship from the perspective of the teacher and the child with chronic illness, as well as healthcare professionals.

**KEYWORDS:** chronic illness, communication, parent, school

COMMUNICATION BETWEEN HOME AND SCHOOL FOR PARENTS OF  
CHILDREN WITH CHRONIC ILLNESS

KERI EDWARDS

A Dissertation Submitted in Partial  
Fulfillment of the Requirements  
for the Degree of

DOCTOR OF EDUCATION

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2018

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COMMUNICATION BETWEEN HOME AND SCHOOL FOR PARENTS OF  
CHILDREN WITH CHRONIC ILLNESS

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## CONTENTS

	Page
ACKNOWLEDGEMENTS	i
CONTENTS	ii
TABLES	x
FIGURES	xi
CHAPTER	
I.    THE PROBLEM AND ITS BACKGROUND	1
Framing the Problem	1
Defining the Population	3
Impact on the Family	4
Legal Basis for Educating Children with Chronic Illness	6
Statement of the Problem	8
Purpose	9
Definition of Terms	9
Key Terminology	9
Methodology Related Terminology	13
Terms related to the description process	13
Terms related to the analysis stage	14
Terms related to the interpretation phase	15
Conceptual Framework	15
Ecological Systems Theory	15
Family Systems Theory	16
Need for the Study	17
Background on the Child with Chronic Illness as a Student	17
The child with chronic illness as a student	18
The parent/family of the child with chronic illness	19



The primary health care provider of the child with chronic illness	20
The educator of the child with chronic illness	21
Pilot Study: Parent Perspectives on the Support Needs of Children with Special Health Care Needs: Implications for Supports Needs Assessment and Planning	22
Call for Research	24
Research Questions	25
Scope and Limitations of the Study	26
Method	27
Institutional Review Board	27
Qualitative Methods	28
Data Collection and Analysis	28
Credibility	29
II. REVIEW OF RELATED LITERATURE	31
Ecological Systems Theory	33
Family Systems Theory	36
Relevant Constructs of Bowen Family Systems Theory	36
Eight Interlocking Concepts of Bowen Family Systems Theory	39
The Student with Chronic Illness	42
Health and Wellness Variables	42
Physical	43
Social	43
Behavioral	44
Cognitive	45
Impact on Academic Performance	46
Attendance and engagement	46
Learning outcomes	47
Educators	48
Knowledge and Confidence	49
Training and Education	51
Behavior	54

Communication between Parents and Educators	55
Summary	58
III.    METHODOLOGY	59
Research Questions	59
Research Paradigm	60
Positionality	62
Research Methods	66
Social Context	66
Type of Study	66
Participants	67
Sampling	67
Description of Cases	67
Recruitment	68
Setting	68
Data Collection	69
Data Analysis	71
The description process	71
The analysis stage	72
The interpretation phase	73
Ethical Considerations	74
Validity	76
Summary	78
IV.    RESEARCH PARTICIPANTS	80
Mary	82
Susie	85
Justin	88
Amy	90
Kevin	92
Caroline	95
Patrick	97
Bryan	99
Lizzie	101
Emily	104
V.    RESULTS	108
Research Sub-Question a: How do Parents of Children with Chronic Illness Expect and/or Prefer to Communicate with Their Child's Teacher?	111

Process of Communication	112
Method of communication	113
Timing of communication	115
Content of Communication	115
Content of communication: child-related issues	116
Managing information related to health updates	116
Managing information related to change in staff or managing the class	117
Content of communication: teacher-related concerns	118
Teacher knowledge	119
Teacher skills	120
Teacher attitude	122
Overall Valence of Communication	123
Positive	123
Negative	124
Neutral comments	126
Summary of Findings for Research Sub-Question a: How do Parents of Children with Chronic Illness Expect and/or Prefer to Communicate with Their Child's Teacher?	127
Research Sub-Question b: What Academic and Social Expectations do Parents of Children with Chronic Illness Have for Their Child?	127
Physical Development	128
Physical activity	129
Abilities/activities	129
Environment	129
Pain and symptom management	131
Staff knowledge	131
Medical equipment	132
Schedule/timing	132

Dietary issues	133
School participation	133
Attendance	133
Participation	134
Social and Emotional Development	134
Peer and social relationships	135
Knowledge	135
Peer awareness of differences (positive)	135
Parents	136
Self-esteem	137
Self-confidence	137
Self-consciousness/fear/embarrassment	137
Peer response	138
Emotional support	139
Behavior	139
Concentration	140
Self-expectation	140
Teacher-expectation	140
Self-regulation	141
Independence	141
Cognitive Development	142
Ability/aptitude	142
Achievement	143
Summary of Findings for Research Sub-Question b: What Academic and Social Expectations do Parents of Children with Chronic Illness Have for Their Child?	144
Research Sub-Question c: What Supports do Parents of Children with Chronic Illness Perceive Are and/or Should Be Available at School?	144

Physical Development	147
Environment	147
Environmental cleanliness	147
Environmental contamination	147
Medical treatment	148
Staff knowledge	148
Staff resources	149
Medical equipment	150
Schedule	150
Dietary issues	151
Participation	151
Physical environment/structure	151
School day participation	152
Extra-curricular participation	153
Social and Emotional Development	153
Peer interaction	154
Knowledge provided	154
Support provided for the child with chronic illness	154
Self-esteem	155
Emotional support	155
Behavior	156
Self-care	156
Independence	157
Concentration	157
Cognitive Development	157
IEP	158
504 (or similar) plans	158
No plan	159
Home schooling/tutors	159
Instructional support provided	160

Instructional support not provided	160
Extra work	161
Positive	161
Negative	161
Advocacy	162
Awareness	162
Preparation	163
Summary of Findings for Research Sub-Question c: What Supports do Parents of Children with Chronic Illness Perceive Are and/or Should Be Available at School?	164
VI. FINDINGS AND RECOMMENDATIONS	165
Statement of the Problem	166
Methodology	166
Summary of Data Analysis	167
Overview of Results	167
Findings	168
Communication	170
Physical Development	174
Social and Emotional Development	176
Behavior	179
Cognitive Development	181
Advocacy	182
Limitations	184
Recommendations	186
Future Research	187
REFERENCES	189
APPENDIX A: QUESTIONS FOR INTERVIEW	198
APPENDIX B: PARENT PARTICIPANT INFORMED CONSENT FORM	200
APPENDIX C: ADAPTED ILLNESS INTRUSIVENESS RATING SCALE (A-IIRS)	201
APPENDIX D: RECRUITMENT EMAIL	202

APPENDIX E: DATA ACCOUNTING LOG	204
APPENDIX F: RESEARCH PARTICIPANT INFORMATION	205
APPENDIX G: PARENT PERSPECTIVES ON THE SUPPORT NEEDS OF CHILDREN WITH CHRONIC ILLNESS: CODING MATRIX	207
APPENDIX H: CONSTRUCT MATRIX: COLLABORATION & COMMUNICATION	209
APPENDIX I: CASE-LEVEL DISPLAY FOR PARTIALLY ORDERED META MATRIX	223
APPENDIX J: CASE-ORDERED DESCRIPTIVE MATRIX: SUPPORT NEEDS	237
APPENDIX K: CONTRAST TABLE: COLLABORATION & COMMUNICATION	242

## TABLES

Table	Page
1. Relevant Constructs of Bowen Family Systems Theory	37
2. Eight Concepts of Bowen Family Systems Theory	40
3. Research Sub-Question a: Summary of Communications Themes	112
4. Research Sub-Question b: Summary of Parental Expectations Themes	128
5. Research Sub-Question c: Summary of Perceived Supports Themes	146
6. Summary of Findings	169



## FIGURES

Figure	Page
1. Conceptual Framework: Parent Perspectives on the Support Needs of Children with Special Health Care Needs	23, 111
2. Bronfenbrenner's Ecological Systems Theory	34
3. Research Participant Information	81
4. Data Accounting Log	82

## CHAPTER I: THE PROBLEM AND ITS BACKGROUND

### **Framing the Problem**

A child with chronic illness has a physical or behavioral condition that affects the child's daily functioning, lasts longer than three months, and requires medical intervention such as medication, hospitalizations, and/or home care (Newacheck, McManus, & Fox, 2001). Chronic illness interferes with all areas of development, including physical, social, emotional, and cognitive functioning. Children with chronic illness are a subset of children with special health care needs (CSHCN) and, according to the National Survey of Children's Health (2009/10), between 78- 85% of CSHCN have one or more functional difficulties, including bodily or physical difficulty, activity and participation concerns, and other emotional or behavioral issues. Additional survey data show that 19.8% of all children have special health care needs (14.6 million) and 6.5% of all children (9.4 million) experience some degree of disability because of chronic health conditions (NSCH, 2009/10).

Although the specific needs of children with chronic illnesses will differ in important areas from those of the larger, heterogeneous group of CSHCN, national data of CSHCN provides important insights into the challenges faced by children with chronic illnesses and their parents. The U.S. Health Resources and Services Administration (HRSA) found that CSHCN, when compared to typically developing children, experience inadequacies in regard to healthcare, education, health of family, and maintaining a healthy lifestyle (NSCH, 2009/10). CSHCN also have trouble accessing mental health care services (NSCH, 2009/10). Academically, CSHCN are at an increased risk for excessive absenteeism, disengagement in the classroom, and repeating a grade level (Shaw & McCabe, 2008; Shiu, 2001). Physically, CSHCN are less likely to exercise, more likely to be overweight or obese than their peers, and

are at higher risk for inadequate sleep (NSCH, 2009/10). These challenges may be related to social consequences, such as difficulty in connecting to peers and making friends. Parents/guardians of CSHCN experience challenges as well, including increased levels of stress, decreased health, and feelings of inadequacy and self-doubt regarding their parenting skills (NSCH, 2009/10). While parent/ guardian may include any person who has primary custody and responsibility for the care and well-being of CSHCN, the term parent will be used to represent this relationship in this research.

Chronic illness affects between 10% and 20% of American children, with about 2% affected by severe chronic illnesses such as diabetes, cancer, arthritis, and sickle cell anemia (Shaw & McCabe, 2008). The most frequent pediatric illnesses are asthma, diabetes, juvenile rheumatoid diabetes, and cancer (Webb, 2009). The diverse needs of children with chronic illness can be illustrated by considering the diverse needs presented by different diagnoses. For instance, the incidence of asthma has risen dramatically in recent years. It has been diagnosed in 13% of children under the age of 18 years and 6% have had an asthma attack in the previous year. It is the primary health-related cause of school absence, hospitalization, and emergency room visits (Currie, 2005). In contrast, cancer is a chronic illness which upon diagnosis is associated with particularly high levels of anxiety. It is diagnosed in 20,000 children and adolescents annually. Cancer survival rates vary, and are above 80% for many cancers (Mulhern & Butler, 2004). A third contrast is sickle cell disease, which is one of the most prevalent genetic diseases. It is found in 1 in 400 African American newborns, and results in recurrent pain which can cause frequent hospitalization and school absenteeism. It also has the potential for neurological impairment and poorly sustained attention and memory (King, Tang, Ferguson, & DeBraun, 2005). As can be seen in comparing these three conditions (i.e. asthma, cancer, and

sickle cell disease), the different nature of the medical conditions results in a very diverse population of students with chronic illness, and therefore unique circumstances for different students and their families.

The purpose of this chapter is to provide an overview of children with chronic illness and the impact that their health care needs have on their education. I begin by framing the problem. I continue by reviewing the characteristics and population parameters of children with chronic illness, and the impact on the family unit. I offer an overview of the legal basis for educating children with chronic illness and define key terms that are used throughout the project. Next, I provide a brief summary of the conceptual framework for the project and review research related to the needs of children with chronic illness, and the roles of the parents, primary health care providers (PCPs), and educators. Finally, I present the research questions that formed the basis for the current investigation as well as an overview of methodology.

### **Defining the Population**

Children with special health care needs (CSHCN) are defined by the U. S. Department of Health and Human Services, Health Resources and Services Administration as, “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (U.S. Department of Health and Human Services, 2013, p. 5). This is considered to be a broad, inclusive, and consequence-based definition which covers a wide range of diagnoses. Disability in this context is defined as limitations in educational participation such as excessive missed school days and/or restricted social functioning (e.g. play) (Newacheck & Halfon, 1998; Shaw & McCabe, 2008). Chronic childhood conditions can be placed into three categories: chronic medical conditions (e.g. asthma, diabetes), developmental disabilities (e.g.

autism), and mental health problems (e.g. depression, conduct disorder) (Ahmann & Rollins, 2005.) Each of these three categories affects children in a different manner in regard to development. The current study focused on parents of children with chronic medical conditions, hereafter referred to as *children with chronic illness*, to differentiate from the overall population of CSHCN.

### **Impact on the Family**

As was alluded to earlier, much of the research on the experience of children with chronic illness and their families is embedded within research studies that have focused on the broader category of children referred to as CSHCN. It is difficult to separate information about children with chronic illness from the overall population of CSHCN. Where possible, specific information is noted, in this section, however, information is presented about the overall population of CSHCN and their families. The prevalence of CSHCN within the overall population depends on several factors, including gender, age, socioeconomic level, and family household education. According to the NSCH (2009/10), gender was the strongest predictor of special health care needs. Almost 58.1% of CSHCN are male and 49.4% are female (NSCH, 2009/10). Age is also a strong predictor, with an increasing prevalence of health care needs as children age. During early and middle childhood, children experience a higher incidence of illness due to exposure to other sick children and an immune system that is still developing. School-age children are nearly twice as likely as toddlers to require special needs care (Newacheck & Halfon, 1998).

More than one in five households (23%) in the United States has at least one child with special health care needs (NSCH, 2009/10). Family structure correlates with higher incidence of CSHCN, as single parent families are 40% more likely to have a CSHCN than two-parent households (Newacheck & Halfon, 1998). Parents of CSHCN are less likely to have full-time

employment and more likely to have Medicaid insurance (van Dyck, Kogan, McPherson, Weissman, & Newacheck, 2004). Economically, it has been estimated that CSHCN account for more than half of all child-related health care costs (van Dyck et al., 2004).

Having a CSHCN has an impact on the family. Families with a CSHCN experience high levels of stress. They may even experience symptoms similar to post-traumatic stress disorder which impairs family functioning. The intensity of stress experienced by families in lower socioeconomic status (SES) categories appear to be especially high (Phelps, 2006). This is a concern, because families with an income below the federal poverty level are almost 30% more likely to have a CSHCN. Parents of nearly 17% of CSHCN report cutting back on work hours and an additional 13% stop working completely due to their child's medical needs (NSCH, 2009/10). This clearly relates impacts a family's income; 26% of CSHCN live in poverty. Families with less than a high school education also have higher occurrence of CSHCN (Newacheck & Halfon, 1998). However, families of CSHCN also consistently demonstrate resilience and exhibit behavior that is as adaptive and functional as other families (Phelps, 2006).

CSHCN need access to a wide range of health care and related services to maintain their physical and mental health and development. A variety of factors influence children's access to health care and support services. One is the availability and adequacy of health insurance coverage. Despite many individual and family challenges, CSHCN may have better outcomes than non-affected children in preventative health care, according to the U.S. Department of Health and Human Services. They may have a higher rate of having health insurance than the overall population, including otherwise typically developing, or normal, children (NSCH, 2009/10). However, one-third of families of CSHCN reported that insurance coverage was not always sufficient to meet their child's needs (NSCH, 2009/10). They did more frequently

complete recommended health screenings, including developmental screenings, annual primary care and bi-annual dentist visits (NSCH, 2009/10).

### **Legal Basis for Educating Children with Chronic Illness**

Over time, regulations based on federal legislation have evolved to guide school systems and educators in addressing educational issues for children with chronic illness. The number of children with chronic illness who qualify for special education services has increased with advances in medical care. As these children live longer, reach school age, and spend more time in school, they have a prominent and frequent presence in the classroom (Anderson, 2009; Nabors, Little, Akin-Little, & Iobst, 2008). School is a “values normal” setting for a child’s life, meaning that school can provide a routine that gives children with chronic illness a purpose, a distraction from their medical circumstances, a feeling of returning to normalcy, a sense of belonging, a sense of accomplishment, a sense of hope in the possibility of fulfilling their potential, and a feeling of belonging to a peer group (Webb, 2009). In order to provide the best educational services to any child, and especially to children with chronic illness, accurate and complete information needs to be shared among the family members, health care professionals, and educators.

The Individuals with Disabilities Education Act (IDEA) is a federal law ensuring services to children with disabilities throughout the United States (IDEA, 2004). In 1975, Public Law 94-142 (originally called the Education for all Handicapped Children Act) asserted the right of every child to receive a free and appropriate education (FAPE) in the least restrictive environment (LRE) regardless of disability (Education for All Handicapped Children Act, 1975; Willits et al., 2013). IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and

youth with disabilities. Currently many children with chronic illness are eligible for special education services under the IDEA of 2004, and those not eligible under IDEA are eligible for accommodations under section 504 of the Rehabilitation Act of 1973 (Shaw & McCabe, 2008). The last major revision of IDEA was in 2004 with regulations published in 2006 (Part B for school-aged children) and 2011 (part C for infant and toddlers). This law and the accompanying regulations were of considerable importance because they provided more explicit direction and placed increased emphasis on the need for students to access the general education curriculum. IDEA ensures the rights of students with disabilities, including students with chronic illness, to a free and appropriate public education (FAPE) and an individualized education program (IEP) that addresses their unique needs. IDEA emphasizes the access of all students to the general education curriculum. Children with chronic illness are most often determined to be eligible for special education services within the categories of other health impaired (OHI) or a specific learning disability (SLD). It is important to acknowledge that children can be eligible for special education services under more than one classification or category.

For students with chronic illness whose disability is determined to not impact school achievement in a manner that is sufficiently significant for eligibility for services under IDEA, protection is provided under Section 504 in the Rehabilitation Act of 1973. Section 504 is a comprehensive disability rights statute which includes the following text:

No otherwise qualified individual with a disability in the United States... shall, solely by reason of his or her disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or actively receiving Federal financial assistance. [29 U.S.C. §794(a), 34 C.F.R. §104.4(a)]



The definition of disability under Section 504 is broader than the 13 specific disability categories used under IDEA, and the language of this law makes it virtually inconceivable that a child with a chronic illness would not qualify. Section 504 requires educators to evaluate requests for accommodations, to oversee provision of any accommodations, and maintain relevant data. Although schools do not receive additional federal funding for Section 504 accommodations, the state may lose funding if schools are found to be out of compliance (Webb, 2009). Because each state takes plenary responsibility for educating children living within the state, failure to comply with Section 504 would result in the loss of all federal funding, including funding for infrastructure (e.g. roads), funding for research at public universities, etc. Therefore, states must comply with Section 504 and children with chronic illness must be accommodated.

### **Statement of the Problem**

Despite severe chronic illness affecting approximately 2% of the school population, little research has been conducted that fully explores the experience of these children related to schooling (Shaw & McCabe, 2008). Chronic illness interferes with many areas of development including physical, social, emotional, and cognitive functioning. As a result, many of these children and their families need special education supports and services that other children and families do not need (Anderson, 2009; Nabors et al., 2008).

As children with chronic illnesses live longer, they both reach school age and are healthier, spending more time in school; they have a more prominent presence in the classroom than in previous cohorts of school children. Special care needs during the school day (such as decreased periods of alertness and energy) and frequent absenteeism (due to health issues as well as medical appointments) are examples of factors that can impact both academic performance and peer relationships (Shaw & McCabe, 2008; Shiu, 2001). The school system has

responsibility for providing effective and appropriate instruction to meet the needs of these students, and in order to do so educators need accurate, current, and complete information about medical treatments and prognoses, and how health conditions may impact the child emotionally, behaviorally, or cognitively. Educators not only need to understand a child's condition and the potential effects that treatments and medications may have on academic and behavioral functioning within the classroom, but they also need to understand how a child's family life might be impacted as well as the corresponding needs of family members (Akram, Thomson, Boyter, & McLarty, 2009). Effective communication between parents and educators is essential in order for accurate information to be provided to all involved in the lives of children with chronic illness. Research is needed to understand communication between home and school to identify issues that interfere with effective communication as well as practices which result in enhancing communication.

### **Purpose**

The experiences of parents communicating with their child's teacher or school were investigated in order to better understand and improve communication between parents and educators. Specifically, parental preferences for communicating with educators, parental academic and social expectations for their children at school, and different educational supports that parents perceive are and/or should be available were examined.

### **Definition of Terms**

#### **Key Terminology**

A child with chronic illness has a physical or behavioral condition that affects the child's daily functioning, lasts longer than three months, and requires medical intervention such as medication, hospitalizations, and/or home care (Newacheck et al., 2001). A child with chronic

illness may be healthy or ill at any given time, but they are always living with their condition. Chronic illnesses generally cannot be cured. Chronic illnesses may include: cerebral palsy (CP), diabetes, chronic renal insufficiency, epilepsy, and other inherited chromosomal anomalies, cystic fibrosis (CF), heart conditions, cancer, juvenile rheumatoid arthritis (JRA), asthma, severe eczema and psoriasis), leukemia, and various types of anemia.

Children with special health care needs (CSHCN) are, “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally” (U.S. Department of Health and Human Services, Health Resources and Services Administration, 2013, p. 5). Children with chronic illness are a subset of CSHCN.

The Individuals with Disabilities Education Act (IDEA) is a federal law ensuring services to children with disabilities throughout the United States. IDEA regulates how states and public agencies provide early intervention, special education, and related services to eligible infants, toddlers, children, and youth with disabilities (U. S. Department of Education, 2014). IDEA requires that all students have access to the general education curriculum and are educated in the least restrictive environment (LRE). IDEA ensures the rights of students with disabilities, including children with chronic illness, to a free public education that meets their unique needs.

As defined by the IDEA: “An individual with a disability means any person who: (i) has a mental or physical impairment that substantially limits one or more major life activity; (ii) has a record of such an impairment; or (iii) is regarded as having such an impairment” [34 C.F.R. §104.3(j)(1)]. An impairment as described in Section 504 of the Rehabilitation Act may include any disability, long-term illness, or various disorder that “substantially” reduces or lessens a student’s ability to access learning in the educational setting because of a learning-, behavior- or

health-related condition. A physical or mental impairment does not constitute a disability for purposes of Section 504 unless its severity is such that it results in a substantial limitation of one or more major life activities. In this study, disability is defined as diagnosed conditions that are determined by limitations in educational participation such as excessive missed school days and/or restricted social functioning, such as play (Newacheck & Halfon, 1998; Shaw & McCabe, 2008).

An Individualized Education Plan (IEP) is “a written statement for each child with a disability that is developed, reviewed, and revised in accordance with 34 CFR 300.320 through 300.324” (U.S. Department of Education, 2014) and is required by the IDEA. An IEP is a document that describes the programs and special services that eligible children require to be successful in school, and its purpose is to assure that the proper services are in place to help a student with special needs be successful at school. The IEP must include certain information, such as current levels of performance (i.e. achievement), annual goals and learning objectives, special education and related services, accommodations, transition services, as well as how progress will be measured (U.S. Department of Education, 2014).

An Individualized Family Service Plan (IFSP) is a written plan required by the IDEA that is developed by the child’s family and a team of professionals to document and guide the early intervention process for children birth through 2 years old (just before their third birthday) who have disabilities (U. S. Department of Education, 2014). The IFSP is used to guide effective early intervention services. The IFSP includes the necessary early intervention services that will be provided, outcomes or expected gains from the intervention services, and methods to assist parents/primary care givers to support the child’s development (Lerner, Lowenthal, & Egar, 1998; Willits et al., 2013).

A Primary Health care Provider (PCP) is a physician, nurse practitioner, or other health care provider who delivers comprehensive health care. Primary care includes health promotion, disease prevention, health maintenance, counseling, and patient education, as well as diagnosis and treatment of acute and chronic illnesses in a variety of health care settings.

Teachers refers to all teaching staff at the school. These may include general educators and special educators as well as classroom aides and paraprofessionals. As appropriate, in this study, the specific teacher role will be identified.

Other school staff refers to other professionals employed by the school who have interaction with the children with chronic illness or with their parents. These may include school administration and non-teaching staff (such as the school secretary, lunchroom staff, and custodian). For the purposes of this study, other school staff does not include those otherwise defined as related services.

Related Services, according to the U.S. Department of Education (2014), means transportation, and such developmental, corrective, and other supportive services (including speech-language pathology and audiology services, interpreting services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, social work services, school nurse services designed to enable a child with a disability to receive a free appropriate public education as described in the individualized education program of the child, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services, except that such medical services shall be for diagnostic and evaluation purposes only) as may be required to assist a child with a disability to benefit from special education, and includes the early identification and assessment of disabling conditions in children. [IDEA, 2004]

Specific related services are based on the individual needs of the children and are dependent on the diagnosis, severity of condition, and course of treatment.

Section 504 of the Rehabilitation Act of 1973 is a federal civil rights law that protects qualified individuals from discrimination based on their disability. Section 504 ensures equal access and treatment for individuals with disabilities for employment, education, and public activities (Phelps, 2006). Students who do not qualify for services under IDEA may receive a 504 plan, which could make them eligible to receive accommodations and modifications. Section 504 specifies that qualified children are “entitled to appropriate modifications within their educational program to accommodate their special needs, regardless whether their classroom placement is considered regular education or special education” (American Academy of Pediatrics, 2007, p. 1219).

Supports are “resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning” (Schalock et al., 2010, p. 224).

Support needs is “a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning” (Schalock, et al., 2010, p. 224).

## **Methodology-Related Terminology**

### **Terms related to the description process.**

data accounting log—a management method that documents on a single form when and what types of data have been collected from participants

research participant information log—a tool managing the information related to research participants; allows for transparency in data collection; encourages clarity and detail in description of participants as well allowing for identification of patterns in demographics

first cycle coding—initial method used to code data chunks and summarize data

provisional coding—beginning with a start list of researcher-generated codes based on what investigation suggests might appear in the data before data are collected or analyzed

descriptive coding—assigns labels to data to summarize in a word or short phrase the basic topic of a passage of qualitative data

### **Terms related to the analysis stage.**

second cycle coding—working with the results of first cycle codes; pattern coding as a way of grouping or summarizing results into a smaller number of categories, themes, or constructs

coding matrix— a matrix designed to show the intersection of two lists; designed to show basic codes along with coding categories or patterns along with the code descriptions/definitions

construct matrix—a matrix that includes data that highlight the variable properties and/or dimensions of one key construct (or concept, variable, category, etc.) of interest; contains representative data about one important element of the study for enhanced analysis

case-level display for partially ordered meta matrix—a master chart that assembles all descriptive data from each of several cases in a standard format; simplest form juxtaposes (or stacks up) all single-case displays into a single chart. Data can then be separated and grouped so that contrast between cases and variables becomes clear.

case-ordered descriptive matrix—contains first-level data from all cases, but the cases are ordered according to the variable being examined; it coherently displays the basis data for a major variable across all cases

### **Terms related to the interpretation phase.**

contrast table—brings together a range of representative extremes, exemplars, and/or outliers from cases into one table to explore a selected variable

## **Conceptual Framework**

As a researcher, I identify as having a strong developmental foundation, as well as looking at issues from an ecological and family systems perspective. I am concerned with the best interest of the child while realizing that people may not all define this in the same way based on a combination of factors including religion, history, ethnicity, culture, age, socioeconomic status (SES), and health to name a few. I believe, as people, we actively construct knowledge, beginning as children. I combine a mixture of individualism and collectivism, finding that context is essential in studying and understanding a situation. To combine these ideas of understanding the context and the experienced of individuals and their families, Bronfenbrenner's Ecological Theory (Bronfenbrenner, 1979) and Bowen's Family Systems Theory (Kerr & Bowen, 1988) and a phenomenological approach to inquiry provided the conceptual basis for this research study.

### **Ecological Systems Theory**

Bronfenbrenner's Ecological Theory focuses on how individuals are affected by different levels of their environment (Bronfenbrenner, 1979; White & Klein, 2008). Ecology has its roots in biology, but human ecology has come to be more commonly studied from a sociological perspective (White & Klein, 2008). People are seen as innately social. Commonly, ecological



theory recognizes five system levels: microsystem, mesosystem, exosystem, macrosystem, and chronosystem. Bronfenbrenner was influenced by Lewin who believed people's interactions with their environment affected development (Bronfenbrenner, 1979; White & Klein, 2008). Ecological systems theory brings the nature and nurture aspects of development together, illustrating how the two interact with one another. This is a bi-directional influence. In this theory, an individual's actions cannot be understood without looking at the entire system (White & Klein, 2008). For example, we cannot understand why a child is upset without looking at how that child is interacting with their environment (Maes & Lievens, 2003). Parental expectations can be organized using Bronfenbrenner's Ecological Theory of human development. Families of children with chronic illness may develop expectations concerning their child, their role as a parent, and their interactions with professionals in relationship to the well-being of their children.

### **Family Systems Theory**

Bowen's Family Systems Theory focuses on relationships between family members, family multigenerational behavioral patterns, and how families work together. Bowen posited that family members are emotionally interdependent and functional in reciprocal relationships with one another (Kerr & Bowen, 1988; Smith & Hamon, 2012). In family systems theory, individuals cannot be understood in isolation from one another (Becvar & Becvar, 2008; Kerr & Bowen, 1988). Individuals must be understood as part of the whole or in context, as part of the family. A key premise of Bowen's work is the idea that, within the family unit, relationships are formed by how individuals deal with stress (both within and outside the family system) (Smith & Hamon, 2012). When stressful situations arise, families either come closer together, or they distance themselves from one another, which is described as an emotional cutoff. Experiencing high levels of family conflict or stress may lead to family members cutting themselves off when

entering adolescence or even as far as into adulthood. When a family includes a child with chronic illness, it can impact the stability of the family system. “Family systems theory demonstrates how characteristics of families, such as openness, permeability, and flexibility, vary in degree and influence the family’s capacity to adjust to change” (Thompson, 2009, p. 32). The roles of family members may change in order to maintain or establish a new equilibrium. Patterns of behavior and how family members relate to one another may reveal how they may respond to different situations or solve problems.

### **Need for the Study**

#### **Background on the Child with Chronic Illness as a Student**

Chronic conditions, including chronic illness and physical disabilities, may interfere with development in all areas of the child’s life, including physical, social, emotional, and cognitive. Typical school activities are disrupted in up to one-third of children with chronic conditions. This can impact both academic performance and peer relationships (Shaw & McCabe, 2008). Absenteeism from school or school activities as well as lack of engagement, such as interference with the ability to sustain effort and concentration, are among the factors affecting learning outcomes. Direct neurological sequelae related to some chronic illnesses or their treatments (e.g. motor or coordination problems, seizures, serious headaches) may also directly or indirectly impact school experiences and learning outcomes (Bryan, Burstein, Chao, & Ergul, 2006; Mulhern & Butler, 2004).

Typically, educators and health care professionals interacting with a child with a chronic illness recognize the more specific concerns related to an acute medical event (e.g. hospitalization), but the long-term impact may be overlooked. Cognitive impairment and behavioral side effects, ranging from mild to significant, are a potential long-term consequence

of treatment. For example, educational support may be provided to someone who receives chemotherapy as part of cancer treatment during the initial outpatient treatment and early diagnosis. Important changes in cognitive abilities and behavior, however, may not appear until weeks, months or even years after chemotherapy treatment (Mulhern & Butler, 2004). Educational staff may misattribute learning issues to disability, motivation, or other explanations rather than understanding that the etiology of learning issues was related to medical treatment (Currie, 2005). As a result, educational support may be overlooked or the supports provided may be a poor match for the problem. These side effects and the related support, or lack thereof, may either directly or indirectly impact the ability of the student with chronic illness to attend school or to fully engage in educational opportunities and activities.

**The child with chronic illness as a student.** A child with a chronic illness may miss an average of 16 days of school in a year in comparison to approximately 3 days of school missed for a typically healthy child (Shaw & McCabe, 2008; Shiu, 2001). The amount of learning loss is amplified when combined with the inconsistency of attendance, the psychosocial and peer relation impact, and behavioral outcomes. In childhood, all areas of development are intertwined. The effects of a chronic illness on a child's physical development may be the most obvious but the effects on cognitive, behavioral, and psychosocial development may be equally important in terms of impact on education and academic performance (Bryan et al., 2006; Erickson, Splett, Mullett, & Heiman, 2006; Mulhern & Butler, 2004; Sexson & Madan-Swain, 1993).

School is the typical environment for most children five to eighteen years of age and provides a principal place for peer interactions, support, and socialization (King et al., 2005). A return to the normal routines of childhood can provide a sense of purpose and hope for the future

(Anderson, 2009), and school reentry provides a sense of normalcy and a return to more familiar daily interactions and activities (e.g. homework, recess, teachers, peers, and even riding the bus).

**The parent/family of the child with chronic illness.** Family is the most consistent environment for a child. Other settings or caregivers may change (e.g. day care, school, hospital), but parents/guardians are a constant in the child's life. And as a constant, the parents are the most knowledgeable individuals regarding the overall development and health of a child (Anderson, 2009; Oeseburg, Jansen, Reijneveld, Dijkstra, & Groothoff, 2010). They have important knowledge to contribute in planning their child's care and education. Frustrated parents often find a lack of information or coordinated communication between service agencies, such as between education and health care settings or between schools or classrooms when a student is promoted or transferred. When a parent registers their child for school, information relevant to the student's chronic illness may be shared with the kindergarten teacher or a primary homeroom teacher. Appropriate medical information is recorded in the student's school record. This information, however, may not be shared appropriately with substitute teachers, when the student transfers, or at other times of educational transition unless the parent or student is vigilant about providing it.

Another important issue relates to supporting students as they reenter the classroom or otherwise transition from health care or rehabilitation to education settings (Anderson, 2009; Sexson & Madan-Swain, 1993). Anderson (2009) reported that parents perceive they are acknowledged as experts, but also feel that teachers should be better educated about the impact of chronic illness on their child. There is a concern when changes in medication or other treatments may impact various aspects of the student's ability to attend or fully engage in education opportunities. Additionally, parents believe that health care professionals should

understand the impact of illness beyond the physical health and development of their child (Anderson, 2009; Oeseburg et al., 2010). Parents perceive a lack of communication between health care professionals and educators, which is reflective of their differing professional points of view related to the impact of illness on children's performance in educational settings, particularly in terms of long-term outcomes (Anderson, 2009; Oeseburg et al., 2010). In summary, the parent's perspective is that a more thorough, comprehensive, developmental impact should be understood by educators and health care professionals alike (Oeseburg et al., 2010; Sexson & Madan-Swain, 1993).

It is noteworthy that parents may place a limitation on the communication between education and health care professionals, when they do not provide permission for specific information to be shared. If the parents fail to give permission, then collaboration and open communication between settings is necessarily restricted. Even when parents intentionally desire to keep a separation between settings, educators and health care professionals can still communicate with the exception of divulging specific information (Shaw, Clayton, Dodd, & Rigby, 2004).

**The primary health care provider of the child with chronic illness.** The health care system is changing to include increasing amounts of outpatient care (Shaw & McCabe, 2008). This is rendering the importance of coordinating information and care between the home, school, and health care environments as more important than ever. This decentralized approach may decrease the access of students with chronic illness to support as well as decrease transition services traditionally available within both the school and health care settings. The primary health care provider (PCP) does not, and cannot, communicate directly with anyone other than the family of the student with chronic illness. The transition back to school and communicating

relevant medical information to educators often becomes the primary responsibility of the family of the student with chronic illness. The health care team, however, must continue to play an important role in facilitating the student's reentry into the classroom (Badger, 2008; Sexson & Madan-Swain, 1993; Shaw et al., 2004).

**The educator of the child with chronic illness.** Teachers who are knowledgeable about the specific chronic health illnesses of the children in their classroom can provide more responsive and effective instruction (Shaw & McCabe, 2008). Truly individualized instruction can only be provided when the teacher has the necessary information about a child to formulate and deliver effective strategies. Depending on the multiple factors (e.g. the nature of the diagnosis, course of illness, treatment and medications, and prognosis) communication between home and school can be especially critical in targeting the specific needs of the child with chronic illness.

A teacher may be unaware of the specific areas of long-term and significant impact of chronic illness on academic performance as well as in other areas of development (Gartin & Murdick, 2009; Nabors et al., 2008; Shaw & McCabe, 2008). Nabors et al. (2008) referred to teachers as "a front-line resource" because they are often the first to respond to a child, but they may feel unprepared and lack confidence in their training and preparation in working with students with chronic illnesses. When asked to rate their knowledge and confidence in having a student with a chronic illness in their class, less than half of teachers surveyed felt well-informed about medical conditions. Although most teachers reported feeling confident in meeting the academic needs of their students with a chronic illness, they did not feel as confident in meeting the psychosocial needs of the same students (Nabors et al., 2008; Shaw & McCabe, 2008).

Overall teachers reported higher levels of confidence than knowledge in working with students

with a chronic illness (Nabors et al., 2008). Communication barriers due to misunderstandings cannot only have an immediate impact on a student with chronic illness, but long-term impacts on their teacher, classmates, and family members can also result.

### **Pilot Study: Parent Perspectives on the Support Needs of Children with Special Health Care Needs: Implications for Supports Needs Assessment and Planning**

I conducted a pilot study in 2013 exploring the perspective of parents of children with chronic illness related to home-school communication. I sought to understand the supports that parents believed their children need from educators. Semi-structured interviews (Appendix A) with three parents of children with chronic illness were conducted and transcripts of the interviews were analyzed using qualitative methods.

Parents were asked about home-school communication and collaboration, and were also asked about the supports needed by their children at school, including classroom accommodations that their children might need. Before beginning an interview, parents signed a consent form (Appendix B) and completed the Adapted Illness Intrusiveness Rating Scale (Devins, 2010) (Appendix C). Items in the Adapted Illness Intrusiveness Rating Scale (A-IIRS) referred to the extent to which the child's health care needs and/or treatment impacted different aspects of the child's life and the family life. This scale provided a quantitative measure of the intensity of impact of the chronic illness on a child's life and his/her family's life. Demographic information was also collected regarding children and schools.

Interviews were recorded and transcribed; initial data analysis was done using descriptive coding and provisional coding based on Miles, Huberman, and Saldana (2014). Emerging patterns were identified during second cycle coding. Through constant comparison of themes and coding, a concept map was created (Figure 1). The concept map was revised throughout the

coding process (and may continue to evolve as future data is collected and analyzed). During the pilot study, transcripts were independently coded and reviewed by two researchers to check for and establish confirmability. Conclusions were drawn regarding themes, and issues for further investigation were identified.

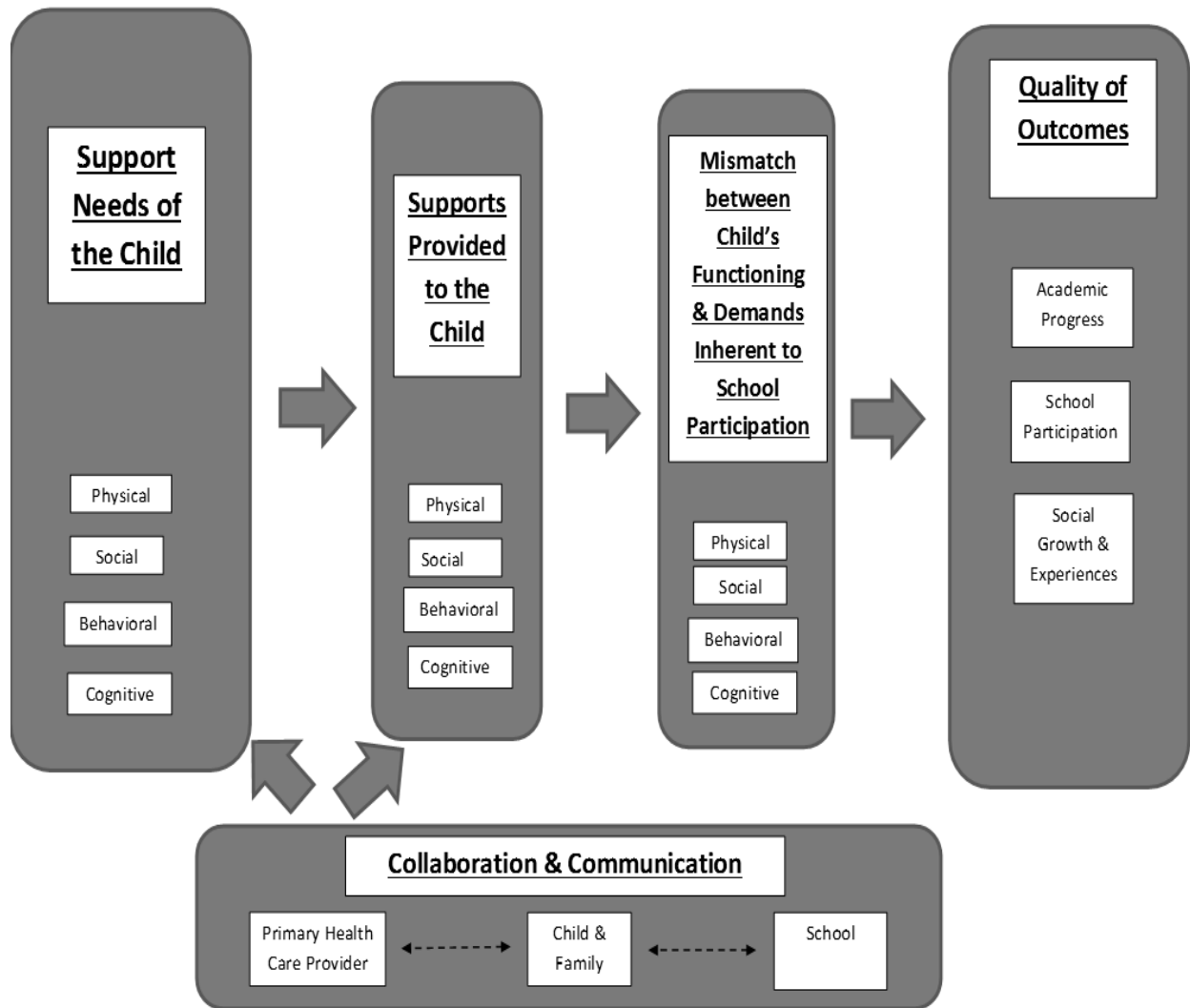


Figure 1. Conceptual Framework: Parent Perspectives on the Support Needs of Children with Special Health Care Needs



The parents in the pilot study provided mostly positive reports related to their interactions with educators and how schools were meeting their children's needs. Upon further exploration, I found that communication was always initiated by the families, but schools were receptive to family concerns and requests. Parents reported that they were more satisfied with educator dispositions (attitudes regarding supports and willingness to make accommodations) than with educator competencies (knowing what to do or how to support their child's learning and school participation). These findings are consistent with research findings reported by Nabors et al. (2008) and Shaw and McCabe (2008) who found that teachers themselves reported higher levels of confidence compared to knowledge when working with children with chronic illness.

A key conclusion from the pilot study was that attaining parent perspectives is an important first step in understanding how to improve communication and collaboration between home and school for children with chronic illness. Additionally, the perspectives of educators, PCPs, and children with chronic illness need to be better understood. It is important for future researchers to investigate aspects of communication between school and home in order to arrive at evidence-based strategies to improve communication. The pilot study focused on understanding how the parents of children with chronic illness prefer to communicate with their child's teacher, the parents' academic and social expectations for their child, and the types of educational supports that parents believed were and/or should be available for their children with chronic illness at the school.

### **Call for Research**

The need for a better understanding of home-school communication is supported through the results of the pilot study and research findings from the professional literature on children with chronic illness. As both previously described and further detailed in "Chapter II: Review

of the Literature”, several researchers have concluded that open and respectful communication between parents and classroom teachers is essential to assuring children with chronic illness receive educational experiences that offer them the best chance to achieve optimal learning outcomes (Bobo, Kaup, McCarty, & Carlson, 2011; Bobo, Wyckoff, et. al, 2011; Erickson et al., 2006).

Parents and professionals each possess valuable perspectives, knowledge, and information that the other does not have. Collaboration allows all parties access to accurate, current, and complete information and is essential to promote the care and development of the whole child. By examining home-school communication from the perspective of the parents of children with chronic illness, knowledge and understanding can be gained to encourage successful collaboration between home and school which will ultimately lead to safer and healthier learning environments for children as well as educators.

### **Research Questions**

The current study focused on the parents’ experiences, perceptions, and expectations.

The current study addressed one main question and three sub-questions:

What is the nature of the experiences of parents of children with chronic illness with their child’s school and teacher?

- a. How do parents of children with chronic illness expect and/or prefer to communicate with their child’s teacher?
- b. What academic and social expectations do parents of children with chronic illness have for their child?
- c. What supports do parents of children with chronic illness perceive are and/or should be available at school?

## Scope and Limitations of the Study

The purpose of this study was to explore the experiences of parents of children with chronic illness in communicating with their children's educators. This study was limited to 10 cases, including the three cases from the pilot study and seven additional cases. Each case was a parent (mother or father) of a child with chronic illness. Cases from the pilot study were recruited using purposive sampling, with both purposive and snowball sampling used for the seven additional cases. This may be a limitation as parents who nominated others and/or those agreeing to participate may differ in important ways from the population of parents of children with chronic illness, and therefore may not have representative experiences.

Another limitation was related to understanding communication between home and school. Communication is inherently a two-way process. During this phase of research, however, only parents were contacted. Because no information was collected from educators or health care providers, only a limited insight regarding home-school communication can be garnered.

While both fathers and mothers were recruited and interest was expressed by both, all parents who participated in the study were mothers of children with chronic illness. This may be a limitation when seeking to understand the overall experience of parents of children with chronic illness. Mothers and fathers may not have the same communication styles nor have the same social and academic expectations for their children.

An additional limitation may be related to the nature of the study. Parents may have been sensitive to sharing information related to the health, education, and outcomes of their children, especially when discussing concerns related to authority figures, such as those in the education or health care fields. Although it is expected that parents were truthful in interviews, it is

possible that parents were not be completely forthcoming regarding their full range of feelings and opinions.

A final limitation is related to generalization of findings emerging from qualitative research. Only 10 cases were represented within this study, and no pretense is made that the experiences, expectations, and hopes of all parents of children with chronic illness will be uncovered as a result of these interviews. Qualitative research, according to Denzin and Lincoln (2005), studies "things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them" (p. 3). This description can provide better understanding of complex situations, such as parental perspectives regarding the education of children with chronic illness. Although findings can contribute to improvements in parent-professional relationships, professional practice, and public policy, generalization of findings specific to these 10 cases cannot be assumed. Qualitative research does not seek to generalize. The goal is greater understanding of social issues. While generalization is not possible, the objective is to bring understanding which can be transferrable to other settings.

## **Method**

### **Institutional Review Board**

Institutional Review Board (IRB) approval was received for the pilot study and all appropriate IRB approval was received for further stages of research. Participation was voluntary and safeguards were in place to assure confidentiality. Individuals choosing to participate signed the informed consent form (Attachment A). All information regarding study participation was confidential. Participants were assigned pseudonyms, and pseudonyms were used during transcription and data analysis.

## **Qualitative Methods**

Qualitative research provides thick, rich description and allows complex social phenomena to be explored (Creswell, 2009). Qualitative research methodologies are valuable when the goal is to understand the experiences of a group, particularly an underrepresented group as children with chronic illness and their families. Qualitative methodology was determined to be appropriate for this study in order to meet the goal of gaining a rich understanding of the experiences of parents of children with chronic illness in communicating with their children's educators.

This was a phenomenological study using a semi-structured interview as the primary method of data collection (Denzin & Lincoln, 2005; Turner, 2010). Phenomenological research is intended to explore and understand the experience from the perspective of the research participant. Phenomenological inquiry has been described as "meaning making" and as describing the "structure and essence of this experience" for people (Patton, 1990, p. 60). With phenomenological research there is no single, objective truth. A person's subjective experience related to health or the provision of health care may also be looked at through a phenomenological methodology (Benner, 1995).

## **Data Collection and Analysis**

An overview of the methodology is provided in this section, and a more detailed description of the study methodology is provided in "Chapter III: Methodology". In this study, parents of children with chronic illness were the participants. They were selected based on their willingness to participate. Their eligibility was also confirmed based on degree of illness intrusion in their life, as measured by their score on the Adapted Illness Intrusiveness Rating

Scale (A-IIRS) (Devins, 2010). A combination of purposive and snowball sampling was used to identify participants (Miles et al., 2014).

In purposive sampling, participants are selected based on specific characteristics. The intent was to recruit families whose children and health conditions represented a range of illness intrusiveness and gain perspective on how this might impact a parent's communication experiences with the school. Parents scored from the 14 to 70 on the A-IIRS (range of scores is 7-70, low to high). Ten parents participated in the study. All were parents of children with chronic illness, ranging in age from 5 to 12 years old. The children had a variety of special health care needs, including allergies, asthma, ADD, celiac's disease, developmental delay, gastrostomy, seizures, tracheostomy, urological issues, and visual deficits (requiring glasses). Most children had at least two health related issues, as listed by parents.

A semi-structured interview format was used which contained open-ended questions with follow up questions used to probe for additional information (See Appendix A). Analysis of data was based on a three-phase plan utilizing strategy of Miles et al. (2014) to identify themes regarding parental expectations related to communication and collaboration.

### **Credibility**

Based on the Glesne (2011) framework, triangulation and member checking were used to monitor credibility. Multiple reviewers confirmed the coding of the participant interviews. Member checking allowed for participants to contribute as the research progressed through transcription and analysis. Participants provided feedback in regard to the extent to which their experiences, as told during their interviews, were being characterized accurately. A rich, thick description of data "that allows the reader to enter the research context" (Glesne, 2011, p. 49) of communication between teachers and parents of children with chronic illness was the overall

goal. Credibility was achieved through interrater reliability and agreement from research team members in coding, categorization, and theme identification as part of the process of triangulation.

## CHAPTER II: REVIEW OF RELATED LITERATURE

Close and ongoing communication between parents and educators, in addition to healthcare professionals, is essential in order to provide accurate information about the impact of chronic illness on a student, including issues such as treatment schedule and medication side effects. Information shared can allow for appropriate expectations in the home and school environments. Knowledge, attitudes, and behaviors of parents, family members, and educators may both directly and indirectly influence the school behaviors of a child with chronic illness.

A child with chronic illness has a physical or behavioral condition that affects the child's daily functioning, lasts longer than three months, and requires medical intervention such as medication, hospitalizations, and/or home care (Newacheck et al., 2001). Children with chronic illness are a diverse population. Most obviously, they differ in regard to their medical diagnosis, severity of symptoms, and prognosis. But they also differ in terms of the timing of where the child is at in the course of their diagnosis, treatment approaches, and the range of unique issues the child and family are dealing with at any particular point in time. This may be important, for example, because although a child with chronic illness is likely to miss approximately five times as much school, there is a wide variation based on timing and also on the specific diagnosis. The range of missed school for a child with chronic illness is from 3-5 days (same as a typically healthy student) to up to 80 days (Currie, 2005; Gartin & Murdick, 2009). This wide variation may impact the effect on learning and development, particularly in relation to the relative importance of some variables. For example, physical symptoms may be central at some stages and therefore skew the overall effect (Mulhern & Butler, 2004; Obringer & Coffey, 2008).

The school readiness and academic performance of a child with chronic illness are affected both directly and indirectly by acute and chronic illness (Currie, 2005; Gartin &



Murdick, 2009; Sexson & Madan-Swain, 1993). Students may be impaired cognitively. For example, memory, language delay, and fine motor processing have all been associated with treatment for chronic illness and related special health care conditions (Gartin & Murdick, 2009). Behavioral concerns (such as fatigue, stress, depression, and anxiety) may also impact school readiness, performance, and engagement. Impulse control may be affected by various treatments and medications (Currie, 2005; Sexson & Madan-Swain, 1993). School readiness may be affected by decreased participation in activities considered important for school preparation as the time necessary for medical appointments and treatments takes priority. Parents may additionally be reluctant to allow a child with chronic illness to participate in group activities, contributing to the perception that the child is vulnerable or incapable (Anderson, 2009; Currie, 2005; Rehm & Rohr, 2002; Sexson & Madan-Swain, 1993).

This chapter is presented in six parts. First, I present an overview of the topic and related literature. This introduction prepares the reader for the next section, which presents summaries of *Ecological Systems Theory* and *Family Systems Theory* as models for understanding interactions of behavior. *The Student with Chronic Illness* presents a look at the effects of chronic illness on a child in their cognitive, behavioral, and psychosocial development. Next, the impact of chronic illness on the child with chronic illness is specifically addressed in terms of school attendance, engagement in educational opportunities, and academic outcomes. *Educators* presents basic information about teachers and education professionals related to working with children with chronic illness. I address educator knowledge and confidence, training and education, and behaviors. In this section, the lack of research related to chronic illness in general is apparent, as most research focuses on specific chronic illnesses. There is simply too much illness-specific information for an educator to learn. Therefore, communication related to the

individual child's needs becomes vital. *Communication between Parents and Educators* addresses the need for the relationship between parents of children with chronic illness and educators and each person's role.

### **Ecological Systems Theory**

Bronfenbrenner's Ecological Systems Theory focuses on the interdependence between humans, as both living and social beings, with the environment. The reality that humans do not develop in isolation, but rather grow up within a home, a family, a community, and within a society forms the basis of the ecological framework or ecological model for conceptualization of human behavior and interaction (Bronfenbrenner, 1979; Smith & Hamon, 2012). White and Klein (2008) explain that proponents of the ecological model view individual development as occurring within the complex system of relationships that are present in the environment. Individual development is being powerfully shaped by the interactions between a person's own biology, immediate family, community, environment, and the larger society. Ultimately, an individual's development stems from the interaction that occurs at the multiple levels and therefore understanding environmental context is especially important (Bronfenbrenner, 1979; Smith & Hamon, 2012; White & Klein, 2008).

The ecological framework is rooted in systems theory. As previously stated, one cannot understand people without considering their social relationships and environment, aspects which affect development. It is the weaving together of the many aspects that form the whole person that is critical, and the whole person is greater than the sum of their parts. Conceptually, the individual is placed in the middle and is surrounded by their environment, made up of systems of family, school or work, and friends, as well as community, society, and culture (Bronfenbrenner, 1979; Smith & Hamon, 2012).

Bronfenbrenner posited five basic nested systems (See Figure 2). The first system is the microsystem. This is a child's immediate environment and the one in which they have immediate contact. The microsystem is where individuals spend most of their time. The microsystem encompasses family, peers, school, child care center, neighborhood play area, church group or religion, and health services. Relationships in the microsystem are bidirectional. This is the most influential level of the ecological systems theory (Smith & Hamon, 2012). In regard to children with chronic illness, their families can be overwhelmed by the diagnosis, the treatment, and the many professionals with whom they must interact and relationships in the microsystem may suffer (Anderson, 2009; Oeseburg et al., 2010).

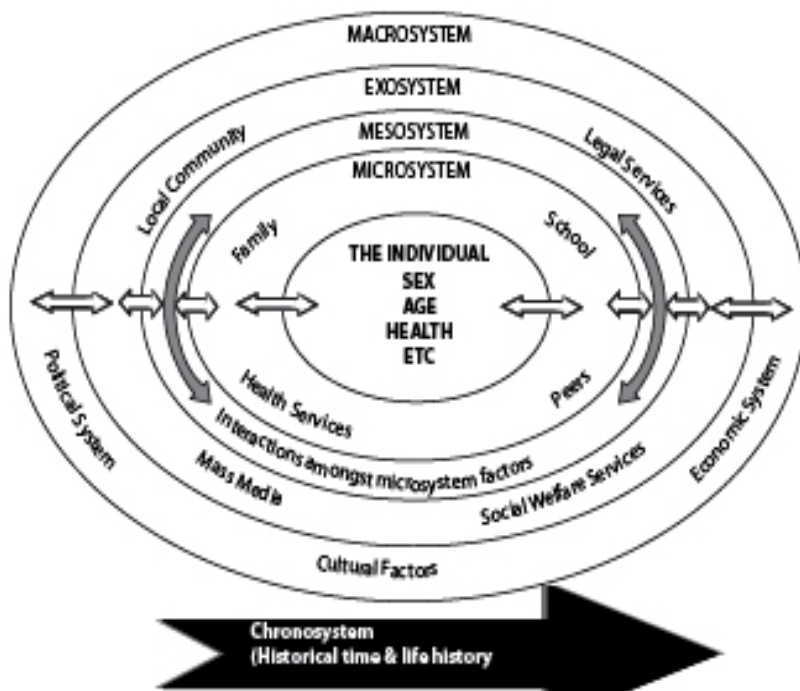


Figure 2. Bronfenbrenner's Ecological Systems Theory (Santrock, 2007, p. 27)

The second system is the mesosystem. The mesosystem consists of the interactions between the different parts of the microsystem. The mesosystem is where a person's individual microsystems do not function independently, but are interconnected and assert influence upon

one another. These interactions have an indirect impact on the individual. Parents of a child with chronic illness may feel stressed trying to balance new responsibilities. Both the child with chronic illness and their family may experience a loss of their usual role. Hospitalization and other changes in family routine may lead to changes in family daily interaction and their environment, including separation from daily routine. The quality of the connection between home and school is a critical part of the mesosystem.

The third system is the exosystem. This system is the external environmental setting that affects the individual in a less direct manner. The person is not an active participant, but the exosystem still affects them. This includes decisions that have bearing on the person, but in which they have no participation in the decision-making process. This system consists of government agencies, religious institutions, and the media. The extent to which a child is impacted by changes in a parent's work responsibilities and the parent's ability to be present during treatment is an example of how the exosystem could affect a child with chronic illness.

The fourth system is the macrosystem. This level includes cultural beliefs, values, attitudes, governmental systems, and the economic system. The macrosystem can have either a positive or a negative effect on a person's development. Education and healthcare policies, insurance, and religious attitudes toward illness may have impact at this level. For example, a person who is a Jehovah's Witness does not believe in receiving blood transfusion or blood products. This may have health implications for a child with hemophilia or sickle cell disease (Currie, 2005; King et al., 2005; Swallow et al., 2012).

Bronfenbrenner refined his work and added the chronosystem (Bronfenbrenner, 1979; Smith & Hamon, 2012). The chronosystem symbolizes time, patterning of environmental events and transitions over the life of an individual as well as sociohistorical circumstances. Events

such as socio-historical conditions (e.g. the Great Recession or the invention of the Internet are two modern examples) impact an individual's development as well as specific events within the life of the child (e.g. diagnosis with a chronic illness or divorce of parents). All of these systems must be taken into account as a means to fully understand the individual's overall development. Ecological systems theory emphasizes environmental factors as playing a major role in development.

Placing the child in the middle of the ecological model reflects the child's individual characteristics, such as their sex, age, and specific diagnosis (i.e. chronic illness). However, these are not the only defining aspects for the individual's development. Ultimately, the child's outcomes depend upon interactions within the entire family system.

### **Family Systems Theory**

#### **Relevant Constructs of Bowen Family Systems Theory**

Family systems theory can aid in understanding the behavior of a family member in a given situation (Becvar & Becvar, 2008; Kerr & Bowen, 1988; Smith & Hamon, 2012). Family systems are organized to meet the daily challenges and adjust to the developmental needs of family members. Bowen Family Systems Theory, introduced by Dr. Murray Bowen, examines the family as a single emotional unit made up of interlocking relationships existing over multiple generations (Kerr & Bowen, 1988). Individuals, therefore, cannot be understood apart from one another, but rather are part of the family unit. Holism is a key construct to family systems theory (see Table 1). The holistic focus takes into consideration relationships and environment (Becvar & Becvar, 2008; Smith & Hamon, 2012).

Table 1

*Relevant Constructs of Bowen Family Systems Theory*

Construct	Description
Holism	The family is a single emotional unit made up of interlocking relationships existing over multiple generations
Hierarchies	Families are organized into smaller units or subsystems which work together to form the larger family system
Boundaries	Influence relationships and the flow of information; Systems are either open or closed with boundaries as a measure of the permeability of the system
Feedback Loops	Patterns of interaction and communication; may facilitate movement toward either system growth or stability

Hierarchies describe how families are organized into smaller units or subsystems that work together to form the larger family system. Subsystems are organized by gender, generation, and relationship (e.g. marital, parental, sibling). When the members or tasks of a subsystem become indistinct, families can have role confusion and other difficulties which may require intervention (Kerr & Bowen, 1988; Smith & Hamon, 2012). When the family structure changes, there is a shift in where family members exist in the hierarchy. When a child is diagnosed with a chronic illness, the mother may play more of the nurturing and caregiving role whereas the father may play the breadwinner/financial role. Mom may be present more frequently (e.g. during treatment, hospitalization, or at IEP conferences) than dad because of the different roles and responsibilities that each caregiver has in the family system.

In all families, individual members have important roles. Every family member plays an important role as part of the functioning family unit. Each family establishes their own roles for family members to play. A change in parental roles may help maintain stability within the family system, but it may also push the family system towards a new equilibrium. When something in the family remains the same, homeostasis is maintained. This could be a behavior, a rule, or a style of communication. When a child has a chronic illness, a parent may give up their paid employment to become a full-time, stay at home parent to meet the daily needs of managing the child's health. This can change the financial and parenting roles of each parent.

Boundaries are related to both holism and hierarchies (Kerr & Bowen, 1988; Smith & Hamon, 2012). Families create boundaries to determine both what is inside and outside of the system. Boundaries influence relationships and the flow of information. Systems are either open or closed, with boundaries as a measure of the permeability of the system (Smith & Hamon, 2012). Closed boundaries are defined by having great censorship and restriction. This can result in members not being able to adequately grow physically, psychologically, or socially due to the withholding of necessary elements for the growth. Open boundaries have little or no impediment to energy or information sharing. This can equally have risks. Any information can get into the family system. The result can be that members lose their identity as they are not distinguished from the outside world (Becvar & Becvar, 2008; Smith & Hamon, 2012). When a family has a child with a chronic illness, the family may have to reevaluate flow of information, both in regards to access as well as control. Educational systems and healthcare have strict regulations regarding access and the parent is the conduit between the two systems. One parent is often more involved and responsible for the flow of information.

Feedback loops describe the patterns of interaction and communication that facilitate movement toward either system growth or stability (Smith & Hamon, 2012). Negative feedback loops are those patterns of interaction that maintain stability or constancy while minimizing change. Negative feedback loops help to maintain homeostasis. Positive feedback loops, in contrast, are patterns of interaction that facilitate change or movement toward either growth or dissolution. Although the words negative and positive are used within systems theory, it is not meant to characterize the communication as good or bad. No value is implied in the labels (Becvar & Becvar, 2008; Smith & Hamon, 2012) but rather, the terms indicate level of change (negative = no change; positive = change). When a family has a child with a chronic illness, change is common at the point of initial diagnosis or when treatment demands hospitalization with extended time away from the home. These are often stressful and impact the family patterns of communication and communication. New systems must be established, which may be either positive or negative in connecting the family toward growth or dissolution.

### **Eight Interlocking Concepts of Bowen Family Systems Theory**

Family systems theory consists of eight interlocking concepts which build on the family as an emotional unit (See Table 2). Triangles are the foundation for the larger emotional system and are formed when there is conflict or anxiety from a stressful situation. Within this concept, individuals will include a third person or element to help relieve the anxiety or look for advice to solve the conflict. Sloper (2000) suggested that mothers of children with cancer use the support from other parents of children with a similar diagnosis and hospital staff members to help reduce their distress. The support from other parents and hospital staff would be the third party helping reduce the stress, or triangulation.



Table 2

*Eight Concepts of Bowen Family Systems Theory*

Concept	Description
Triangles	A three-person relationship system; manages more tension than a 2-person relationship as tension shifts among the three-persons
Differentiation of self	The ability to distinguish yourself from those around you; families and social groups affect how you think, feel, and act
Nuclear family emotional system	Basic relationship patterns that govern problems in a family; providing support for one member of a family enhances outcomes for others
Family projection process	How parents transmit their emotional problems; an extension of the nuclear family emotional system
Multigenerational transmission process	How generations maintain and repeat patterns of behaviors
Emotional cut off	Managing unresolved emotional issues with other family members by reducing or totally cutting off emotional contact
Sibling position	Sibling position in the family impacts development and relationships; those in the same sibling position have important common characteristics
Societal emotional process	How the emotional system governs behavior on a societal level; similar to that within a family

Differentiation of self is the only concept within the eight that focuses on the individual in depth. Differentiation of self is the ability to distinguish yourself from people around you.

Bowen believed that it is healthier to be able to differentiate yourself from others than to be too immersed with other people (Becvar & Becvar, 2008; Kerr & Bowen, 1988). Individuals with a well-differentiated sense of “self” can recognize realistic dependence on others but are confident and able to voice their own decisions and views. The parent of a child with chronic illness must be the able to make education and health care decisions, often taking into account differing professional opinions (Anderson, 2009; Oeseburg et al., 2010).

The nuclear family emotional system refers to the nuclear family that you are born into; how strongly connected we are within our “first” family. Providing support for one member of the family enhances psychosocial outcomes for the other members of the family. Family projection process is an extension of the nuclear family emotional system and describes how parents transmit their emotional responses to their children. The more intense an attachment, the more likely there will be projection. The results can be lower levels of differentiation. The transmission of emotional reactions from a parent to a child can also have an effect on how well the child will react to their diagnosis. If the parent/caregiver is anxious or expressing signs of discomfort or worry, these emotions may be passed on as well, resulting in the child also becoming anxious or expressing signs of discomfort or worry.

Multigenerational transmission process is the fifth concept and describes how generations maintain and repeat patterns of behaviors from one generation to the next. Beliefs about health and wellness, as well as communication and coping styles, are passed down from parent to child. Emotional cut-off refers to an extreme reaction to the family projection process. Emotional cut-off takes place when an individual family member separates from the family with little to no contact, being independent and isolated from the family. An individual may use emotional cut-off as a form of coping with a diagnosis or may be expressing signs of anger or denial about the illness (e.g. refusal to acknowledge the diagnosis or hiding in their room during treatments).

The seventh concept is sibling position and emphasizes a factor in determining personality. People who grow up in the same sibling position demonstrate similar characteristics. Bowen believed that each sibling had a place in the family hierarchy (Becvar & Becvar, 2008; Kerr & Bowen, 1988). For example, older siblings are more likely to be seen as responsible leaders, whereas the youngest children often prefer to be followers. A child with

chronic illness who is the oldest sibling in a family will be more comfortable with responsibility and may take charge of their own health sooner. Finally, societal emotional process is the concept which describes how the emotional system governs behavior on a societal level. Family systems theory can be used to help family members understand and cope with a stressful situation, such as a chronic illness.

### **The Student with Chronic Illness**

#### **Health and Wellness Variables**

Chronic illness may interfere with development in all areas of the child's life including physical, social, behavioral, and cognitive development. All areas of development are intertwined during childhood. The impact on development for a child with a chronic illness may be most noticeable in the area of physical developments; however, development in all areas is impacted. Cognitive, behavioral, and psychosocial development are additionally affected, particularly impact on education and academic performance when exploring consequences on the student role (Bryan et al., 2006; Erickson et al., 2006; Mulhern & Butler, 2004; Sexson & Madan-Swain, 1993). In the area of physical impact, direct neurological sequelae (i.e. gross and fine motor or coordination problems, seizures, serious headaches, pain, or nausea) as related to some chronic illnesses or their treatments may influence learning outcomes either directly or indirectly, or both (Bryan et al., 2006; Mulhern & Butler, 2004).

Behavior can also be impacted through interactions with peers (Gartin & Murdick, 2009). School is the archetypal environment for most children and thus provides one of the primary settings for peer interactions (King, MacDonald, & Chambers, 2010). The school setting is important for peer interaction, support, and socialization, and peers are essential in establishing self-esteem and identity (King et al., 2010; Nabors et al., 2008). Returning to school provides a

sense of regularity and a return to more familiar daily routines and activities for most children with chronic illness.

**Physical.** The physical impact of chronic illness may be direct or indirect. A child with a chronic illness may experience symptoms directly related to the illness or the treatment (Bobo, Kaup, et al., 2011; Bobo, Wyckoff, et. al, 2011; Erickson et al., 2006). These may be side effects of medications, such as albuterol inhalers or chemotherapy, or they may be related to other medical concerns. Side effects in some medications may be seen in 30 - 50% of those taking the medication (Obringer & Coffey, 2008). Side effects may be physical such as nausea, blurred vision, dry mouth, or dizziness. They may also be behavioral such as nervousness. Some of these may relate more directly to class work. A student with blurred vision cannot see the board or read. A student who is dizzy or lethargic will have difficulty concentrating. The student with chronic illness may experience pain or fatigue, either of which may interfere with his/her ability to concentrate. The student with chronic illness may experience symptoms related to breathing, dizziness or nausea (Gartin & Murdick, 2009; Mulhern & Butler, 2004). Hearing loss and blurred or double vision are other specific physical outcomes related to certain medical treatments (Gartin & Murdick, 2009; Mulhern & Butler, 2004). These physical symptoms may have a direct or an indirect impact on attendance and engagement by interfering with necessary learning behaviors such as the ability to concentrate.

**Social.** The psychosocial impact of chronic illness can also be significant. The child and family may face extreme disruption in their home life, as well as at school and work for other members of the family. The school environment is an important arena for socialization and peers are essential in establishing self-esteem and identity (King, et al., 2010; Nabors et al., 2008). The perceptions and attitudes of peers in the classroom should also be addressed in order to

decrease the potential fear, anxiety, and misperceptions of everyone involved and to smooth the transition for school reentry (Badger, 2008; King, et al., 2010). According to Shaw and McCabe (2008) two-thirds of students with a chronic illness reported issues with peers after diagnosis, including being more likely to be ignored by peers, verbal abuse, and being subjected to “excessive” questioning.

The student with chronic illness may experience stress, anxiety, and depression (Currie, 2005; Gartin & Murdick, 2009; Sexson & Madan-Swain, 1993). These may translate into social expectations and perceptions. A student returning to school after experiencing a chronic illness or injury may experience anxiety about the reaction of peers (King et al., 2010). Concern about the reaction of peers and other developmental issues related to establishment of self-esteem and identity may be interfered with if the student with chronic illness lacks the pro-social skills to make friends or connect successfully with peers. King et al. (2010) suggested that school avoidance and attendance are issues which may be strongly impacted by these issues. School re-entry programs are recommended in order to ease the transition for both the student with chronic illness as well as their classmates.

**Behavioral.** Some behavioral effects related to a chronic illness may be physical and some may be social/emotional. A student with a chronic illness may have physical effects that appear behavioral (e.g. increased irritability or decreased attention span) (Bryan et al., 2006; Sexson & Madan-Swain, 1993). Behaviors that are physical, although appearing behavioral, are often attributed as side effects of medication or treatment (Bryan et al., 2006; Sexson & Madan-Swain, 1993). Another physical impact, with behavioral consequences, may be decreased energy level of a student which lowers student participation in activities through ability, interest, or

mobility concerns, which in turn affects school attendance and/or engagement (Sexson & Madan-Swain, 1993).

Behavioral effects related to the emotional impact of having a chronic illness are often connected to difficulty with peer interactions. When returning to school, students with chronic illness may feel a separation from peers and have increased feelings of anxiety and isolation (King et al., 2010). This may impact their participation, increase aggression or stress, and be related to changes in perceived personality (Gartin & Murdick, 2009; Sexson & Madan-Swain, 1993).

**Cognitive.** Chronic illness can have both immediate and latent effects on student cognitive or intellectual skills and therefore can result in a decline or delay in academic achievement. Memory loss (particularly spatial and verbal), language delay, and loss of overall cognitive deterioration have been identified as a possible effect in studies of children with cancer (Gartin & Murdick, 2009; Mulhern & Butler, 2004). Slowed information processing, spatial deficits, memory difficulties, and errors in executive function have also been found in children with other chronic illnesses, including those with diabetes and asthma (Currie, 2005; Shaw & McCabe, 2008).

For some students, however, the sheer volume of missed days of school will require direct intervention, especially when combined with decreased ability to concentrate which negatively affects engagement and attendance (Sexson & Madan-Swain, 1993). Although a majority of children with chronic illnesses are able to return to school without major cognitive deficits, others will require specialized support (e.g. accommodations or tutoring) in order to catch up academically. Educators need to be prepared to support students as they reenter the classroom or otherwise transition from health care or rehabilitation to education settings

(Anderson, 2009; Sexson & Madan-Swain, 1993). This may include knowledge of the physical symptoms, as well as awareness of both cognitive and social-emotional impact of the chronic illness on the student's academic performance.

### **Impact on Academic Performance**

Chronic illness may impact the ability of the student to attend school or to fully engage in educational opportunities and activities. Absenteeism from school or school activities and lack of engagement, such as interference with the ability to sustain effort and concentration, are among the leading factors related to undesirable learning outcomes. The amount of learning loss can be exacerbated when combined with the inconsistency of attendance, the psychosocial and peer relation impact, and behavioral outcomes. Educators need to be aware of the specific needs of the individual student with chronic illness and create effective strategies based knowledge relevant to a specific chronic condition, course of treatment, or medication (Badger, 2008; Shaw & McCabe, 2008).

**Attendance and engagement.** A student with chronic illness misses an average of five times as many days of school in a year compared to a typically healthy child (Shaw & McCabe, 2008; Shiu, 2001). The amount of lost formal and informal learning opportunities is magnified when inconsistent attendance is combined with the social and emotional impact on peer relations and behavioral outcomes. All child health and wellness variables are connected. The physical health of the student with chronic illness may impact their desire and ability to attend school regularly. Physical symptoms related to the chronic illness or treatment, such as fatigue or nausea, may interfere with attendance (Erickson et al., 2006). As well, peer relationships impacted by behavioral or social outcomes related to the chronic illness may impact ability or desire to attend school. Upon school re-entry, students may feel a separation from peers and

increased anxiety and isolation. Desire to avoid peers may lead to school refusal (King et al., 2010). Mediating all of these factors are the attitudes, behaviors, and expectations of both parents and educators.

For some students the amount of missed days of school is not the only concern. Child health and wellness variables impact student engagement. Children with chronic illness may not only miss more school, they may pay less attention when they are in school due to the physical symptoms they are experiencing (Shiu, 2001). Decreased ability to concentrate along with their potential for continued absences combine to create an additional risk to the student's learning outcomes (Sexson & Madan-Swain, 1993). While at school, children with chronic illness are affected by the expectations of educators, parents, and peers. Assumptions about the student's abilities may lower expectations and concurrently lower engagement. Conversely, unrealistic expectations can lead to resignation and an almost equal lack of effort or will (Erickson et al., 2006). Depression and poor social adjustment are not uncommon in children with chronic illness (Boonen & Petry, 2011; Shiu, 2001). Relationships with peers are a strong link to both academic and behavioral issues, especially when there is negative behavior (Aycan et al., 2012; Shiu, 2001), but positive peer relationships can be a factor related to increased coping for students with chronic illness (Shiu, 2001).

**Learning outcomes.** Valid assessment is important to understanding the impact of chronic illness on cognitive development or academic performance. Since we cannot know in advance if or when a student will be diagnosed with a chronic illness, we must use available school and medical assessments in order to assess the impact of the chronic illness from diagnosis to treatment and school reentry (Badger, 2008). It is important that educators collect on-going educational assessments in order to make data-driven decisions related to instruction



and student placement, following diagnosis or other changes in treatment. For the student with chronic illness, this information may be supplemented with developmental assessments completed by healthcare professionals, school social workers, psychologists, or other professionals (Sexson & Madan-Swain, 1993).

A baseline of student performance measured as close to the time of diagnosis as possible is beneficial in measuring the impact of the chronic illness (Gartin & Murdick, 2009). Timing may be dependent on the student's health and school attendance. This data should be supplemented with student grades, measures of academic aptitude and achievement, and student attendance. It is important that impact on learning outcomes be considered over time as effects of chronic illness and treatment and may show up immediately or as delayed effects weeks, months, or even years later (Mulhern & Butler, 2004). Ongoing performance assessment data may then be compared to data collected prior to the diagnosis or treatment, during treatment, and after treatment or school reentry in order to assess the impact of the chronic illness on the learning outcomes of the student with chronic illness. Continual monitoring of student progress is essential in order to make timely decisions about accommodations and educational placement.

### **Educators**

Educators are now more likely to teach students who require complex health procedures (e.g. catheterization and gastrostomy feedings) due to innovations in medical technology and the emphasis on including these students in general school settings. If educators are knowledgeable about the specific health and chronic illness concerns of the children in their classroom, more responsive and effective instruction may be provided that targets the child's specific needs. The nature of communication between home, educators, and healthcare professionals may be related to the nature of the diagnosis, course of illness, treatment and medications, and prognosis.

Personalized supports that result in individualized instruction and maximize student learning can only be provided when educators have the necessary information about an individual child (Badger, 2008; Shaw & McCabe, 2008).

When educators have increased knowledge of a student's individual needs, the attendance, behavior, and chance for success of the children with chronic illness is increased (Erikson et al., 2006; Nabors et al., 2008). It is also important that the information and knowledge that the teacher has is current and accurate. Although some educators know more than they are aware or acknowledge, others may have inaccurate or outdated information. Misinformation is often a more serious risk for the child with chronic illness than lack of knowledge or preparation (Aycan et al., 2012).

### **Knowledge and Confidence**

In a foundational study, Sexson and Madan-Swain (1993) reported that up to one out of five educators were (a) unaware that they had a child with chronic illness in their classroom, or (b) aware they have a child with a chronic illness, but did not know what the illness was. This correlated with results from a later study by Nabors et al. (2008). This was true even in cases when the illness required immediate attention. Their study, albeit dated, clearly indicates the need for communication between educators, parents, and health care professionals. Sexson and Madan-Swain further reported that educators were uncomfortable and unsure of what was and was not a relevant concern related to the health of a student with a chronic illness. They were unsure of what information to share, when to share it, and with whom to share it.

Educators have reported minimizing the student's capabilities related to educational achievement and underreporting symptoms, having assumed the responses were purely behavioral or attention-seeking and therefore not medically-relevant. There is also evidence that

educators tend to overestimate the effects of the chronic illness, such as on the student's behavior or cognitive abilities, leading to lowered expectations. Educators of a child with chronic illness have a further tendency to assume that when the child with chronic illness is experiencing a decreased ability to focus, limited mobility, verbal or memory delays, or difficulties with peer interactions, it is always due to their illness or treatment (Sexson & Madan-Swain, 1993; Shaw & McCabe, 2008). More recent studies provide a somewhat more encouraging picture, but it is clear that educators, parents, and health care professionals still have a long way to go in terms of collaboration.

Brook and Galili (2004) reported that the presence of a child with chronic illness in the classroom correlated with higher levels of teacher knowledge. All teachers reported they should know about the chronic illness. Educators may have limited knowledge of all areas in which the chronic illness is impacting a child's development. These impacts may appear in both the immediate and the long-term. Educators need to acknowledge the significant impact of chronic illness on academic performance, as well as in other areas of the child's development (Gartin & Murdick, 2009; Nabors et al., 2008; Shaw & McCabe, 2008).

Teachers are essentially first-responders with regards to children's needs in the classroom (Nabors et al., 2008). At the same time, teachers feel unprepared and lack confidence in their training and preparation in working with students as children with chronic illness. Educators surveyed about both their knowledge and confidence in having a child with chronic illness in their class responded with less than 50% feeling knowledgeable about the child's medical conditions. Results indicated that although most educators reported feeling secure in meeting the academic needs of children with chronic illness, they lacked confidence in meeting psychosocial needs of these same students with chronic illness (Nabors et al., 2008; Shaw & McCabe, 2008).

Educators reported feeling anxious and inadequate, most particularly in meeting the physical needs of children with chronic illness in the classroom. For instance, educators commonly reported that they did not know what to do in an emergency situation (Aycan et al., 2012; Shiu, 2001). Nabors and colleagues (2008) reported that educators generally indicated more confidence in their abilities to work with children with chronic illness than overall knowledge.

It is important for educators to neither attribute all of a student's school-related problems to chronic illness nor discount the impact of chronic illness on the student, moreover, educators need guidance on what information to monitor and report. If each educator individually decides which symptoms or behaviors to report, data recorded and conveyed may not be accurate and complete (Gartin & Murdick, 2009; West, Denzer, Wildman, & Anhalt, 2013).

Miscommunication and misunderstandings create barriers that are suffered in the immediate by the student with chronic illness, but in the long-term by their teacher, classmates, and family as well.

### **Training and Education**

Many educators are ill-prepared to deal with issues of chronic illness in the schools (Clay, Cortina, Harper, Cocco, & Drotar, 2004; Stalls, Hedge, & Ballard, 2018). In surveys to assess public school educators' familiarity and comfort with health procedures and sources of training, at least half of the respondents had received training in first aid, cardiopulmonary resuscitation, care of teeth and gums, seizure monitoring, and universal precautions, while more than 75% had no training in 16 other listed procedures to meet the special healthcare needs of their students (Becker, Johnson, & Greek, 1996). Looking at the change from the early 1990s to the early 2000s, Clay et al. (2004) examined the degree to which educators face health or problems associated with chronic illness in their pupils, the extent to which they feel responsible

for addressing such problems, and the amount of training to deal with these problems. Of the educators responding, 43% felt moderately to very responsible for dealing with issues of chronic illness while 59% reported no academic training and 64% reported no on-the-job training for dealing with issues of chronic illness (Clay et al., 2004).

As discussed previously, educators reported feeling unprepared to meet the physical needs of children with chronic illness in their classroom. This relates directly to not knowing what to do in an emergency situation (Aycan et al., 2012; Shiu, 2001). This may be a serious concern for children with chronic illness in the classroom who may rely on the teacher to not only meet their daily needs, but to notice if they are in distress and to activate an emergency response. Brook and Galili (2004) reported that three-quarters of educators believe it should be mandatory to increase awareness of chronic illness in the school setting.

Educators of students with chronic illnesses may feel overwhelmed or unprepared. They reported being uncomfortable and unsure of what is and is not a relevant health concern. Teachers and paraprofessionals need additional training to be prepared for the additional responsibility of having a child with chronic illness in their classroom. Aycan et al. (2012) discussed the importance of increasing “diagnosis-specific knowledge” in the classroom (e.g. awareness of diabetes and understanding diabetes management strategies). Other programs have been designed to increase awareness of sickle cell disease, asthma, or other chronic health conditions (Currie, 2005; King et al., 2005; Swallow et al., 2012). Increasing knowledge and comfort with student health management often has a direct impact on education attitude and behavior.

It is often reported that peers have different expectations of children with chronic illness due to their health conditions. Educators reported they believed that peers benefited in

understanding their classmates with chronic illness (Brook & Galili, 2004). This can translate into different attitudes and behaviors toward children with chronic illness. The impact of peer relationships on the child with chronic illness has been previously discussed.

Educators need to be aware of the medications a child is taking and knowledgeable about the side effects of common medications for a diagnosis, such as asthma, cerebral palsy, or seizures (Obringer & Coffey, 2008). Not only does such knowledge have implications for providing instruction that is individualized to the needs of a student, but it is essential that educators keep track of specific details and document any side effects that impact student's academic progress. Teachers also need to be knowledgeable about medicine and potential side effects in order to effectively communicate with parents and other school staff, and provide accommodations as appropriate.

Progress monitoring and data-driven instruction are highly relevant to providing appropriate education in the general or special education environment (Gartin & Murdick, 2009; Mulhern & Butler, 2004). A teacher who is aware of the needs of a student and documents ways in which health factors influence student learning and performance will be able to use this to provide appropriate instruction, will be following educational best practice, and will be in a position to assist the student in balancing academic and health care concerns. This is particularly relevant in the case of students with chronic illness as they are actively, or have recently been, receiving medical treatments which have known side effects that may interfere physically, behaviorally, and/or emotionally interfere with the child's ability to perform at their maximum ability in academic settings.

Educators need to be aware of the importance of differentiating strategies for a child based on knowledge relevant to a specific chronic condition, course of treatment, or medication

(Shaw & McCabe, 2008). In order to do this, the classroom teacher must have communication with the parent of the student with chronic illness that provides appropriate and relevant medical information. For example, educators may design IEPs that adjust to the student's medication schedule, adapt to their physical needs, and are focused on the academic or social needs of a student. Additionally, because educators have daily contact with students, they are in a position to notice physical, behavioral, and cognitive changes over time. It is important that educators be aware of what specific symptoms or behaviors to watch for, and who to inform. The student with chronic illness will ultimately pay the price for poor (or lack of) communication.

### **Behavior**

Educators of children with chronic illness have a history of underestimating student capabilities related to educational achievement and underreporting symptoms because they assumed student responses were purely behavioral or attention-seeking (and therefore not medically-relevant) (Sexson & Madan-Swain, 1993; Shaw & McCabe, 2008). Conversely, there is also data indicating overestimation of the effects of the chronic illness leading to lowered expectations. Educators of a child with chronic illness may assume that the students are experiencing a decreased ability to focus, limited mobility, verbal or memory delays, or difficulties with peer interactions (Gartin & Murdick, 2009).

Although educators must be aware of the effects of the illness on behavior, a child's actions should neither be automatically attributed to nor excused by the illness. Communication with parents and healthcare providers is important so that realistic expectations may be established. Clearly written goals and strategies in the student's IEP or 504 plan will also be valuable in establishing expectations (Robinson & Summers, 2012). Educators are less willing to implement accommodations that were perceived to be burdensome (West et al., 2013).

Appropriate baseline assessment of achievement and subsequent progress monitoring is as important for the child with chronic illness as it is for all students.

Side effects from treatment and various medications may be seen in one-third to half of those taking various medication (Obringer & Coffey, 2008). These side effects can impact a student's learning outcomes both directly or indirectly. An educator who is aware of these side effects can track and document them, and may provide relevant information about the child's behavior and performance to parents, who can then communicate with primary health care providers (PCP) (Shiu, 2001). Communicating with parents may result in changes in medication regimen. Perhaps the timing of when a medication is given can be adjusted or perhaps the medication will be changed. Without thorough information it is difficult for these decisions to be made. Educator-to-parent and parent-to-educator communication is essential when a medication change is made (Aycan et al., 2012; Boonen & Petry, 2011; Obringer & Coffey, 2008).

Medication side effects have implications for behavior, social, and cognitive outcomes, but may be especially significant in the area of academic performance. In academic performance all three areas coalesce into one. A child who cannot stay awake due to drowsiness or dizziness, who cannot focus due to blurred vision or lightheadedness, and who missed class due to nausea or constipation may not be able to function to their full potential. Such children may be excluded socially and will almost certainly miss instructional time.

### **Communication between Parents and Educators**

Close and continued communication between parents and educators is essential in order to provide accurate information about the impact of chronic illness on a student, including issues such as treatment schedule and medication side effects. Overall, school professionals have positive attitudes about children with chronic illness in the classroom (Olson, Seidler, Goodman,



Gaelic, & Nordgren, 2004). Positive attitudes were impacted by the degree to which accommodation for the specific child with chronic illness was burdensome or intrusive (West et al. 2013). However, concerns about specific diagnoses and treatment issues still exist. Sharing information allows for appropriate expectations in both the home and school environments. Knowledge, attitudes, and behaviors of parents and family members, as well as educators, will both directly and indirectly influence the school behaviors of a student with chronic illness. Parent-educator communication and involvement in the multidisciplinary planning process enhances opportunities for students to receive the best education possible. An expanded collaborative role enhances the educational experiences of students with chronic illness (West et al., 2013).

Parents most often find themselves in the position of being the go-between and translating or communicating between school and health care staff, including the PCP. This puts parents in a position of explaining both side's issues and decisions, and may potentially be beyond the parents' comfort level and understanding (Anderson, 2009; Oeseburg et al., 2010). If parents provide most of the disease information, some of the educators' specific concerns may not be addressed (Olson et al., 2004). The parent must effectively communicate in order for the PCP to have the information necessary to make diagnoses and treatment plans and for educators to design IEPs that are aligned with a student's unique health needs. A key role for the PCP is to provide parents and educators with appropriate information about the risk and functional impact of childhood chronic health conditions (Olson et al., 2004).

Educators are responsible for providing students with opportunities to learn basic concepts and apply them in meaningful ways. Teachers need to be aware of the importance of differentiating strategies for a child based on knowledge relevant to a specific chronic condition,

course of treatment, and/or medication (Badger, 2008; Shaw & McCabe, 2008). For example, a child in pain may be on medication which alters their ability to concentrate or inhibits memory, a child receiving medication which are steroids may have difficulty being “still” (sitting at their desk) for extended periods, or a child receiving chemotherapy may have issues with emotional regulation or memory. In order to make appropriate accommodations, teachers must communicate with parents of children with chronic illness in ways that assure appropriate and relevant medical information is shared. Close and ongoing communication is essential in order to provide accurate information about the impact of chronic illness on a student.

Open and respectful communication between home and educators will allow students with chronic illness to receive the best education with the best chance for optimal learning outcomes (Bobo, Kaup, et al., 2011; Bobo, Wyckoff, et. al, 2011; Erickson et al., 2006). Knowledge and evidence need to be the basis for decision making, and information available to each side can inform and enhance the decisions made by the other. Collaboration between educators, health care professionals, and parents, will assure that all professionals have access to accurate, current, and complete information. Parents and professionals each possess valuable knowledge and information. When everyone’s knowledge and insights are brought to the table, the development of the whole child can be addressed and the most effective strategies developed. When knowledge, clear communication, and a team approach are the foundation, a safer and healthier learning environment for the child with chronic illness and safer and more comfortable work space for educators can be the result.

## Summary

This chapter reviewed Bronfenbrenner's Ecological Systems Theory and Bowen's Family Systems Theory. Key concepts were described and implications to children with chronic illness were provided.

The impact of chronic illness on the student was related to each area of development: physical, social, behavioral, and cognitive. The impact on academic performance was addressed through attendance and engagement and learning outcomes. Next, the knowledge and confidence of educators regarding having children with chronic illness in their classroom was discussed, as was educator training and education. The impact of educator behavior on children with chronic illness was covered. Finally, communication between parents and educators was reviewed. The next chapter presents a comprehensive description of the methodology used to explore the key research question in the current study: "What is the nature of the experiences of parents of children with chronic illness with their child's school and teacher?"

## CHAPTER III: METHODOLOGY

Children with chronic illness have a more frequent presence in today's classroom than in the past. The effects of diagnosis and treatment for chronic illness impact children both immediately and in the long-term. To be successful, children need educators who understand their unique needs and how to address these needs in the classroom. In order to do this, educators need close and ongoing communication with the parents of children with chronic illness. In the current research study, I explored communication between parents of children with chronic illness and their children's educators from the parental perspective.

In this chapter, I describe the methodology used for the current study. First, I discuss the research questions and then my research paradigm and positionality with respect to the current study. Then, I give a brief review of the pilot study, previously discussed in Chapter I, followed by an outline of the research methods, including the type of study completed, the participants, sampling techniques, and data analysis procedures. A rich, thick description of the data "that allows the reader to enter the research context" (Glesne, 2011, p. 49) of communication between educators and parents of children with chronic illness is the overall goal. I explain the social context and sampling methods used and describe data collection for the study. The three-stage process of data analysis (including description, analysis, and interpretation) is outlined. Finally, I present ethical considerations and issues of validity and confirmability of the data.

### **Research Questions**

The purpose of this study was to explore the experiences of parents of children with chronic illness in communicating with their children's educators. While communication is not a one-way process, the need for a better understanding of home-school communication is supported through the results of the pilot study and research findings from the professional

literature on children with chronic illness. Researchers have concluded that open and respectful communication between parents and classroom teachers is essential to assuring children with chronic illness receive educational experiences that offer them the best chance to achieve optimal learning outcomes (Bobo, Kaup, et al., 2011; Bobo, Wyckoff, et. al, 2011; Erickson et al., 2006). The current study focused on the parents' experiences, perceptions, and expectations. The current study addressed one main question and three sub-questions:

What is the nature of the experiences of parents of children with chronic illness with their child's school and teacher?

- a. How do parents of children with chronic illness expect and/or prefer to communicate with their child's teacher?
- b. What academic and social expectations do parents of children with chronic illness have for their child?
- c. What supports do parents of children with chronic illness perceive are and/or should be available at school?

### **Research Paradigm**

An interpretivist paradigm operates under the assumption that multiple realities exist (Glesne, 2011). Furthermore, it holds that meaning exists in each individual's interpretation of the world. Interviews are one method to gather detailed information about individual experiences (Denzin & Lincoln, 2005). For this research, interviews were conducted to acquire detailed descriptions of the participant's experiences as parents of children with chronic illness. Within an interpretivist paradigm, there is no assumption of a single, objective truth or reality. What is true is negotiated through exploration of common experience and there may be multiple claims to knowledge. As meaning emerges from the research process, reality is socially-

constructed and fluid. The interaction between the researcher and the participants, through the interviews and subsequent member checking, allows for collaborative construction of a meaningful reality (e.g. for parents of children with chronic illness). A deeper understanding of the experience of parents of children with chronic illness when communicating with their child's educators, through finding common themes and patterns, was the focus of the current study. This better understanding of the experience of parents may provide direction to improve the educational outcomes for children with chronic illness, impact home-school communication, and present suggestions of areas for future research.

This research applied a phenomenological approach in order to explore the subjective experience of the parents of children with chronic illness. Phenomenological research is intended to explore and understand the experience from the perspective of the research participant. Phenomenological inquiry has been described as "meaning making" and as describing the "structure and essence" of this experience for people (Benner, 1995; Davilla & Pearson, 1994). This type of approach can be used with single cases or designated samples. In research with multiple participants, the strength of the inference increases rapidly when factors repeat with more than one participant (Denzin & Lincoln, 2005).

Phenomenological research can explore how family interactions and everyday lives are related to the construction of childhood experiences (such as school). With phenomenological research, there is no single, objective truth. A person's subjective experience related to health or the provision of health care may also be looked at through a phenomenological methodology (Benner, 1995). Phenomenological research can be strong in demonstrating the presence of factors and their effects in individual cases. However, we should be cautious in suggesting a relationship to the population from which the participants were selected. Phenomenological

research may make more direct comments about an individual situation and should not be used to make generalizations. In order to find patterns or common meanings, parents of children with chronic illness were interviewed. When examined comparatively, individual experiences and truths may lead to common patterns and meanings (Denzin & Lincoln, 2005).

### **Positionality**

According to Creswell (2009), those engaging in qualitative research should systematically reflect on who they are as part of the research process. Personal experience, history, and biography can influence the course of a study. It is incumbent upon the researcher to identify and acknowledge those interests, values, biases, and conflicts which influence the study.

As a certified child life specialist (CCLS), I have worked with thousands of children and families during my 10 years of clinical experience working at a children's hospital and I witnessed the resultant impact on children's development and family relationships associated with health and illness issues. Many of these children had chronic illnesses and related special health care needs. I worked with children with acute medical issues, those who were newly diagnosed, and those who had chronic conditions or children with special health care needs (CSHCN). I worked with children from birth through 18 years of age. As a CCLS, it was my job to provide support and advocacy, enhance coping, and decrease anxiety by providing developmentally appropriate explanations of illness and health care. As I worked with children at the hospital, I also had the opportunity to work closely with their families. I was able to see the impact of the communication and relationships between children, parents, and professionals. I had numerous opportunities to discuss with families and with children what it meant to go to school and to miss school, what they wished for, reactions they received from teachers and peers,

and expectations they had. I provided both direct services as well as indirect services, providing educational in-services and serving on hospital committees, such as the Teen Advisory Board and the Family Centered Care Committee.

I also had the opportunity to give presentations at schools, sometimes at the request of the school and sometimes at the request of a family. Some of these were related to the school re-entry of a child returning to school after a diagnosis or course of treatment and some of the presentations were more educational without any specific student in mind. Teachers and students alike expressed gratitude and appreciation for the information. Frequent comments related to the value of the information and how they wished others could hear or wished they had known sooner. I truly believe a strong relationship between the education system and the health care system will provide for the best education and the best health care for children. For this to happen, the relationship needs to be multi-disciplinary and respectful from both sides.

Additionally, I facilitated a support group for children who had a parent who had been diagnosed with or who had died from a chronic illness. These experiences bring me to my interest in the impact of chronic illness and special needs on children as well as the importance of communication between parents, school, and other professionals. I have experienced a wide range of differences in communication reflected in the comfort level, the amount, and timing of information shared between the parent and the professional. This varied by the child, the diagnosis, the parent, the family situation, the support, and combinations of factors. The sharing of information often had a subsequent impact on the patient or student as well those around him. As a CCLS, I was obliged to follow the parent or family wishes related to sharing of information.

I am now a university instructor and I educate the next generation of students who will become early childhood educators, teachers, family life education specialists, social workers,



child life specialists, and a variety of careers working with children and families. I educate and advise students whose goal it is to work with children and families in a variety of settings. I share my experiences and encourage my students to work to strengthen their knowledge of child development and family theory and to apply what they have learned to their clinical experiences. I want to understand what is happening when I work with a child or a student or a family and why. I want to use this knowledge to foster better practices in understanding development and selecting appropriate interventions and education strategies. I hope to help my students understand how they can make the best decisions in their daily practice—first understanding the what and the why of “best” practice and then following through by putting this into effect in their future careers. Evidence-based practice is a common standard in both academic and clinical disciplines. Qualitative research can be helpful with this process. Evidence as support for decision making establishes a rationale (Stake, 2010). Qualitative research can provide evidence that is useful for “improvement in decision making” which is a primary goal of social research (Stake, 2010, p. 122).

I also have a sister who has special health care needs. She was a CSHCN, having both a chronic medical condition and acquired developmental disabilities, from a very early age, experiencing multiple and extended hospitalizations. Many of her experiences and developmental outcomes have been influenced, both positively and negatively, as a result of communication and collaboration between home, school, and healthcare providers. I wonder what the effects would have been if she had not had such strong advocates in her home and healthcare worlds. I saw the impact of lack of consistency in her education. As mentioned previously, I have been a professional working first in a children’s hospital and now at a university. I am an “insider” to the complex worlds of both healthcare and education. As a

family member, I also know what it is like to be an outsider trying to navigate these systems simultaneously. It is important to acknowledge these dual aspects of insider research that may impact my perspective.

With a background in human development and family studies, I have a strong belief in family involvement and families as the experts in the care of their own children. This may lead to a potential bias related to the knowledge of the family or bias related to the desire of the family to be involved in the care of their child and decision-making concerning education or healthcare decisions. It is important to recognize that while families should be respected and offered the information and opportunity to participate, some families may choose not to participate or may participate to a lesser degree. This can be based on a wide degree of factors from cultural and financial to family systems and coping mechanisms. If appropriate, information should be provided in a manner designed to allow and encourage communication and collaboration while respecting family differences and decisions.

It is my intent in this research to explore the experience of the parents of a child with chronic illness while recognizing that communication is a multi-dimensional process. I seek here to start by exploring the parents' perspective. The school and teacher perspectives are also important to understand, and part of my role as a university instructor, but not within the scope of the current research. I acknowledge that the issues related to communicating with educators at different grade levels vary. As a university instructor, I do not claim to understand the issues at all levels of education. Due to the developmental impact, this research will focus on children with chronic illness in grades 2-8. The impact of the communication to and from the PCP is also a factor but again outside the scope of the current research. While having some experience working in a health care environment, communicating with health care professionals will relate

to a wide array of health care professionals, those in hospitals, clinics, offices, and the community. This research will focus on communication in the education setting. I believe that professionals in both the education and healthcare communities possess a unique piece of the puzzle for best care and, when we bring it all together, we are providing respectful care for the development of the whole child.

## **Research Methods**

### **Social Context**

Chronic illnesses affect up to one out of five school-aged children (Kaffenberger, 2006). Currently more and more children with chronic illness are spending time in school. Homework, peer interactions, recess, sports, and even riding the bus are common childhood issues. Chronic illnesses are also a common childhood issue, according to the *Journal of the American Medical Association* and they are “Stealing Childhood” in the metaphorically titled article by Zylke and DeAngelis (2007). As addressed previously, school is the typical environment for most children and provides a principle place for peer interactions, and therefore support and socialization (King et al., 2010). A return to this routine of childhood can provide a sense of purpose and hope for the future (Anderson, 2009). Communication between parents and educators is essential in order to provide accurate information about the impact of special health care needs on the student. This research explored communication and collaboration between educators and parents of children with chronic illness from the perspective of the parent.

### **Type of Study**

This was a phenomenological study using a semi-structured interview as the primary method of data collection (Denzin & Lincoln, 2005; Turner, 2010). The semi-structured format contained open-ended questions with follow-up questions used to probe for additional

information (Appendix A). An analysis of the data utilizing Miles et al. method (2014) for detailed analysis was performed in order to report themes regarding parents' expectations related to communication and collaboration.

### **Participants**

I interviewed 10 mothers of children with chronic illness. Both mothers and fathers were recruited to participate in the interviews. An effort was made to encourage participation from both mothers and fathers. Both mothers and fathers expressed initial interest but only mothers were available and completed the interview process. I had a research goal of enrolling 10 participants based on Fischer (2001), a review of previous research with parents of children with chronic illness, which indicates this as a level of recruitment and participation which is expected to be adequate for "saturation in thematic areas" (p. 345).

### **Sampling**

Initial participants were identified using purposive sampling. In purposive sampling, participants are selected based on specific characteristics. Additional participants were identified through snowball sampling, a technique where initial participants identify additional potential participants. Snowball sampling may provide a researcher with an escalating set of potential contacts and may be used to overcome problems associated with understanding and sampling-concealed populations which may be socially isolated, such as the parents of children with chronic illness (Atkinson & Flint, 2004).

### **Description of Cases**

The description of participants in this study are all provided using pseudonyms given to ensure confidentiality. Additionally, significant identifying child and family information may

have been omitted. However, all information relevant to the child's chronic illness, treatment, developmental impact, education or learning outcomes, and classroom placement are factual.

Three interviews were conducted during the pilot study. Seven additional interviews were conducted. More thorough participant description is provided in "Chapter IV: Research Participants".

### **Recruitment**

Parents of children with chronic illness, who are known to the researcher, were contacted about their interest to participate in the study. Parents of children with chronic illness who were known to the researcher were contacted in person or through e-mail (Appendix D) about their interest to participate in the study. If individuals who were contacted expressed interest, information about the study was provided. If an interview was scheduled, further details about the study were provided in person and informed consent was obtained (Appendix B). The additional participants identified through snowball sampling were also contacted by the researcher by phone or email (Appendix D). If these individuals expressed interest when contacted, further information about the study was provided, an interview was scheduled, and informed consent was obtained.

### **Setting**

Once potential participants were contacted, I met with them at a location and time of their choosing and obtained informed consent. Participants were informed that they could end their participation or withdraw consent at any time during the interview. Participants identified a time and meeting location that was comfortable to them. The settings were private homes, my office, their office, a coffee shop, and at a clinic.

## Data Collection

Results from the pilot study previously discussed in Chapter I were used to refine the interview protocol for the current study. Based on the review of the interviews in the pilot study, the order of the questions in the research protocol was modified (Appendix A). The question order was changed to allow for participant's answers to move from broad to more narrow in focus and to group topics more easily during future data analysis.

The primary method of data collection was participant interviews. Interviews were semi-structured (Appendix A) but allowed for follow-up probing. It was expected that interviews would take approximately 45 minutes. Sessions were scheduled for an hour in order to allow ample time for participants to share additional information and to avoid loss of time. Interviews were one-on-one and semi-structured with open-ended questions (Appendix A). Participants were asked about their communication with the school, their child's health care needs at school, their expectations for their child, how prepared they felt educators were to meet children's health care needs at school, and what supports were or should be available at school for children with chronic illness. The interview ended with a final open-ended question allowing participants to share about anything additional they wished to share which had not been asked during the interview.

Interviews were conducted by the primary researcher. I am a doctoral student in Special Education and have a master's degree in Human Development and Family Studies. I worked at a children's hospital for 10 years as a certified child life specialist and it was my job to provide support and advocacy, enhance coping, and decrease anxiety by providing developmentally appropriate explanations of illness and health care. Through this professional experience, I had the opportunity to work with many children with chronic illness and families of children with

chronic illness. Through my doctoral studies I have obtained training in consent procedures, interview protocols, and interview techniques.

Interviews were audiotaped using a digital audio recorder. Audio files were transcribed and, once transcription was complete, the electronic files were destroyed. The transcriptions allowed for an accurate analysis of the interviews. Participants were informed that their real names would not be used in any written form during the research process. Names were not used during the recorded interviews. If names were inadvertently used during the interview, they were removed and replaced with pseudonyms during the transcription process. I used a pseudonym to identify the participants during the transcription and subsequent analysis. All materials were stored in my office which is in a secure, locked location.

Before beginning the interview, parents completed the Adapted Illness Intrusiveness Rating Scale (A-IIRS) (Devins, 2010). The original scale was created as a self-report instrument developed for individuals affected by chronic illness. The scale can be administered to those with a range of chronic illness, ranging from life-threatening to less severe, in order to determine the impact of the illness on the individual's life in areas of psychosocially meaningful activity. The scale was adapted for administration to parents of children with chronic illness to determine the impact of the chronic illness on the family's life. Items on the A-IIRS scale asked about how much the child's healthcare need and/or its treatment impact different aspects of the child's life and the family life, such as school participation, active and passive recreation, relationships with peers, and family financial situation. During the interview demographic information was also collected regarding the children with chronic illness, family, and schools.

## Data Analysis

For the current study, I structured a systematic analysis of data using the strategies of Miles et al. (2014). Data analysis followed a three-stage process of description, analysis, and interpretation.

**The description process.** The first step of the process was to transcribe the interviews. During this first stage, a data accounting log and a research participant information log were created. The data accounting log (Appendix E) promotes both systematic tracking of the research process and transparency throughout data collection and analysis. The research participant information log (Appendix F) additionally allows for transparency in data collection and encourages clarity and detail in description of participants as well as allows for identification of patterns in demographics, particularly those related to family, health care need, school demographic, and other unexpected issues.

Continuing the description phase, I completed first cycle coding according to Miles et al. (2014) using provisional coding and descriptive coding. The provisional codes included codes based on review of the professional literature and an understanding of the theoretical frame of family systems and ecological systems. Themes were also generated during the pilot study and include codes in the following categories: (a) demographic information, (b) communication and collaboration, (c) the child's functioning, (d) support needs, (e) supports provided, and (f) outcomes (Appendix G). Within the category of communication and collaboration, codes were related to health care provider, child and family, and school. Within the categories of child's functioning, support needs, and supports provided, codes covered the areas of physical, social, behavioral, and cognitive functioning and needs, respectively. Within the category of outcomes, codes covered academic progress, school participation, and social and growth experiences.



Additional descriptive codes were used if the provisional codes did not capture the meaning or intent of an interview. A descriptive label was assigned to the data to summarize in a word or short phrase the overall focus, if needed. Descriptive coding was used to describe the basic topic of a sentence or section of an interview. Codes were reviewed and revised on an ongoing basis. This was an emerging process with codes not considered to be final until all interviews were coded. Further sub-coding was also used as a method if the provisional codes were too broad or encompassing and a more refined code was deemed helpful.

**The analysis stage.** Data analysis continued with the analysis stage. Second cycle coding (Miles et al., 2014) focused on revealing patterns and relationships. I created a coding matrix (Appendix G) and constructed matrices to explore the information revealed through the coding of the participant interviews and to explore a deeper understanding of potential relationships and themes. Construct matrices (Appendix H) highlight specific properties of key concepts, such as communication and collaboration. A case-level display for partially ordered meta matrix (Appendix I) was created in order to compile all of the descriptive data from the interviews into a standard format for comparison. A case-level display for partially ordered meta matrix is a simple format which allows for all of the interviews to be compared in a single display. This allowed for comparison and was helpful in identifying themes and patterns.

Additionally, a case-ordered descriptive matrix (Appendix J) was created. A case-ordered descriptive matrix contains first-level descriptive data from all interviews which is then ordered according to the variable of interest. Here, a case-ordered descriptive matrix was created to look at the interviews in relation to each of the variables within the research: support needs, supports provided, and learning outcomes. The variables of communication and collaboration were also explored through the use of a case-ordered descriptive matrix.

During the next phase, a contrast table (Appendix K) was completed. With a contrast table, the intention is to explore a variable by bringing together a range of examples from each interview into one table. In this study, a contrast table about communication and collaboration was created based upon the relevant construct matrix in order to get a clear look at the value (positive, negative, neutral) of statements made about communication in each of the coding areas within each interview. A contrast table was helpful in looking at the polarity of statements across interviews.

**The interpretation phase.** Finally, for the interpretation phase of data analysis, exploration of meaning was undertaken. Here I returned to connect the data analysis to theory and to my experience as well as to that described by the participants. I created displays to test my conclusions (e.g. looking specifically at different amounts of positive, negative, and neutral communication comments and how these may relate to the Adapted IIRS status). Another comparison explored the direction of communication. I measured if there were more comments within the interviews, at the different levels of Adapted IIRS, for communication from school to home versus from home to school. Additionally, I explored the type of communication preferred, the academic and social expectations, and the supports parents discussed during the interview and whether there were differences notable in any of these based on the A-IIRS status. Essentially, how did the intrusiveness of the child's illness impact their parent's nature and experience in communicating with the teacher?

Other ways to explore meaning, or test and confirm findings according to Miles et al. (2014), that I have included are to follow up on surprises in the data and to the inclusion of feedback from participants. If any information was exposed through the research that was beyond or outside of my expectations, I explored what this revealed about my expectations and

assumptions. For example, when looking at the overall valence of communication, there were comments three times as many positive comments related to communication as there were negative comments. I report this in the results and follow up in the discussion, also considering the meaning as related to the A-IIRS scores of the participants. I also reviewed the theoretical and conceptual theories used as a basis for this research to explore if I could identify where the unexpected data fit or if there was a need to expand or modify my framework. Furthermore, I weighed the evidence and considered if some data were stronger or more valid than other data. In making any decisions, I was explicit in detailing my process and the reasons through description of relevant circumstances, such as those related to data collection, data quality, or participants. In this, the data accounting and research participant information logs provided useful detail for description and discussion. Available research participants were contacted and provided the opportunity to participate through member checking. Member checking allows for participants to contribute in the research progress through transcription and analysis. Participants have a say in whether their experiences, as told during their interviews, are being characterized accurately or not.

### **Ethical Considerations**

The purpose of this study was to explore the experiences of parents of children with chronic illness in communicating with their children's educators. The purpose and design of the study were explained to any person interested in participating. Items related to the scope and limitations of the study were discussed in "Chapter I: The Problem and Its Background". Items discussed include the number of cases included in the study, the study of communication from one perspective, the fact that mothers were the primary research participants, and the nature of the study (parents may be sensitive to sharing information related to the health, education, and

outcomes of their children). Last, the risk previously discussed within the limitations of the risk of generalization of findings must be considered. Although qualitative findings contribute to the understanding of parental perspective, generalization of findings specific to these 10 cases cannot be assumed. Qualitative research does not seek to generalize. Interpretivist research, in particular, recognizes that knowledge is constructed by people and is experiential, with no one objective truth for all. The goal is greater understanding of social issues, such as the experience of the parent of a child with a chronic illness in communicating with their child's teacher. While generalization is not possible, the aim is to bring understanding that can be transferrable to other settings beyond the classroom.

Institutional Review Board (IRB) approval was received for the pilot study and all appropriate IRB approval was received for further stages of research. Participation was voluntary and safeguards were in place to assure confidentiality. Individuals choosing to participate signed the informed consent form (Appendix B). All information regarding study participation was confidential. Participants were assigned pseudonyms used during the transcription and data analysis.

There was no direct financial compensation to participants. Reciprocity in qualitative inquiry occurs when there is give-and-take between the researcher and the research participant. In terms of reciprocity, a sincere appreciation was expressed to each participant and each was offered the opportunity to have a copy of the final research product if they desired. Also, I will make available the results of the research, in the form of a written report or a presentation, directly to the participant's schools upon request of the participant. The benefits of understanding the perspectives of parents of children with chronic illness may lead to improved communication and collaboration. It may also generate professional development for educators

that could improve the supports that schools provide to children with chronic illness. This may additionally generate benefits for children with chronic illness and their families, as well as for the educators of children with chronic illness.

In this research, I negotiate the complex social situations of children's health and education. Within my paradigm, reality is socially constructed. Therefore, it is essential that participants are an active part of the research process. When this happens, this is also reciprocity. In the current study, I encouraged participants to choose the time and location for interviews for their convenience. I also utilized member checking as a part of the research process. This encouraged participants to actively contribute as the research progressed through transcription and analysis. I also gained knowledge from the research process as I grew in my understanding of the needs of children with chronic illness through exploration of the communication experiences of their parents.

### **Validity**

The trustworthiness of data is an important consideration in qualitative research (Glesne, 2011). To facilitate trustworthiness, I employed both triangulation and member checking, based on the Glesne (2011) framework. Triangulation, a method used to check and establish validity in qualitative research, was achieved in the current study was through use of multiple reviewers in the analysis process. Four reviewers coded participant interviews, with multiple reviewers used to confirm the coding of interviews. All reviewers were known to the researcher—the research, two committee members, and a graduate assistant working with the researcher. All research team members were individuals who had a background in education, had completed CITI training, were students or faculty in the special education or family and consumer sciences departments, and had or were provided with training on the research procedures necessary to

transcribe, code, and categorize data. Credibility was achieved through inter-rater reliability and agreement from research team members in coding, categories, and themes as part of the process of triangulation. In order to check coding, a second researcher coded the entirety of each transcript. An additional research coded approximately 30% of each interview. All coders were members of the research team. They were provided with a list of codes and code definitions (Appendix G). If a coding discrepancy occurred, another researcher coded that section of the transcript and codes were discussed and reviewed until consensus was achieved. Initial comparison of coding revealed interrater reliability at 87%. After any discrepancies were reviewed and discussed, final interrater reliability was achieved at 96%, with the primary research making final decisions on the few sections where consensus was not achieved in individual coding.

Member checking is a routine practice in which research respondents, the original source of the material, were asked to check the findings and interpretation. It is a measure of validity or confirmability for research findings. Member checking allowed for participants to contribute as the research progressed through transcription and analysis. Transcripts were sent by email to half of the participants who were then able to review their interview and had a say in whether their experiences, as told during their interviews, were being characterized accurately or not. None made any substantive changes; one participant added a comment which she felt clarified an experience and another changed a few words within a story she had shared, also for clarity. All expressed overall a clear feeling that they appreciated being able to share their experiences. Additionally, a rich, thick description of the data “that allows the reader to enter the research context” (Glesne, 2011, p. 49) of communication between educators and parents of children with chronic illness was the overall goal. The use of direct quotes from the interviews allows for

description of the experience from the perspective of the participant. It also avoids the potential for bias from the researcher. I became interested in this topic through personal and professional experience. The goal was to explore the experience of parents of children with chronic illness and, in order to be aware of my own subjectivity, I maintained diligent research records regarding research participant information (Appendix F), participant contact (Appendix E), transcribing of interviews (Appendix E), and coding of themes (Appendix G). I returned to the interviews (i.e. the original data) to compare emerging themes and patterns. I created a variety of matrices, as previously described, in order to avoid forming opinions based on a single analysis of the data.

This study aimed to explore the experiences of parents of children with chronic illness in communicating with their children's educators. The methodology for the current study followed a three-part format of description, analysis, and interpretation. Parents were interviewed with semi-structured interviews, including the A-IIRS. Within interpretivism, what we know is understood within cultures, social settings, and relationships with other people (Denzin & Lincoln, 2005). Using an interpretivist paradigm, interviews were explored in order to construct meaning. Themes and patterns that were discovered through analysis and through interpretation of experience are discussed. The hope is that understanding may be transferrable to other settings.

### **Summary**

In this chapter, I provided a detailed description of methodology used in the current study. I explained my research paradigm and positionality as related to the study of children with chronic illness. The use of qualitative research methodology to answer questions related to subjective experiences provides a thick, rich description to enhance the understanding of the

experience of the parents of children with chronic illness in communicating with their child's educators. In the next chapter, research participants and interviews will be described to give context to the research findings.



## CHAPTER IV: RESEARCH PARTICIPANTS

Family is the most consistent and influential environment for a child. Even as other settings or caregivers may change (e.g. day care, school, hospital), parents are a constant in the child's life. As such, the parents are the experts regarding the overall development and health of their child (Anderson, 2009; Oeseburg et al., 2010). Therefore, they have important knowledge to contribute in planning their child's health care and education. While parents perceive they are recognized as experts on their child's care, they also believe that teachers should be more knowledgeable about the impact of chronic illness on their child's development and academic performance (Anderson, 2009). Parents also perceive a lack of communication between health care professionals and educators, specifically in terms of long-term outcomes and related to the impact of illness (acute as well as chronic) on children's performance in educational settings (Anderson, 2009; Oeseburg et al., 2010).

In this chapter, I provide in-depth descriptions of the participants in this study. It is important to note that pseudonyms are used to ensure confidentiality. Additionally, significant identifying child and family information may have been omitted. All information relevant to the child's chronic illness, treatment, developmental impact, education or learning outcomes, and classroom placement are factual as provided by the child's parent. I did not gather information directly from any of the children with chronic illness. Some of the children are present during the interview, depending on time and location selected by parent, but none participate directly in information gathered for this research (Figure 3).

	Mary	Susie	Justin	Amy	Kevin	Caroline	Patrick	Bryan	Lizzie	Emily
<b>Child Demographics</b>										
Gender	F	F	M	F	M	F	M	M	F	F
Age	10	13	8	10	6	13	7	10	13	15
Grade	4	6	1	4	Pre-K (second year)	7	1	4	7	9
SHCN (special health care need)	ADD; allergy induced asthma; celiac's disease; urological issues	no esophagus; tracheotomy; gastrostomy tube; developmental delay	asthma; glasses (bifocals)	allergies; asthma	ALL; autism spectrum disorder	Leukemia (in remission)	ALL	allergies; asthma	scoliosis	diabetic-type I
<b>Family Demographics</b>										
Adapted IIRS Score (7-70)	42	70	14	28	37	39	42	28	41	40
Parents	married	married	married	Divorced; mom remarried	married	married	married	divorced	married	married
Siblings Age	11, 8	32, 31, 30	Only child	8	2 ½	7, 10	11, 17	11 ½	3 ½, 10	11
<b>School Demographics</b>										
Public/Private	private	public	public	public	public	private	public	public	private	private
Class Size	14	21	22	20	11	22	23	22	10	58
School Size	135	400	500	200	400	200	470	500	100	225

Figure 3. Research Participant Information

I interviewed 10 mothers of children with chronic illness. An effort was made to encourage participation from both mothers and fathers. Both mothers and fathers were recruited to participate in the interviews and interest was expressed by both; however, only mothers were able to schedule and complete interviews. Three interviews were conducted during the pilot study. Seven additional interviews were conducted during this research study for a total of 10 research participant interviews. An overview of interview scheduling is provided in the Data Accounting Log (Figure 4).

Parent/ Child	Date/Time	Length of interview	Location	Additional information	Who was present	Additional information
<b>Heather/ Mary</b>	2/07/2013	58 min	Participant's home	Family living room; open area	Participant	Also at home spouse & 3 children
<b>Pamela/ Susie</b>	4/14/2013	46 min	Friend of Participant's home	Upstairs, closed door	Participant	friend
<b>Larissa/ Justin</b>	5/08/2013	37 min	My office	Closed door	Participant	
<b>Evelyn/ Amy</b>	5/27/15	32 min	My office	Closed door	Participant	
<b>Trina/ Kevin</b>	6/12/15	23 min	Clinic	Private waiting room	Participant & 2 children	Waiting for apt, RN briefly interrupts, children playing
<b>Allison/ Caroline</b>	6/12/15	14 min	Clinic	Open waiting area, no one else close by	Participant & daughter (not very engaged, busy with tablet)	Staff present in area, waiting 30 min to take vitals
<b>Melanie/ Patrick</b>	6/12/15	19 min	Clinic	Private waiting room	Participant & son (engaged off & on)	Waiting for apt, RN briefly interrupts
<b>Cassie/ Bryan</b>	6/17/15	28 min	Coffee shop	Public area; no one else seated close	Participant	
<b>Christine/ Lizzie</b>	6/29/15	35 min	Friend of Participant's home	Family living room; no one else in home	Participant	Family friend outside
<b>Shauna/ Emily</b>	7/01/15	21 min	Participant's office	Open office door	Co-worker	

Figure 4. Data Accounting Log

### Mary

Mary is 10 years old and in the fourth grade. Her parents are married and her mother is the interview participant. Mary has two siblings, ages 11 and 8 years. Mary is the middle child. Mary attends a private school, in a large urban area, which has approximately 135 total students.

There are 14 students in her class, with 11 boys and 3 girls. On the Adapted Illness Intrusiveness Rating Scale (A-IIRS), Mary's mother scores a 42 (range of 7-70), indicating a mid-range moderate impact related to Mary's healthcare and/or its treatment on the different aspects of Mary's life and the family's life. According to her mother, "Mary is a very smart, very bright girl who is very good at...I don't know what the right word is, I am not quite sure its compensating but she just makes you so happy that you just don't care."

The interview with Mary's mother, Heather, is completed at the family home, on a couch in a common living room space. The entire family, including Mary's father, Mary, and both siblings, and Mary are present in the home at the time. The interview is scheduled in the evening, after family dinner, and lasts for 58 minutes. This is the first interview and also the longest. Only Mary's mother participates in the interview, with other family members in adjacent rooms, aware of the interview but occupied with other activities and not actively participating. Heather is a teacher and clearly says she that as a parent and as an educator she is eager to participate and share the impact of her daughter's chronic illness on the family and her daughter's education. Mary sits and listens quietly for a few minutes at one point during the interview before leaving.

Mary was diagnosed with attention deficit disorder (ADD) in the first grade. She did not have the hyperactivity that can sometimes be associated with that diagnosis and exhibits only the impacted attention and focus. In the third grade, she was diagnosed with celiac disease. This has resulted in a variety of dietary restrictions. She also has fairly severe allergy-induced asthma. Until recently, this has not been well-managed. It caused her to have a lot of illness and sinus trouble, and resulted in missed school. Mary has had urological issues since she was young.

Some of the medications Mary took exacerbated her other conditions. It is an on-going struggle to balance her medical needs.

Mary's various diagnoses have led to interventions which are medical as well as environmental. She takes medications and has a restricted diet. She also must be cautious about coming into contact with gluten, which can occur in seemingly benign circumstances such as playdough as an in-class manipulative or in-class treats. She needs to use the bathroom on a regular basis and sometimes with urgency which may not match the classroom routine. She has needed to have a letter from her pediatric urologist to support this need. According to her mother,

I think Mary is very comfortable in her own skin...but I think that there are times when it pulls on her self-confidence. I think we are very lucky she can verbalize, so at this point it hasn't affected her socially.

School work is the area where Mary has the greatest struggle with managing the impact of her various diagnoses. She often has to stay in from recess to complete required work and has long hours of work in the evening to complete homework. There are nights "she has no play or release." Her ADD medicine wore off in the evening, adding to the struggle to focus. "I am not sure that we found a perfect balance. We are still trying to find, and I think that will always be her um her struggle and even she notices it." If the ADD medicine is increased, her weight is impacted, so again, it is a matter of balancing needs, according to Mary's mother. Mary's needs are:

a little more internal, a little more easily hidden, and you can forget about them. That I think she runs the other end and it's not that people under expect for her, it's almost that we put it so high that we forget to make accommodations. I think that is the biggest thing, we forget to make accommodations. And then she gets in this unreal place where she can't get herself out of it or when. She is at unobtainable levels for her.

Mary's mother is an educator who doesn't think schools have done a good job at disseminating good practical information about how to work with children with chronic illnesses. She understands the need to meet educational standards while meeting individual student needs, bridging health care and education.

### **Susie**

Susie is 13 years old and in the sixth grade. She has missed a large amount of school and been held back twice because of frequent and extended absences. Susie lives with a foster family. Her foster parents are married and her foster mother is the interview participant. Mary has three foster siblings, ages 30, 31, and 32 years. In this home she is the youngest, although she is the only child living in the home full-time. In her biological family, Susie also has siblings. These siblings are closer in age although she did not see them regularly. Four of her biological siblings are older and one is younger. Susie attends a public school, in a rural community, which has approximately 400 students. She is in a full-time main streamed class, with no special education services, and there are 21 students in her class. On the A-IIRS, Susie's mother scores a 70 (range of 7-70), indicating a considerably high impact related to Susie's healthcare and/or its treatment on the different aspects of Susie's life and the family's life. According to her mother, Susie is a "very resilient young lady, she has kind of a cute sense of humor... [who] is not above using her big brown eyes to get her way."

The interview with Mary's foster mother, Pamela, is completed at the home of a family friend in an upstairs bedroom behind a closed door for privacy, at the request of Pamela. The family friend and Susie are also present in the home. I meet Pamela at the location and we chat briefly with her friend and Susie before going to the separate room to complete the interview.

The interview is scheduled in the afternoon, to accommodate Susie's schedule, and lasts for 46

minutes. Pamela is a retired nurse and asks about the purpose of the research before the interview began. She expresses that she wishes she had been better informed before interacting with Susie's teachers. Pamela offers that I may contact her for any follow-up information needed for the research. Only Susie's mother participates in the interview, although Susie indicates an interest in the research and offers to provide information at a later date if appropriate for future research.

Susie's mother is a nurse who has experience working with CSHCN. She has worked with Susie since Susie was 22 months old, first as a home health nurse, then as a respite provider, and finally as a permanent placement foster family. She was asked by Susie's biological mother to provide both respite and foster care services. She has attended school with Susie as her nurse for years and has seen the impact of Susie's health on her education and development in a range of settings and school systems.

Susie has no esophagus, related to an incident when she was an infant, which required an extended hospitalization and led to further medical issues. These extensive medical issues were the cause of her first stay in foster care, as she required specialized care when leaving the hospital. Susie has a gastrostomy, a feeding tube, since she has no esophagus, and a tracheotomy, a tube to help so she could breathe without inhaling her secretions. She has had pneumonia repeatedly from aspiration and therefore she has compromised lungs. Susie has also been diagnosed with developmental delay. When she was younger, Susie had to have a nurse or other adult with her at all times. Susie takes multiple medications and completes numerous breathing treatments daily. When she gets sick, she gets sick quickly, and she is highly susceptible to illness and infection. Both of these factors have added to her missed school and disconnection from peers.

Due to Susie’s multiple medical diagnoses and intensive daily treatment regimens, she has regularly missed large amounts of school and been held back more than once. With her recent move from the hospital to permanent placement with this foster family, she is now attending school regularly for the first time in several years. At 13 years old, Susie should chronologically be entering eighth grade, however, academically and developmentally she is not prepared for this grade. She has been placed in the sixth grade as an academic and social compromise between the school staff and the family. Cognitively “by no means is she ready to be in the 8<sup>th</sup> grade, even in the special ed 8<sup>th</sup> grade”, according to her foster mother. Physically Susie is also small in stature and socially unprepared to spend time with peers her own age. The agreement was made to place her in sixth grade, to give her “more time to develop normally and educationally.” Communication with peers may be difficult, as due to her trach, Susie does not speak clearly. She also does not eat by mouth, which interferes with a common social routine.

When considering school, managing Susie’s health is a delicate balance. When Susie gets sick, she gets “very sick, very quickly.” The local hospital could not accommodate her complex medical needs and she must often be sent to a larger medical center, four hours away. More mild illnesses can be managed at home or locally, but physically as well as emotionally there is an impact on her behavior. As mom says, “we have discovered that she is sensitive...so since we know that, we can help prevent the extreme crabbiness when she gets [ill]. She gets very, very, very crabby and unreasonably demanding.”

Unfortunately, due to her complex needs, Susie could not attend school unless a nurse is on the premises. This lead to concerns from the school with issues such as what to do if she gets in trouble for something like unfinished homework. The nurse leaves at 3:30. Susie cannot be



kept in the building late (after traditional school hours) with no nurse present. Mom's response is,

What happens to the normal kids, well they stay after and do their work, okay I will be at school and I will sit in the office to make sure she is safe while she completes her work. We think that is important for her development in many ways. She has to learn to be accountable for herself.

Susie's foster mother and foster family have tried to normalize her routines and expectations.

One of the primary goals they have for Susie is life skills. She is well-accepted in her community. It may be important to note that Susie is Native American and that her foster family is not. Her foster family tries to honor her native traditions through contact with her biological family and a representative from her tribe.

### **Justin**

Justin is 8 years old and in the first grade. His parents are married and his mother is the interview participant. Justin is an only child. Justin attends a public school, in small town suburb of a larger urban area, which has approximately 500 students. He is in a full-time general class, with no special education services. There are 22 students in his class. On the A-IIRS, Justin's mother scores a 14 (range of 7-70), indicating a considerably low impact related to Justin's healthcare and/or its treatment on the different aspects of Justin's life and the family's life. According to his mother, Justin "likes Legos and he likes coming up with crazy inventions and things in the house and being creative and playing outside and he's an only child so there is plenty of time to think up things to do."

The interview with Justin's mother, Larissa, is completed in the researcher's office at the university, with the door closed to ensure privacy as this a professional setting with many other people present. The interview is scheduled during the afternoon, at the convenience of the Justin's mother, and lasts for 37 minutes. Larissa has experience with the research process but is

eager to share her experience as a mother of a child with chronic health issues. She expresses that she felt that as an educator she sees both sides of the issues but also believes it is important to provide an evidence based account. Her passion as a parent and for research are evident, although she is clearly present as a mother. As the interview occurred in the work setting and during business hours, no other family members are present. The interview is completed with no interruptions.

Justin was diagnosed with asthma when he was seven months old. It was primarily something that required treatment when he was sick and did not otherwise require maintenance medication or treatment. Within the last year, his asthma has required more treatment with nebulizers and medication in order for him to be able to be active and participate in school and regular physical activity.

Justin was diagnosed as an infant and his parents were originally told he would outgrow the asthma by the time her was three years old. His mom wondered if the fact that both parents have related breathing issues was connected to the reason Justin's respiratory issues have lasted longer than expected. While he is becoming more independent as he has gets older, this is a concern to mom, as he is away from her direct supervision and control more often. He has fewer daily medical needs but she is concerned that he didn't recognize when it became a concern. She is trying to "train" him to know the signs and to ask for help if needed. She considers herself "just a mom and really nervous that he would have an asthma attack at school and he won't know what to do or whatever". And says, "it's been a much bigger issue that we've have been dealing with and you know figuring out just how this will affect him in the future" is something that she concerns her.

Additionally, Justin also wears bifocal glasses to help correct the amblyopia in his right eye. He has worn glasses since he was three years old. According to mom, he is just starting to notice the he looks different and “it hurts his feelings when kids say that his glasses are cracked and he has to keep explaining to them that they are not cracked that they are bifocals and that is the way they are suppose to be”.

Justin’s parents both work full-time in the education field. They are concerned with how Justin’s asthma and bifocals impact him, and they do believe that they have had an impact on his overall development, although “the whole not breathing thing freaks me out more than not being able to see”, according to mom. She expresses concern related to his self-esteem, his peer relationships, and his school performance (both in the classroom and in playground, lunchroom, etc.).

### **Amy**

Amy is 10 years old and in the 4<sup>th</sup> grade. Her parents are divorced and her mother is recently remarried. Her mother is the interview participant. Amy has one sibling, age 8 years. Amy is the older child. Amy attends a public school, in a moderate sized urban community, which has approximately 200 total students. Amy receives primarily general education with pull-out special education services for two classes. There are 20 students in her “general” class, with 11 boys and 3 girls; there are 7 students in her special education classes, with two of these also included in her general education classes. On the A-IIRS, Amy’s mother scores a 28 (range of 7-70), indicating a low moderate impact related to Amy’s healthcare and/or its treatment on the different aspects of Amy’s life and the family’s life. According to her mother, Amy is “just less willing to talk [at times]. She’ll just be really quiet...her sister really notices the difference. She’s just like, Ok, Amy’s having a moment. But she’s not attributing it to allergies.”

The interview with Amy's mother, Evelyn, is completed in the researcher's office at the university, with the door closed to ensure privacy in this professional setting. The interview is scheduled during the evening, at the convenience of the Amy's mother, and lasts for 32 minutes. The interview occurs in the work/ educational setting and a time requested by the participant. Evelyn is a graduate student and has many work life obligations. As a graduate student, she has a unique perspective when communicating with a teacher about the needs of her child with a chronic illness. She herself is both a parent and a student. Amy and her sibling are not present but are home with their step-father. The interview is completed with some limited phone interruptions from Amy and her sibling, an indication of the daily need for work-family balance in Larissa's life.

Amy has high functioning autism, per her mother. She also has a variety of both food and seasonal allergies. Some of her allergies have been determined by medical testing and others are assumed, based on her physical and behavioral responses. Amy has asthma which has required her to use an inhaler before strenuous activity, such as gym class. She also has a nebulizer for home use, as needed. She takes daily medications to treat her allergies and must be aware of what she eats, which may be difficult in peer situations. With her related developmental diagnosis of autism, communication is a concern. Mom says, "her autism makes it harder in determining what's going on. She doesn't describe what's going on clearly."

While Amy has autism, this is a developmental disability, which is outside of the focus of the current research and will not be explored in-depth. However, as related to her ability to clearly communicate her medical needs, her autism is clearly a complicating factor. This could place Amy at higher risk in many situations related to her asthma or her allergies. For example, Amy has an allergy to animals but she likes dogs and many other animals. Recently, a therapy

animal had come to school and Amy pet the dog and then rubbed her face. “Amy shouldn’t pet dogs even though she’ll ask, because they said Amy specifically asked to pet the dog...She’s like, “Can I pet the dog?”

Amy’s typical demeanor is noted as naturally quiet and low activity, and therefore, determining if she is not feeling well or is simply unmotivated to perform an activity is said to be difficult. One frustration her mother shares,

I want her to go to school so sometimes determining when to take her to school or when... she’s not feeling well can be kind of hard to determine sometimes. Sometimes it’s like, well she’s complaining, it may just be, well I may don’t feel too good but I just want to stay at home. Or if it’s really bad because there have been sometimes when it was actually really bad when I just thought “You’re just being Amy. You’ll be fine.” And then I get a phone call and I’m, like, ”Oh no, you’re the worst parent ever.”

Mom does not want Amy to get in the habit of staying home or sleeping. Mom says she is usually “really good at doing her work.” Mom is in the process of continuing her own education and valued education for her children. She is involved in her children’s school academic and extra-curricular activities; she is also interested in the future of research and the possibility of expanding to look at communication with the health care professional and the CSHCN. Mom volunteered to continue to participate if there are future stages of this research, offering interviews with her daughter or information for contact with her daughter’s teacher or health care providers.

### **Kevin**

Kevin is 5 years old and in his second year of pre-kindergarten (pre-K). Kevin is the youngest CSHCN represented in this research. He is repeating an additional year of pre-K due to the amount of missed school. His parents are married and her mother is the interview participant. Kevin has one sibling, age 2 ½ years. Kevin is the older child. Kevin attends a public school, in a small rural town, which has approximately 400 total students. He is in a

special education class as part of an inclusion program; there are 11 students in his class, with three others on the autism spectrum. On the A-IIRS, Kevin's mother scores a 37 (range of 7-70), indicating a midrange moderate impact related to Kevin's healthcare and/or its treatment on the different aspects of Kevin's life and the family's life. According to his mother, Kevin is "Energetic. Into everything. Typical 5-year-old boy, other than having a few learning delays."

The interview with Kevin's mother, Trina, is completed in a private waiting area, attached to the main play room/ waiting room, at a weekly medical clinic which Kevin must attend. Kevin and his younger sibling are present in the private waiting area, playing during interview. There are several other children and families, as well as medical staff, in the main waiting room. The interview is scheduled while Kevin waits for his appointment at clinic and lasts for 23 minutes. Only Kevin's mother participates in the interview; Kevin and his sibling play, regularly checking in with Trina to ensure she is close by, paying some attention to them, and aware of their activities. Trina is a stay-at-home mom, skilled at balancing her time and attention. She says clinic focuses on medical needs but she is eager to talk about the "other" impacts of Kevin's chronic illness. Toward the end of the interview, a nurse briefly interrupts to give mom some information about pending lab results and to update her about wait time for appointment.

Kevin was diagnosed with acute lymphoblastic leukemia (ALL) on December 28, 2012 when he was two years old. At the time of the interview, he is on week 115 of the treatment protocol and has 5 weeks left. He comes to clinic every Friday for his scheduled treatment and he receives oral medication nightly at home. He also has a few learning delays and is on the autism spectrum, as related by mom. He has high functioning autism, diagnosed after his ALL. Mom says people have related this to Kevin having "chemo brain," which is the idea that the

chemotherapy impacts the ability of the brain to function clearly, particularly related to memory and information processing.

While in his second year of pre-K, according to mom, it has basically amounted to one year based on the amount of days he has missed, reported to be about 65% of the school year. Kevin will therefore be repeating another year of pre-K. Mom expresses a preference for his current home schooling and wishes that this option had been suggested sooner in the treatment regimen, before he missed such a large amount of school.

I honestly think they waited too long to do the at home bound schooling because if he would have been on that home bound schooling sooner, I think he'd be progressing faster. Because since he's had that home schooling he has progressed so much more. He works so much better with the teacher.

Mom also has concerns about the long-term impact of Kevin's cancer diagnosis and the chemo therapy treatments. She explained that, now that he is on maintenance treatment, it is frustrating when "people think he should just be fine now and that he should just be a normal kid. But what they don't understand is that chemotherapy draws a huge delay, no matter the age." She says they still "don't know if he is at his full expectation of learning or not. He really could be just like, okay we're done with chemotherapy, I'm gonna talk now. I'm gonna use that potty."

Kevin's mother clearly expresses her frustration. "You live with it for years without even knowing you have it. So what part of this is okay? None of it." She says her mother told her to be happy she has two healthy children. And she says, "I don't have 2 healthy children. My child has been going through cancer for the last 3 years." She worries about the possibility that Kevin's sibling may also have cancer or a related health issue, as they do not know if any part of this is genetic. She wants better information from the medical professionals about the long-term

impact on her child and would have appreciated clearer direction from the education system about how to help her child.

### **Caroline**

Caroline is 13 years old and in the seventh grade. Her parents are married and her mother is the interview participant. Caroline has two siblings, ages 7 and 10 years. Caroline is the oldest child. Caroline attends a private school, in a moderate sized urban community, which has approximately 200 total students. She is in a full-time general class, with no special education services. There are 22 students in her class. On the A-IIRS, Caroline's mother scores a 39 (range of 7-70), indicating a moderate impact related to Caroline's healthcare and/or its treatment on the different aspects of Caroline's life and the family's life. According to her mother, Caroline is "a typical teenage... Very helpful. Responsible. Artistic. Caring. Loving. Depending on the day. Ha ha..." At this point, Caroline inserted the aside comment, "Amazing."

The interview with Caroline's mother, Allison, is conducted in an open waiting area in the clinical space at a weekly medical clinic which Caroline must attend. There is no one else in close proximity and this is the where she requested to complete the interview. When offered the opportunity to wait for a more private space, Allison indicates comfort answering questions with the minimal staff presence in the general area. Caroline is also present, as she is waiting for treatment to begin. She is engaged with activities on her tablet and did not visibly or actively participate in interview, even when asked a question by her mother. Caroline and Allison sit side-by-side in chairs during the interview. Allison indicates that she feels comfortable with the topic of the research as she is an educator and Caroline is in remission; they have completed her original treatment protocol, meaning they have been dealing with the healthcare system for years. The interview is scheduled to occur while the scheduled clinic visit occurs and while



Allison and Caroline wait. It lasts for 14 minutes. This is the shortest of the interviews. Only Caroline's mother participates in the interview, with brief interruptions by staff to check Caroline's vital signs.

Caroline was diagnosed with leukemia when she was 6 years old. She is in remission at the time of the interview. She went through treatment for two and a half years and is five years out of treatment. At this time, Caroline comes to clinic for follow up appointments related to her leukemia. Otherwise, she requires standard pediatric well child check-ups.

While diagnosed in the first grade, Caroline's health status did not have a noticeable impact on her relationship with her peers until the third grade. "The kids never thought one thing about it. They were very supportive, and throughout the whole thing" until third grade when a new student started at the school. The other students have been in classes together, in private, school for several years, and were close. A "new girl came, and then she started telling the other kids that Caroline could do whatever she wanted because she had cancer...now they're friends, they've gotten through it. But it was a rough couple of years to get through."

Caroline's mother expresses that they "were pretty lucky" overall. Caroline attends school the majority of the time and "she's really a strong student so I think that helped, too." Caroline's mother is a teacher and "it was easy for me to keep up with what she was missing and do work at home with her." They never had a home tutor, IEP, or felt that she required any specialized education planning.

Being at a small religious school is important to mom. She feels strong support from the school community, such as "a lot of people making us meals, kind of spreading the word, they did some fundraisers at school. They had started somethings called Caps for Caroline." As

Caroline is currently in remission, her mother continues to express appreciation for the support of her co-workers and school provided throughout her treatment.

### **Patrick**

Patrick is 7 years old and in the first grade. His parents are married and his mother is the interview participant. Patrick has two siblings, ages 11 and 17 years. Patrick is the youngest child. Patrick attends a public school, in a moderate sized urban area, which has approximately 470 total students. He is in a full-time general class, with no special education services. There are 23 students in his class. On the A-IIRS, Patrick's mother scores a 42 (range of 7-70), indicating a moderate impact related to Patrick's healthcare and/or its treatment on the different aspects of Patrick's life and the family's life. According to his mother, Patrick is "a very active child. Very animated. Very talkative. Likes to always be on the go...and he has a dog...he's telling me to include the dog...So, it's a very active household full of boys."

The interview with Patrick's mother, Melanie, is completed in a private waiting area next to the main waiting room at a weekly medical clinic which Patrick must attend. Patrick is also present in the waiting area, playing during interview. There are other patients, families, and staff present in the main waiting room. The interview is scheduled while Patrick wait for his appointment at clinic and lasts for 19 minutes. Only Patrick's mother participates actively in the interview; Patrick primarily plays independently, although he does engage with his mother regularly. Melanie answers questions briefly and concisely. While agreeing to participate in the research, she does not elaborate or provide additional information. Melanie appears to be engaged more with her child and monitoring the progress of the medical appointment than in the interview process, reasonable when speaking to a parent with a child with chronic illness while at

a medical clinic. In the middle of the interview, a nurse briefly interrupts to get some information from mom for their appointment.

Patrick was diagnosed with ALL approximately one year ago when he was six years old. He received intensive inpatient treatment for three months and now receives what mom refers to as “maintenance” treatment. He comes to clinic weekly for his treatment and receives medication at home each night. He also receives steroids once a month. There are 90 weeks remaining on his treatment protocol. His treatments lower his immunity and, once released from the hospital, he is homebound for an additional four months. Particularly as it has been “cold and flu season” when he is released, he is unable to be in public, and he has only recently returned to school.

Patrick is one-fourth of the way through the treatment protocol and mom is concerned about the physical and health impact as well and social, peer, and educational outcomes. Mom believes that going to school is good for Patrick. She says, “It was good to finally get to interact with other kids and to be able to concentrate on something other than his illness.” Physically, being at school “took a while to get his strength back up” but she has been concerned that he would have to repeat a grade based on the amount of missed days. However, when he returned for the end of the school year, “the teacher said he really did fine. She said you wouldn’t have known, had you not known the situation, that he had not really missed all of that schooling.” Mom credits the homebound instruction.

Mom is a teacher and works at Patrick’s school and expresses both advantages and disadvantages for this. She is appreciative for her ability to be close while simultaneously expressing frustration with the attitudes of both other staff and parents.

I probably should have said something but I was just so taken back by her response. And it is so hard with me working there too. I don’t want to take advantage...I guess it is nice

that I work there because he doesn't go to the nurse's office at all. If he needs medicine he just comes up to my room. Any problem he has he comes to my room.

Mom feels her experience and Patrick's experience would have been quite different if she had not been both an educator, as well as specifically located in his building. She has knowledge of how to help her son, how to support her fellow teachers and administration, and what to share with other parents. In the end, "just being able to see him and knowing that he was ok kind of put my mind at ease. But had I not been a parent in that building it would be very hard to just send your child off and know that they were being taken care of."

### **Bryan**

Bryan is 10 years old and in the fourth grade. His parents are divorced and his mother is the interview participant. Bryan has one sibling, age 11 ½ years. Bryan is the younger child. The children are with their mother approximately 90% of the time. Bryan attends a public school, in small town suburb of a larger urban area, which has approximately 500 total students. He is in a full-time general class, with no special education services. There are 22 students in his class, with 125 children in his grade. On the A-IIRS, Bryan's mother scores a 28 (range of 7-70), indicating an upper range low impact related to Bryan's healthcare and/or its treatment on the different aspects of Bryan's life and the family's life. According to his mother, Bryan is "an imaginative, creative, complicated child. He brings us joy and makes us laugh. He has a rich inner life. He loves Legos...wants to learn to draw...is loving golf...plays guitar and piano. He's just a very active boy."

The interview with Bryan's mother, Cassie, is completed on a rainy morning at a coffee shop in an open public space. No one appears to be seated close enough to overhear the conversation/ interview. Only mom is present for the interview. For the convenience of Bryan's mother, the interview is scheduled during the day, while Bryan and his sibling are busy with

other activities, and Cassie has available time. Cassie and Bryan’s father are divorced and Cassie works in the school system. Cassie expresses that the viewpoint of parents is not valued in public school settings or in early intervention. She strongly believes parents are experts on their child and, especially in the case of health concerns, communication is vital to the welfare and positive outcomes for the child. The interview lasts for 28 minutes and is completed with no interruptions.

Bryan has asthma and allergies, both of which have been diagnosed since he was two years old. He had an anaphylactic reaction to peanut nut butter and the family is extremely cautious about reading labels. He is not allowed to eat anything baked by another person, unless mom knows that person and knows nothing has been contaminated. He has additional environmental allergies and seasonal allergies, some of which have been proven through testing and others which are indicated by his responses but have not been proven through medical testing. Bryan takes medications every day for both his asthma and his allergies and he is expected to carry an epi-pen, inhaler, and Benadryl with him everywhere he went. He also uses a nebulizer as needed, but doesn’t want to look different from peers, so is embarrassed to ask the PE teacher if he can use it. Mom also sends him separate snacks, which he usually just doesn’t eat, again, to avoid being different.

Bryan is “good in school and he loves learning and he gets excited about it.” While his medical issues are “embarrassing” to him, he has become more independent at handling symptoms and treatments. It affects him in PE and at recess. “He used his nebulizer once at school during the recess and...he’s still traumatized that the other children would see him looking different. So, he does not want to be different with anything.” He also has to sit at the peanut-free table at lunch. This has an impact on peer relationships, according to mom.

In different years of his life sometimes a friend will join him who is not allergic, and sometimes he's eaten from kids from entirely different grades, which is also not very socially normal for him. So, there was a time, I think when he was in 3<sup>rd</sup> grade, when he was eating with kindergarteners with peanut allergies. And it just made me sad that that is your free time and you're not even with peers.

She is proud of how he handled it, but wishes that the embarrassment was less of a concern.

“There's kids who are diabetic, there's kids that have all kinds of issues, and this speaks nothing about your character. It's just about your health.” However, Bryan's allergy is serious enough to raise to the level of a possible anaphylactic reaction, and mom referred to herself as “hyper-vigilant”. She says, “No one's going to put something in his mouth that he doesn't know where it came from.” Mom shares an event that was literally life or death. This occurred at Bryan's child care when a teacher did not recognize an allergic reaction, which became an anaphylactic response requiring emergency treatment.

Mom wants to normalize the idea of having a chronic illness for Bryan. At the same time, she wants to emphasize the importance of awareness and knowledge of chronic illness for teachers and other adults responsible for children, especially CSHCN. She looks forward to Bryan's ability to be independent while simultaneously worrying about his decision making. She says, “It's gotten easier the older he gets.”

### **Lizzie**

Lizzie is 13 years old and in the seventh grade. Her parents are married and her mother is the interview participant. Lizzie has two siblings, ages 3 ½ and 10 years. Lizzie is the oldest child. Her 10-year-old sibling is also a CSHCN. Lizzie is the focus of this research. Lizzie attends a private school, in a moderate sized town, which has approximately 100 total students. She is in a full-time general class, with no special education services. Her class is a combined seventh and eighth grade class and there are 10 students in her class. On the A-IIRS, Lizzie's

mother scores a 41 (range of 7-70), indicating a moderate impact related to Lizzie’s healthcare and/or its treatment on the different aspects of Lizzie’s life and the family’s life. According to her mother, Lizzie is “fiercely independent and she is driven. At the same time those wonder qualities are difficult when dealing with a 13-year-old because she can be stubborn but those qualities also make her very motivated and excited about things.”

The interview with Lizzie’s mother, Christine, is completed at the home of a family friend in an open living space. No one else is present in the home at the time of the interview, although the family friend is outside doing some outdoor work. I met Christine at the home and we talk briefly about her participation in the research and her family. It is summer and Christine’s time is limited as her children are no longer in school. Per participant request, the interview is scheduled toward the end of Christine’s lunch hour and while Lizzie and her siblings are at child care. It lasts for 35 minutes. Only Lizzie’s mother participates in the interview.

Lizzie was diagnosed with scoliosis at nine years old. Mom says that she was “otherwise pretty healthy” and they were shocked to find the scoliosis was determined to be significant. Lizzie did not require surgery at that time, but she did have further evaluation, and bracing was determined to be necessary. There have been frequent appointments, with progress monitoring every six months. She is expected to wear the brace 12-16 hours per day. After four years, she has had to have the corrective surgery. At this time, they discovered that she has been in more pain than anyone was aware but was not telling anyone, as she did not want to have surgery sooner. During recovery she is restricted in some of activities. After her final check-up, she is to be cleared for “normal activity”. Mom expresses concerns about this, after the numerous years of physical restriction.

Lizzie's 10-year-old brother also has special needs, as well as a 3-year-old sister who is typically developing. Her mother describes the family dynamic as "unique". Lizzie is beginning to move into her teen years and "excited about meeting more people and getting into a bigger school...She's ready to meet more people." In comparison to some CSHCN, she has missed relatively few days of school for illness, primarily missing school for scheduled six month monitoring appointments.

Lizzie "definitely is not passive and those types of things. She's definitely on the other end of the spectrum, for sure." When given the option of the 12-16 hours daily to wear the brace, Lizzie chose to sleep in it. Lizzie is active in sports and other activities. She "was not necessarily restricted from activities [related to her scoliosis] but we would monitor, of course, if she had pain or if something was uncomfortable." Her peers and teammates have been supportive.

Her main restrictions occurred recently related to the surgery. She did miss school and got behind on some assignments. Fortunately, academics is not an issue for Lizzie. "She works really well independently and is able to navigate through the material, and they did offer if she needed some extra help with math." However, she is able to make up the work quickly. She is also restricted on physical activity for 6-7 weeks. She was not allowed to participate in PE or recess.

Then there was one day, oh and I didn't know this until we were at a doctor's visit 6, 7 weeks post-op, and she tells us, "Well, I tried the monkey bars yesterday." And I apparently looked like I was crying because she says to me, "Mom, are you crying?" And I said, "Well, I'm going to." Because it was so shocking.

Mom says, "she is still young enough that her decision making is not always going to be there."

Mom worries that because hers is a physical issue that you couldn't necessarily see and she appears functional, people may forget about restrictions. Mom also worries about the emotional



impact. She notes that Lizzie told her classmates she would be back in a week when the doctors had said it would be a month. Then, the transition back is harder than any of them anticipated. She looks forward to the transitions which will occur now. Hopefully, post-surgery, Lizzie will not have any ongoing physically issues related to the scoliosis.

### **Emily**

Emily is 15 years old and in the ninth grade. Emily is the oldest CSHCN represented in this research. Her parents are married and her mother is the interview participant. Emily has one sibling, age 11 years. Emily is the older child. Emily attends a private school, in a moderate sized town, which has approximately 500-600 students in the entire school with 225 students in her level. She is in a full-time general class, with no special education services. There are 58 students in her class. On the A-IIRS, Emily's mother scores a 40 (range of 7-70), indicating a moderate impact related to Emily's healthcare and/or its treatment on the different aspects of Emily's life and the family's life. According to her mother, Emily is "Humble. Compassionate. Intelligent. She really has the attitude that God gave this [her diabetes] to her for a reason...I can't say never, but more times than not, won't. She'll go out of her way to educate than to deny it."

The interview with Emily's mother, Shauna, is completed at the participant's office, in a shared work space with an open door. Shauna's co-worker is present in the shared office space but Shauna states she is comfortable with her continuing to work and she does not want to close the door or change locations. Shauna actually invites her co-worker to add anything to the interview that she feels is important. Shauna and she work in the office at a school and her co-worker is an administrator at that school. It is summer and not a school day with children present. However, the interview is scheduled during the work day, and lasts for 21 minutes.

Shauna is eager to participate and invited me to contact her if I needed any additional information for the research. Only Emily's mother participates in the interview, with her co-worker present although not actively participating.

Emily was diagnosed as a Type I diabetic when she was 10 years old. She wears a pump, a mechanical device that helps to monitor her blood sugar levels. She enters her carbs and it doses her for the amount of food she is eating. It could factor in how she felt, her exercise, or other miscellaneous factors, so she needs to be constantly monitored. Prior to the pump, she used the more traditional method of finger stick and insulin injections. Her current pump adheres to her skin and checks her blood sugar every five minutes. It alerts her to high or low levels through a little iPod like device. A second notification could also be sent to another person, such as a parent. She must change the site every 2 days. This is helpful for Emily in the transition to self-monitoring, as previously, when using finger sticks which had to occur with every meal or snack (approximately 8 pokes a day), she would often choose not to eat to avoid the poke.

Emily's diagnosis has a direct physical impact, which in turn might impact her physical activities, social interactions, and cognitive responses. It can also be a circular interaction. For example, when her physical activity level is high, her necessary level of food or insulin is higher. At the same time, when she is having an issue with her diabetes, she may be lethargic.

She's very active. And that's where the CGM [monitor] is going to come in because she'll be able to monitor it a little bit better than going off. We have a thumbs up or thumbs down signal. So, if she's doing well, she'll thumbs up to the coach. If she's doing bad, she's thumbs down and they take her out.

Cognitively the impact is seen in both her memory, verbal responses, and attitude. Mom expresses strong concern in this area of behavior and information processing. "If she's in a low,

her mind is foggy so she isn't able to participate quite as clearly. If she's in a high that puts her more in an anger type of, she gets kind of antsy, very agitated."

Peer relationships are an area of strength for Emily. "She doesn't allow anybody to treat her differently. I know that sounds like odd...She's got such high expectations for herself that she doesn't let anybody else set them for her." Her classmates and teammates are friends, which is important as Emily could need to rely on someone else to notice changes in her behavior. She also must have a friend walk her to class or present at all times, in case she has a seizure.

Emily's mom works at a school, although not the school which Emily attends. She is highly involved in Emily's daily medical routines and health monitoring. She is concerned about what would happen as Emily transitioned to more independence, with less parental (or adult) monitoring. She also feels it is important to emphasize the individualism of her daughter and every CSHCN. "Get to know them personally. Don't label them as "this is what they are". Because I don't like when you come up and say this is my diabetic daughter. This is my Emily."

While both mothers and fathers were recruited, all 10 of the parents who completed interviews were mothers. While this is consistent with the literature on children with chronic illness, it is important to note that this represents the perspective of mothers and not fathers. Eight of the mothers are married. Of the two who have been divorced, one has remarried. All the mothers are employed and six are connected through their work to the education field. The children with chronic illness are between 6 and 15 years of age and 40% of the children attend private schools, some of them at the school where their mother works. Only one is an only child. The families averaged an A-IIRS score of 36.8 with a range of 14-70. Only one family scores very low and one very high for impact of illness intrusiveness. All others ranged within the low moderate to moderate range (28-42). All interviews occurred at times and in locations selected

by participants, with varying levels of privacy. Only four interviews are completed without interruption. All interviews used the same semi-structured interview format (Appendix A) with clarification questions as needed. Interviews lasts an average of 31.3 minutes, with a range of 14 to 58 minutes. No noticeable connections are made between location, length of interview, and chronic illness, privacy, or other characteristics.

## CHAPTER V: RESULTS

Chapter V is organized to provide the reader with an overall view of the results. It follows the research questions and is guided by the concept map. Results of the study in response to each of the research questions are presented as well as discussion of any additional themes that emerge from the data analysis, but which were not specifically targeted through the research questions. The concept map, originally presented in Chapter I, is a visual representation of the data and provides an additional guide to readers through the results in this chapter.

The purpose of this study was focused on the parents' experiences, perceptions, and expectations. This study proposed one main question and three sub-questions:

What is the nature of the experiences of parents of children with chronic illness with their child's school and teacher?

- a. How do parents of children with chronic illness expect and/or prefer to communicate with their child's teacher?
- b. What academic and social expectations do parents of children with chronic illness have for their child?
- c. What supports do parents of children with chronic illness perceive are and/or should be available at school?

The overarching research question was phenomenological. The goal was to explore the experiences of parents who had a child with a chronic illness in communicating with their child's school or teacher. Experiences are more than one-dimensional and the goal of this study was to understand the experience from the perspective of the parent. This experience is impacted by multiple factors. The primary question was broken down into three sub-questions, which will be used to outline the results. Each sub-question also links directly to the concept map, which will further be used to outline the results.

The first sub-question explored the process of communication specifically. Themes related to methods of communication, timing of communication, content of communication, and overall valence of communication. Content of communication was further broken down into child-related issues and teacher-related concerns (such as questions of knowledge or procedure).

The second sub-question explored expectations parents have for their children, particularly academic and social expectations. Themes were found in each area of development detailed in the concept map: physical, social, behavioral, and cognitive. Within physical development, themes focused on physical activity, pain and symptom management, and school participation. Within social and emotional development, themes focused on peer and social relationships, self-esteem, and emotional support. While not a specific developmental area, behavior was a major area of concern, and therefore specifically detailed. Major themes related to behavior focused on concentration, self-regulation, and independence. Within the area of cognitive development, themes focused on both aptitude or ability as well as overall achievement.

The third sub-question explored the supports both parents perceived were and those that should be available for their child at school. Again, themes related to each area of development detailed in the concept map: physical, social, behavioral, and cognitive. With physical development, themes focused on participation and medical treatments. Within social and emotional development, themes focused on peer interactions, self-esteem, and emotional support. Again, behavior was included, and themes focused on self-care and independence. Within the area of cognitive development, themes focused on supporting academic outcomes, IEP or 504 plans, home schooling or tutors, the impact of extra work, and advocacy.

The concept map has five main sections and functions as a seemingly simple flowchart from left to right, with factors on the left impacting subsequent factors to the right. However, it is significant to note that the “Communication and Collaboration” section is foundational. The other sections are built upon a foundation of communication and may be either supported or undermined by the strength or lack within this section. Also important is the flow within this section. Family is intentionally placed in the center of this section and may either function as a conduit or a barrier to communication and collaboration, again, either strengthening or weakening this foundation. Here, we see parent expectations for communication and teacher ability or willingness to meet these needs. This is primarily reflected in sub-question one.

The sections “Support Needs of the Child”, “Supports Provided to the Child”, and “Mismatch Between the Child’s Functioning and Demands Inherent to School Participation” all reflect each of the primary areas of development. While sub-question two asked directly about academic and social expectations, parents had expectations for their children in all areas. “Mismatch” and “Quality of Outcomes” speak directly to parent expectations for their children. Information was also provided within the sections of “Support Needs” and “Supports Provided” as they discussed the impact of these supports. Sub-question three asked specifically about supports. As parents discussed their perceptions of supports, provided and perceived as should be provided, within the sections of “Support Needs” and “Supports Provided”, they also provided rich data related to children’s outcomes.

The final section of the concept map is “Quality of Outcomes” and is subdivided into academic progress, school participation, and social growth and experiences. Parents provided data for this section within each sub-question—communication, expectations, and supports. Essentially, they wanted to know how their children were doing, in all areas, not matter what. In

general, parents want to know. What they expect from their child may vary and how they want to be communicated with may vary—but they want to be told how their children are doing.

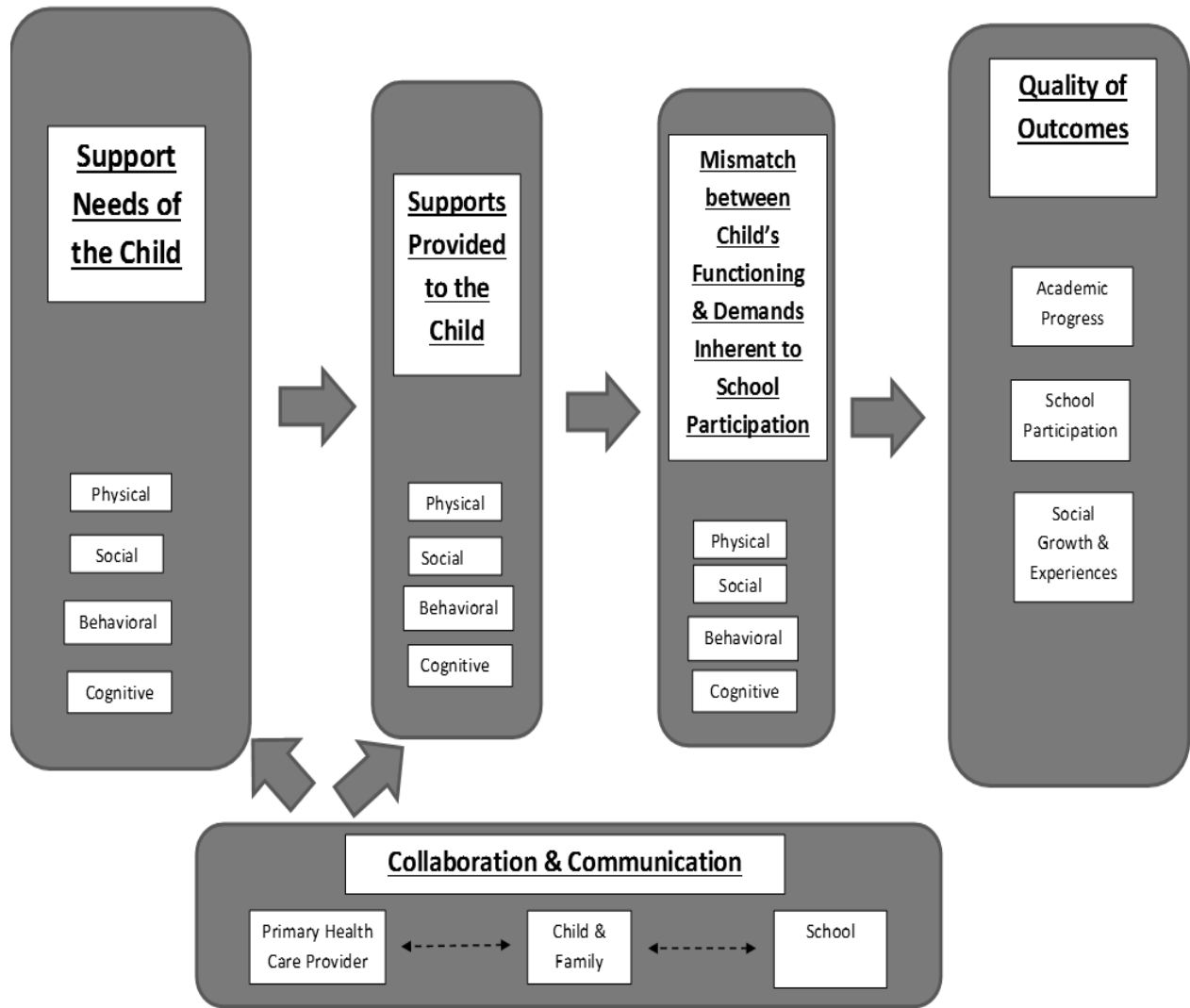


Figure 1 Conceptual Framework: Parent Perspectives on the Support Needs of Children with Special Health Care Needs

**Research Sub-Question a: How do Parents of Children with Chronic Illness Expect and/or Prefer to Communicate with Their Child’s Teacher?**

The first sub-question explored communication specifically (See Table 3).

Communication flowed in both directions, both initiated by parents and by the teacher, although



communication was more frequently initiated by parents. “I think communication comes two ways. One in being able to deliver good information but also I think that both parties in being willing to receive and sometimes in some cases assimilate new information“ (Mary’s mom). Themes related to process of communication, content of communication, and overall valence of communication. Content of communication was broken down into child-related issues (health updates and information to manage the classroom) and teacher-related concerns (knowledge, skills, and attitude).

Table 3

*Research Sub-Question a: Summary of Communications Themes*

Primary Theme	Secondary Themes	Tertiary Themes
Process of communication	Method of communication Timing of communication	
Content of communication	Child-related issues  Teacher-related concerns	Managing info related to health updates Managing info related to change in staff or managing the class  Teacher knowledge Teacher skills Teacher attitude
Valence of communication	Positive Negative Neutral	

**Process of Communication**

The first theme related to the process of communication itself, such as method and timing of communication. Parents related far more similarities than dissimilarities in their preferences in these areas.

**Method of communication.** Parents identified a wide range of communication style preferences, with phone calls most frequently identified. Eight of the ten parents specifically mentioned telephone communications in some form, most often initiated by parent although schools or individual teachers also called parents. Parents spoke to teachers as well as other school personnel, depending on availability or topic to be communicated.

(It) works very well to call and talk to the teacher or the nurse on the phone...It's less likely that we would be interrupting class time with the teacher or the teacher has lots of things going on before school so it's a lot easier to call the nurse. And then the nurse will find the time to tell the teacher. (Susie's mom)

Actually, I think sometimes phone calls work better for me. Just because every once in a while it will be just really busy and I don't read the communicator as much as like I should. I try to read it every day but there just may be like a tough night, tough morning with the girls and every once in a while I will forget it and I wouldn't want to forget something important. So phone calls are the best. (Amy's mom)

(School) always calls me... Usually very seldom talk through email, unless it's something that is coming up, like the school trip type of thing. (Emily's mom)

In order of frequency, in-personal verbal communication was the next most commonly mentioned form of communication, mentioned by six out of ten parents. Again, parents mentioned speaking to the teacher as well as to other school personnel, varying by availability as well as topic of the communication.

I come up to the school to let them know. I talked with the nurse in the office and I talked with her teacher. (Amy's mom)

Well, I talk to the teacher a lot. I talk to her a lot and then I would see her every day before and after school. (Patrick's mom)

Email was utilized by at least four out of ten parents and the common denominators for preferring email were the convenience as well as the desire for a written record of any communications for future reference.

I do a lot of email. I don't like to do the phone because I don't have a record of what I've done. I like having a record and someone can go back and reread my directions if they were confused. That's what I try to do. (Bryan's mom)

Communication by text was the mentioned by three parents. This was a current technology that was appreciated as a modern method of communication.

Another thing that probably speaks of our modern communication is I was texting with her teacher. I would text her updates and communicate. (Lizzie's mom)

We text a lot... When he was not at school she (his teacher) would text me, "We missed Kevin today. How's he doing?" (Kevin's mom)

Finally, some form of daily communication logs or other form of written communication (non-electronic) were mentioned by three parents. These were the most traditional forms of written communication and the most likely to rely on the student as part of the method of delivery.

We have a daily communicator that comes home and sometimes through email. (Amy's mom)

I sent a note to his teacher. (Justin's mom)

But every time there's a field trip, when I sign the permission slip, I say please bring this, this, and this with him. And the morning of, I do email them a reminder (Bryan's mom)

Skype was mentioned by one parent as method of communication utilized when the child was hospitalized. "When we were in the hospital they skyped with her" (Lizzie's mom).

Classroom newsletters, as a general supportive communication, although not child-specific, were also appreciated by two families. "There is a newsletter sent home and it is also sent electronically. Sometimes the teacher will send notes about certain events that the kids are going to be involved in, like the whole class was in the talent show" (Amy's mom).

**Timing of communication.** Three parents preferred daily communication, regardless of method of communication.

We have a daily communicator that comes home and sometimes through email (Amy's mom).

We do have each other's phone numbers. Other than that, when he was going to school, I would hear from all of his teachers daily. Is he sick? Call me when he's better. Are we coming today? (Kevin's mom)

No other parent mentioned a focus related so directly to a daily or weekly schedule, but they related more to timing as impacted by changes which necessitated information (or content) that needed to be communicated. Communication was identified as important related to specific events or when the teacher either needed to ask or relate information, such as changes in the child's medical condition, at the start of a new school year, or when there was a field trip.

The teachers have been really good when I go in for conferences. (Emily's mom)

After I sent her the note and told her, here's what I think is going on, I think we are going to be dealing with this and I already told the office of the beginning of the school year that we've had it available we have never needed to use it. (Justin's mom)

One of the things they have done is to make sure she can be included in a field trip. Of course, with the trach all the things they are not really familiar with can be scary so they are quite willing, they you know if I would like to go on the field trip so she can go and they didn't have to do that. (Susie's mom)

One of the things usually is that our school does what is home visits initially before school starts so at that time we will make the teacher aware of the situations that they have and um encourage them to talk with previous teachers that have had success in helping her. (Mary's mom)

## **Content of Communication**

The second primary theme was related to the content of the communication. Content of communication related to this research was either the child (i.e. health updates, academic issues, behavioral concerns) or to the teacher (i.e. skills or knowledge needed to work with the child).

An additional topic of content could be considered basic factual details related to school or

classroom participation and not related to the individual child with chronic illness (i.e. field trip forms, lunch menus, class birthday lists). This occurred primarily within the child-related communication as classroom management information. Occasionally parents would refer to the teacher's ability to appropriately include, or not include, their child with a chronic illness as a skill.

**Content of communication: child-related issues.** Parents most frequently discussed issues related to their child with chronic illness. Parents discussed health updates related to the medical condition, treatment routine, or diagnosis of their child with chronic illness. Communication also occurred frequently related to the start of a new year, upon change in teacher, or related to classroom management. Parents also requested updates or information at similar times.

***Managing information related to health updates.*** Parents were most likely to communicate when there was a change in the child's condition or treatment routine, or when the child had a change in symptoms or behavior (either physically, socially/emotionally, behaviorally, or cognitively).

If we have a new issue, then I have the doctor write a note and send that to the school.  
(Bryan's mom)

I sent a note to his teacher and what she would do is she would communicate back or she would put a note in his bag with the inhaler when he brought it home if he had to use it at school that day. So that helped me know because sometimes, I don't know, 7 years old don't remember when they used it. (Justin's mom)

I think keeping me posted on they notice changes, in her behavior, they will come to me and say I've noticed over the past couple of weeks she's really seemed unfocused or we've really been struggles, or she has not been eating her lunch. Um they won't wait until it's a chronic issue they will come to me pretty early with it. (Mary's mom)

This spring, I'd say for the last 3 months, when she was in the hospital and when she was coming back it was probably every few days I was texting her. In the hospital it was probably close to daily, just kind of letting them know because they were all worried

about her and how things were going. And then planning to come back to school, I did stop in and visit and do a face-to-face visit with her teacher. But then, there again, I initiated that. (Lizzie's mom)

Teachers are very good at keeping us informed of any changes um and they let me know when they see changes or struggles that they are having. (Mary's mom)

***Managing information related to change in staff or managing the class.***

Communication in this area occurred most when any changes happened in the child's schedule, school personnel, or classroom schedule (such as class parties or field trips). Most obviously this happened at specific times on the academic calendar, such as change in grade, but also when a child changed schools or districts, or a new teacher or principal started.

They need to understand that the child can get tired during the day, that the child needs frequent snacks maybe or breaks. I mean, the whole school really needs to be involved. The PE teacher needs to make accommodations because of his port. The lunchroom staff needs to know that he's got to wash his hands before he eats and after eats and the lunch needs to be fresh when/if he's going through the lunch line. (Patrick's mom)

The teachers are very good at responding, knowing it's there. .... So when they brought in Christmas, her mom decided it was going to be a gluten-free Christmas party, and they made the whole room. ...So I think in the teacher had made sure all the parents were aware. And it wasn't done in a, you know, the teacher even communicated with the other parents in the class, um and she obviously came to me for my permission. (Mary's mom)

The teacher was very accommodating when I, one of the first days she went back to school they had a field trip to the capitol and to the zoo, and so I basically said she wants to go. I don't want her to miss it. I'm going to take her. And, of course, they were fine with that. And she went and she made it through the whole thing, she was pretty tired. But they just let me drive and things. And they had a field trip to Adventureland, which obviously she could not go to. So, we just kept her home. So those are example where we just kind of took case by case basis. (Lizzie's mom)

The one would be her athletic part. And probably the field trips. Have been the ones I have been the most disappointed with. Athletically, they might have snacks on the bus. Well freshmen, of course, serve the lowest level so if there was nothing left they didn't eat. Not realizing that after a big meet, she needs to eat. (Emily's mom)

Another way in which communication related to classroom management included information from the teachers, either to directly the parent of the child with chronic illness or to other parents in the class, which was necessary to make decisions in order to maintain the health

of the child with chronic illness. This communication did not always occur in a timely or helpful manner, according to the parents interviewed.

I wasn't always told exactly when other kids were sick. It was always after the fact, like for instance that one time, there was a child who they suspected had chicken pox, didn't know until Kevin had already played with him 3 days in a row, and the child ended up not coming to school having the diagnosis of chicken pox, which had exposed him for having chicken pox. And they told me after the fact they found out. (Kevin's mom)

I just wouldn't say that they understood the severity of it all. Like for example, the teacher mentioned to me after his first week back... Well, I will back up and say that after his first week he caught a cold. "Cause I went on and on how germs are such a big thing. And she did mention to the parents, I think through a newsletter, that if your child's sick. You know, please don't send them if they have a bad cold or at that time flu was still going around and Fifth's disease was going around in their classroom so she said you know all those things Patrick is very contagious. And she mentioned to me, kind of laughing, that a parent called and said that a child had been sick and should she keep them home? And the teacher said kind of laughed and "No, don't keep your child home, that child needs to be at school." And I was kind of taken back by that because I was like, no, if they parent thought enough to call and ask, then the child probably should be home because that child could probably recover in a day where as if Patrick gets sick it takes a long time. So, I just don't think they understand the severity that if he does get a cold then he ends up in the hospital or the flu or ...And, as I said, she told me that just kind of laughing, like I can't believe this parent called and asked and what a silly question. And I probably should have said something but I was just so taken back by her response. (Patrick's mom)

**Content of communication: teacher-related concerns.** Parents were also concerned about issues related to teacher knowledge, skills, and attitude. Teachers were seen to exhibit a range of knowledge, skills, and attitudes toward working with children with chronic illness through their communication with parents. Parents comments related to communication with teachers are divided into comments in each of these areas—teacher knowledge, skills, and attitude.

**Teacher knowledge.** Some teachers had more knowledge of diagnosis-related issues or how to support children with chronic illness than other educators. Parents also discussed issues related to other supportive personnel within the school system. Their primary and most clearly stated concern was overall lack of knowledge.

They were not prepared at all (to work with her). They were much more in tune with mental deficiencies than they were physical needs. (Susie's mom)

They knew nothing. They were not prepared at all. (Patrick's mom)

I said he has a life-threatening peanut allergy and he's got asthma. She said I don't know anything about that. And so that is my current experience is that I'm going to have to be a lot more assertive with the staff because if they're not reading the papers that I have to fill out for them then I don't know how to. (Bryan's mom)

I don't think they fully understood how life threatening or how difficult it would be for him, especially when there are other sick children. Even if it is just a cough or even if it is just a sniffle, they don't understand how life threatening something like that is towards him. And they just brush it off because kids go to school sick every day. (Kevin's mom)

When parents did discover a teacher with knowledge, it greatly increased their own comfort level. However, they still made sure to communicate. And communication was strongly related to continued positive relationships.

She totally understood what we were doing. And I did talk to the after-school program too, they were totally up with that too. (Justin's mom)

The main thing the teachers needed to do was make sure everything was clean and there was hand sanitizer, and the kids were washing their hands, that kind of thing. And they were all really good about it. (Caroline's mom)

I talked with the nurse in the office and I talked with her teacher. She asked me different questions, like is it airborne, what should we do, how should the medicine be taken. ... So, they now know that Amy shouldn't pet dogs even though she'll ask, because they said Amy specifically asked to pet the dog. No one asked her. She's like, "Can I pet the dog?" (Amy's mom)

Lastly, parents determined that they need to advocate for their children with chronic illness. When teachers exhibited a lack of knowledge, or a perceived lack of knowledge, parents



were the ones who needed to provide the necessary information. Parents worked with teachers, nurses, and principals at an individual and larger-system level in order to provide information related to medical, social, and cognitive needs for their child. Parents said they had to be prepared and could not rely on others to meet the needs of their child with chronic illness.

The school was really at a loss as to what to do. I would say I kind of took over...And the principal was just very open and honest. And the nurse as well. Saying, we don't know what to do. (Patrick's mom)

We did an orientation about Susie and her difficulties and some of her personality things with the teachers, the teaching assistant, and with her main classroom teacher because in this class they then leave the classroom for science social studies. (Susie's mom)  
Before this was diagnosed she was, she was struggling with (various symptoms)... Not feeling well which was just drooping her out. Now, with the diagnosis, working with her teachers to be able to understand what (her medical condition) is and what they can expect of her... (Mary's mom)

They were understanding but I think some of that, or prepared, was because I was really forthcoming with information. And I'm not sure if they would have pursued that if I hadn't really sent an email with a bunch of information or upcoming dates that we're going to be gone. I would give them maybe a week's notice that we're going to be gone and tell them ahead of time. I did even think to myself, if I didn't push, would they even have asked? And I don't know. (Lizzie's mom)

**Teacher skills.** Issues related to teacher skills frequently also connected to knowledge or attitude. Of course, the first issue was having the requisite skills related to working with a child with chronic illness. These skills may relate to understanding their medical or health-related issues, their academic or cognitive needs, or social/emotional or behavioral impacts of their chronic illness.

Communication could be better. Training could be better. I'm a teacher myself in a different district and we have very little training on epi-pens or on inhalers or any of those things. And the truth is, if a child has a reaction, it's not gonna be a school nurse giving that medicine, it's going to be whoever is right there. (Bryan's mom)

I do have to say her full time regular teacher who has her most of the day said to me, "When you go to the doctor, will you please bring me a list of what she can't do." She did directly ask me because Lizzie will ask to do things and, even though it seems like

this is obvious to everyone else, they felt like they were saying, “No, I don’t think you’re supposed to be doing that.” (Lizzie’s mom)

And one thing they did really well that I thought was nice, is that they even told all of the younger kids in the building, “Don’t run up and grab her or hug her.” Those things that these little kids might think, oh she’s here, she’s back, and they’re excited to see her. And so it’s sweet because they’re bring nice but don’t run over, or let her be at the back of the line so she’ snot getting bumped into. I think we did pretty good at trying to prevent that. (Lizzie’s mom)

A person with skill needed to have a commensurate level of knowledge to support the skill. A person who believed that had more skills than they had the knowledge to support was actually more concerning than a person who knew they did not have the skills to intervene.

They are never good at providing someone for her. Have a history of not providing a replacement for her (*supervision of medical needs*). The secretaries seem to think they can take care of it and the secretaries, I think, are the ones they have kind of backed off and kind off they have not attempted to do anything for Susie and I am quite happy with that. (Susie’s mom)

Similarly, with attitude, the person with skills had to be willing to apply the skills if the situation necessitated. Teachers who actively participated in making suggestions, making accommodations, or adapting the environment or situation to assist the child with chronic illness in managing their health while meeting other goals, academic, social, or behavioral, were also highly regarded by parents.

We had one teacher one year that was willing to have this separate epi-pen and Benadryl and inhaler in her classroom. And it was frowned upon, but she said I have done it before, I’m just gonna do it. I’m not even sure if the office knew we were doing that but it made me feel so much better that whole year knowing she’s taking it seriously, it’s in her room, he has it if he needs it. (Bryan’s mom)

And the teachers will just...well, with these last conferences they were wondering instead of having class time taken away by going to the nurse, having her gone for half hour, if she could have everything with her. So, she could run out to her locker, grab a juice, come sit down, still participate in class, and come up at the same time. So, we had a big conversation with the principal for that area and with the nurse and with the teachers and they all realized that it probably would work best to do that. (Emily’s mom)

**Teacher attitude.** While comments on teacher knowledge and skills were mixed, the comments on teacher attitude were overwhelmingly positive. While parents might not have believed or trusted the abilities of their child's teachers, they believed that the teachers had good intentions related to willingness to learn, to help, or to be supportive of their child with chronic illness, whether overall or related to a specific need.

I don't think that they have had kids with all the different things, they have had kids with each one of her things but not all together put into one. But they are very, very willing to learn. (Susie's mom)

Our school nurse hasn't dealt with it, our principal hasn't. You know, no one's really dealt with it so they don't *know* ... what to do. Our principal is awesome. He said I don't know. So if I'm asking stupid questions or doing stupid things, just tell me. And he's very open to whatever. So that's him—at back to school night. So that I could say, "Hey, that was really silly what you did or what you said." And he would be fine with that. (Patrick's mom)

They were willing to bring her work to her if I wasn't at school that day... there was days she wasn't going to have her work because she was tired or didn't feel like it. And they understood that. So, they didn't penalize her or anything, they just let her catchup and get her work done as she could. (Caroline's mom)

Willingness to work with her if she needed extra help. They were more than happy to help her. Or they would come to the house and help her. (Caroline's mom)

They are just supportive. Very, very supportive of her. They never question her on things. Like if she says she has to test or to do anything, they don't question it. They know that she is not lying. (Emily's mom)

And for the most part over the past 4-5 years they have been really understanding about appointments. There was really only a couple of times, I remember one time she had a teacher who kind of didn't understand why she was going to miss part of the day. I suppose maybe they had something important going on in class. (Lizzie's mom)

While the majority of parent comments about teacher attitude was positive, there were instances that indicated a negative, or at least less-open, attitude toward having the child with chronic illness in the classroom. Parents tended to be less direct in labeling attitudes than lack of knowledge or skill, and appeared willing to give teachers credit for attitudes that may be based on lack of knowledge rather than simply a direct reflection of internal standards or values.

Some teachers have been more receptive to understanding some of the needs and some have been a little bit more I don't want to say resistant but some of them don't

necessarily understand and so or they have misinformation themselves and they are not always as open to understanding some of the new information. (Mary's mom)

### **Overall Valence of Communication**

The third primary theme related to the overall valence of the communication. There were 101 comments related to communication. Comments related to communication were rated as positive (i.e. the school is good about calling me), negative (i.e. teachers were not open to new information), or neutral (i.e. preferred method of communication identified as email or phone).

Further analysis was done based on A-IIRS score. With a range of 14 to 70, the mean A-IIRS score was 38.1 and the median score was 39.5. One parent reported an A-IIRS score of 70 (a "perfect" score), which would indicate a high degree of impact on the family related to the child's chronic illness. The majority of the parents rated an A-IIRS score in the mid-range, indicating a moderate impact on the family related to the child's chronic illness. This includes six parents who reported A-IIRS scores between 37 and 42, indicating a moderate impact on the family related to the child's chronic illness. Two parents reported scores indicating low mid-moderate impact, with A-IIRs scores of 28. With an A-IIRS score of 14, one parent indicated a score which would indicate an impact in the low range for the family related to the child's chronic illness.

**Positive.** The majority of comments were positive, with 45.55% of all communication-related comments rated as positive. All ten parents made positive comments related to communication at some point during the interview. Eight of the ten parents made multiple positive comments, with each making comments in more than one area.

The parent with the highest A-IIRS score scored a 70. She tied for highest number of positive comments, at eight comments, as well as highest total number of communication-related comments, at 15. The other parent with eight positive comments had an A-IIRS score of 42, a

moderate score. The parents who made the fewest positive comments, either one or two comments, had A-IIRS scores of 28, 40, 41, and 42 (all in the range of moderate impact). Making five or six comments were parents with scores of 14, 28, 37, and 39 (ranging from low to moderate impact).

Their teachers are very good at keeping us informed of any changes. (Mary's mom, A-IIRS 42)

The teachers have been really good when I go in for conferences. (Emily's mom, A-IIRS 40)

I think in our particular school they do a very good job with parent contact in general. So, I think we are lucky, I mean they really care about the kids and the students and anytime I had any sort of, anytime I had any sort of issue or question or concern, they always responded immediately, wither it was the teacher or the after school program or administration. (Justin's mom, A-IIRS 14)

I do have to say her full-time regular teacher who has her most of the day said to me, "When you go to the doctor, will you please bring me a list of what she can't do." (Lizzie's mom, A-IIRS 41)

She has difficulty with those, but the teachers are very helpful they do understand and they care. There are times when I send a note back saying you know she is just so tired last night that we didn't get the homework done and the teachers are understanding about that. (Susie's mom, A-IIRS 70)

Willingness to work with her if she needed extra help. They were more than happy to help her. Or they would come to the house and help her. (Caroline's mom, A-IIRS 39)

They met the needs of keeping the classroom clean. And when I would go in for school parties it seemed clean. They always called me when other children in the school had pneumonia or stuff like that. (Kevin's mom, A-IIRS 37)

**Negative.** Negative comments were less common, with only 13.86% of communication comments rated as negative. Six of the ten parents made negatively-related comments, with two of these only making one negative comment and another pertaining all negative comments to one area of communication.

The highest number of negative comments was made by the parent with an A-IIRS score of 28 (low moderate impact), who tied for the second lowest score, and who again tied for highest number of total communication-related comments. She had an almost equal number of positive, negative, and neutral comments. Making either two or three negative comments related to communication were parents with A-IIRS scores of 28, 37, and 42 (low-moderate to moderate impact). Two parents made only one negative comment. They had A-IIRS scores of 14 and 41 (low and moderate impact). The four parents who made no negative comments related to communication had A-IIRS scores of 39, 40, 42, and 70 (ranging from moderate to high impact).

And then I get a phone call and I'm like "Oh no, you're the worst parent ever." Do the teachers think I'm not doing my job? When I get that phone call, "Amy's not feeling well." And what I feel like they're saying...I mean, they are really nice, but in the back of their heads I know they're thinking, "I know you saw what she looked like this morning and you sent her to school this way?" It's like a lot of thought went into this, do I want her to miss another day of school? She has missed so many days. (Amy's mom, A-IIRS 28)

And so that is my current experience is that I'm going to have to be a lot more assertive with the staff because if they're not reading the papers that I have to fill out for them then I don't know how to (communicate clearer), you know what I mean. (Bryan's mom, A-IIRS 28)

Figure out the left-handed kid needs left handed scissors before you tell me she can't cut. (Mary's mom, A-IIRS 42)

Some have been a little bit more I don't want to say resistant but some of them don't necessarily understand and so or they have misinformation themselves and they are not always as open to understanding some of the new information even as we um as a better understanding of whether it is ADD or Celica's or some of these things. Some of the older teachers aren't necessarily as open to learning new ways or necessarily incorporating new ways in um but for the most part we have been very, they have been very, I think to the best of their abilities, worked to try to help make um it as best they can for her. (Mary's mom, A-IIRS 42)

I still don't think they take it seriously enough...Some years he has a peanut-free classroom officially and they put a sign up and they take it very seriously and they communicate to parents. And other years the teacher doesn't even seem to know when I arrive for back to school night that he has serious allergies and asthma. So, it is, it's just

a hit or miss, probably depending on the teacher's personality and the office's craziness. (Bryan's mom, A-IIRS 28)

I wasn't always told exactly when other kids were sick. (Kevin's mom, A-IIRS 37)

**Neutral comments.** The number of neutral comments was similar to the number of positive comments, with 41.58% of comments related to communication being neutral. Neutral comments were primarily about either the process of communication or content related to basic factual information about school participation. Again, all ten parents made neutral comments and each made multiple comments. One parent pertained all of her comments within one area of communication.

The highest number of neutral comments, at seven, was made by one of the parents who tied for the highest number of positive comments, and who had an A-IIRS score of 70 (high impact). The next most frequent, with five to six neutral communication related comments, were parents with A-IIRS scores 14, 28, and 39 (low, low-moderate, and moderate impact). Several parents made either three to four comments related to communication, and they had A-IIRS scores of 28, 37, 40, 41, and 42 (low moderate to moderate impact). The parent who made the fewest total communication-related comments, with four, also made the fewest neutral comments related to communication, with only two, and had an A-IIRS score of 42 (moderate impact).

Another thing that probably speaks of our modern communication is I was texting with her teacher. I would text her updates and communicate. (Lizzie's mom, A-IIRS 41)

But every time there's a field trip, when I sign the permission slip, I say please bring this, this, and this with him. And the morning of, I do email them a reminder (Bryan's mom, A-IIRS 28)

### **Summary of Findings for Research Sub-Question a: How do Parents of Children with Chronic Illness Expect and/or Prefer to Communicate with Their Child's Teacher?**

There were three main results identified by parents related to their expectations or preference for communication with their child's teacher. These results were associated with process of communication (method and timing), content of communication (child-related issues and teacher-related concerns), and overall valence of communication. Communication is a foundational issue to any relationship and these findings lay the groundwork. Through communication, parents are enhanced or limited in all other aspects of the relationship, including their ability to discuss expectations for their child with chronic illness (research sub-question b) or request support they believe should be provided for their child with chronic illness (research sub-question c).

### **Research Sub-Question b: What Academic and Social Expectations do Parents of Children with Chronic Illness Have for Their Child?**

The second sub-question explored expectations parents have for their children, particularly academic and social expectations (See Table 4). Themes were found in each area of development detailed in the concept map: physical, social, behavioral, and cognitive. Within physical development, themes focused on physical activity, pain and symptom management, and school participation. Within social and emotional development, themes focused on peers and social relationships, self-esteem, and emotional support. While not a specific developmental area, behavior was a major area of concern for parents, and therefore specifically detailed. Major themes related to behavior focused on concentration, self-regulation, and independence. Within the area of cognitive development, themes focused on two main areas: abilities or aptitude and overall achievement or outcomes.



Table 4

*Research Sub-Question b: Summary of Parental Expectations Themes*

Primary Theme	Secondary Themes	Tertiary Themes
Physical Development	Physical activity	Abilities/activities Environment
	Pain and symptom management	Staff knowledge Medical equipment Schedule/timing Dietary issues
	School participation	Attendance Participation
Social and Emotional Development	Peer and social relationships	Knowledge provided Peer awareness of differences Parents
	Self-esteem	Self-confidence Self-consciousness/fear/embarrassment
	Emotional support	
Behavioral	Concentration	Self-expectation Teacher-expectation
	Self-regulation Independence	
Cognitive	Ability/aptitude Achievement	

**Physical Development**

Physical development was most often the obvious, direct, and most clearly recognized area of developmental impact for a child with a chronic illness. Impacts within physical development, or health-related outcomes, may have an impact on all other areas of development.

Physical impact was also the area most likely to include mention of PCPs and a wide range of other professionals, both within the education field and across other disciplines, involved in managing the child's chronic illness.

**Physical activity.** Physical activity was limited by factors related to the child's health and environmental factors. According to parent report, some of these factors were more within the control of the parent or family and others were out of their control and were within the purview of the teacher or school. Parents expressed considerable concern about issues they felt were not within their control.

**Abilities/activities.** Children with chronic illness were most limited in their ability to participate in physical activities, such as recess or physical education class. Timing of return-to-school after a medical event, appointment, or treatment were necessary to take into account. Sometimes children with chronic illness required interventions at school, in order to be able to participate.

If he played at recess too much or if he played gym in the after-school program for a long time he started having more and more problems with the asthma, so he would have to use the inhaler while he was at school. (Justin's mom)

She only 5 weeks left or 6 weeks left of school when she went back but there wasn't a lot of accommodations in terms of what she could do, because she can't do anything physical like for PE, recess. (Lizzie's mom)

**Environment.** When discussing the ability of the child to participate, parents expressed the importance of managing the environment, when possible. Cleanliness of the environment was a vital issue for many parents, and seen as within the control of the school. However, it was also an issue which several parents commented that was not always taken seriously.

She was a strong student, so I guess the main thing the teachers needed to do was make sure everything was clean and there was hand sanitizer, and the kids were washing their hands, that kind of thing. (Caroline's mom)

This first week he caught a cold. “Cause I went on and on how germs are such a big thing. And she did mention to the parents, I think through a newsletter, that if your child’s sick. (Patrick’s mom)

Related to environmental cleanliness was environmental safety, as related to contamination from other substances which were a danger to the child. Several of the children had severe allergies, one having had a previous anaphylactic reaction, and another needed to avoid all contact with gluten (even physical contact by skin). Parents had a variety of reactions to the safety of their child’s environment related to these various contaminants.

He doesn’t get to eat any baked good that someone else makes unless I really know them and know that nothing’s been contaminated. (Bryan’s mom)

One of the biggest ones is with the Celiac’s she cannot have or come in contact with any gluten which would be wheat, barley, rye which means that um any treats that come into the classroom any foods that she would consume, even play-dough, anything that she is going to have on her hands that could come into contact like with her mouth um there needs to be either one if she’s going to be doing play-dough or a dough that’s an in-class manipulative she would have to make sure that her area was covered or she would need to wash her hands immediately afterward she you know just or in terms of that but if it’s food wise she needs to have a special diet. (Mary’s mom)

They had an Autism Awareness day back in April and they let the kids pet the dogs that they brought. And she’s like petting it and rubbing it even though we talked about this and the allergies came up. (Amy’s mom)

Other environmental factors such as stairs in the building or weather were also factors impacting the child’s ability to fully function within their school environment. These were factors which neither the parent nor the school could control.

We were a little worried about PE and there’s a lot of steps at our school so just getting around physically because it took a while to get his strength back up, but he did ok in the short time that he was there. (Patrick’s mom)

In the spring and fall when the temperatures and the allergens are different, he has more trouble breathing. (Bryan’s mom)

**Pain and symptom management.** Pain and symptom management was the theme with the clearest connection to the child’s chronic health related issues, whether they were visible or not. This was also the area with the most direct impact of staff in areas outside of their area of primary training and comfort. Managing the child’s pain and other symptoms impacted their ability to participate in school, interact with their peers, and make academic progress. Consistent with the literature, parents expressed expectations related to the teacher’s knowledge, willingness, and ability to meet their child’s medical needs within the educational setting. Overall, the parents wanted their child with a chronic illness to be treated as child—as a normal, typically-developing child.

One of the things we try to stress is that, yes, she has all these medical needs and she has to be taken care of her health, but she also has to be a kid. Our expectations are for her to be as normal as possible. Therefore, if she does not get her work done, other kids have to stay after and do their work. (Justin’s mom)

**Staff knowledge.** Parents expressed appreciation when they were requested to provide additional information or clarification related to their child’s illness, medication, or special needs. They did not resent being questioned but saw it as a sign that another person cared about the needs of their child and was taking the medical situation seriously.

I do know that they have their own specific form for allergy-specific. I was given one by her allergist, but they wanted them to fill out a more specific form that all the nurses in the district are familiar with to get information. I like that—that they had a specific form. (Amy’s mom)

They recently hired a nurse. I believe she’s part time. And before I don’t even know what they did, but they did not have that formal position. So this year was the first time anybody ever looked through my medicines and I had forgotten to send Benadryl, which usually I am very careful at the beginning of the year. And she actually called me and said, “We don’t have what you’re supposed to have.” So that led me to believe that all those other years probably no one was looking at my stuff and reading everything I had written and double checking me. And I *love* the quality control. I was so excited that someone was actually paying attention that Bryan needs this available and we have to have it and so I believe they’re getting better. (Bryan’s mom)

**Medical equipment.** In order to attend and participate in school, some children with chronic illness required access to medicine or medical equipment during the school day. This required a variety of accommodations from the school, such as space to store the equipment but also someone to assist the child in making proper decision in properly utilizing the equipment.

We went through a two-month period where I had him use the nebulizer before he went to school to kind of prevent, that had been recommended by the doctors, then I told Justin if he needed to use it during the day, before P.E. or before recess, to use it then instead of waiting until it got bad enough cause I also did not want to scare the teacher. (Justin's mom)

**Schedule/timing.** Part of monitoring a child's chronic illness may also be keeping them on a schedule with medications, diet, and other necessary functions. As children spend seven to eight hours a day at school, parents expect that teachers have responsibility for assisting their child with a chronic illness with monitoring their scheduled needs. Some of these needs were very specific and included documentation from PCPs and others were modifications of daily school schedule, such as transition time between classes.

They have needed a modified schedule in terms of being able to, like with the urologic issues, being to work with some of how to help her be able to be successful and not have accidents but also if she does be able to not have peer ramifications as those. (Mary's mom)

Her pediatric urologist has letter that goes to her teachers that asks them that would rather than waiting for Mary to have the urgency to need to go to the bathroom they would release her at very specific times, say its ten o'clock, ten, say basically she needs to be told to go so to be able help keep her system um managed and not wait for her to manage it. Because she's not yet to that point. (Mary's mom)

And they do give her time between classes if she needs extra time. They allow her to have juice and extra snacks in her locker, instead of trying to go all the way back to the nurse's office first. So she's allowed to do that. And she's allowed to test at any time that she needs to. (Emily's mom)

***Dietary issues.*** One of the final issues of monitoring where parents expressed an expectation for assistance from teachers was in the area of diet. Children eat at least one meal (lunch) at school and are often exposed to many other food related issues—snacks, birthday parties, etc. There are also concerns related to materials in the classroom which may be made of food-related substances.

With the celiac she cannot have or come in contact with any gluten which would be wheat, barley, rye which means that any treats that come into the classroom any foods that she would consume, even play-dough, anything that she is going to have on her hands that could come into contact like with her mouth there needs to be either one if she's going to be doing play-dough or a dough that's an in-class manipulative she would have to make sure that her area was covered or she would need to wash her hands immediately afterward she you know just or in terms of that but if it's food wise she needs to have a special diet. (Mary's mom)

I think it needs to start with the teacher, that they need to understand that the child can get tired during the day, that the child needs frequent snacks maybe or breaks. I mean, the whole school really needs to be involved. The PE teacher needs to make accommodations because of his port. The lunchroom staff needs to know that he's got to wash his hands before he eats and after eats and the lunch needs to be fresh when/if he's going through the lunch line. (Patrick's mom)

**School participation.** One of the areas parents had the most direct and specific expectations was in the area of school attendance. Parents wanted their child to both be able to attend school and to be able to actively participate in school activities.

***Attendance.*** Attendance was a specific and widely-varied issue. Physical and emotional issues had an impact on school attendance. Health issues of the child with chronic issue themselves were important but also health of the other children in the classroom could directly impact attendance. Attendance concerns were short-term (an appointment for an afternoon) and on-going (hospital stays, regular illness).

She was able to be at school more than we had expected. The first year she was in the hospital a few times for treatment but other than that she was able to attend school the majority of the time. (Caroline's mom)

Through the past 4 years our biggest thing is she was pulled out of school for appointments. So she had various days that she lost time at school just to go to appointments even. (Lizzie's mom)

He was at school he was missing weeks out of a month. Maybe he would go one maybe two weeks out of a month. And it was getting to where it was really not worth him going. (Kevin's mom)

**Participation.** When attending school, the child with chronic illness was not always able to fully participate in all parts of the school day. Parents expressed concern about activities that required more energy or concentration. They expected that to attend for a full-day was sometimes more than their child was able to fully participate in, based on ability level. Alternatively, children had so many extra demands on their time that they were not able to participate fully in school or family activities.

Like in P.E., and I didn't even worry as much about that and then when I found out that he really was not participating that much in P.E., then that kind of concerned me, because he needs to do that, I mean, he is required to, and I don't want him to just sit out so that's when I had suggested that he needed to use it as a preventative right before he went there and so that he could keep participating so it wouldn't keep him from other things. (Justin's mom)

But I think they were days she was a little aimless once she got homework finished. What do I do with this time? You know, because she's left out of an activity. (Lizzie's mom)

There are nights when she has no play time or release. Fourth grade is demanding homework wise. And then the next day as the week goes on she is struggling harder which then gets her overtired, cause then she is not sleeping at night so then we end up with this roller coaster kind of thing, so I am not sure that we found a perfect balance. (Mary's mom)

## **Social and Emotional Development**

Social and emotional development issues were least likely to be connected directly to an intervention. Peers are an increasingly essential relationship context during this time in a child's life. Parents indicated concern about the impact that having a chronic illness may have on the

development of these peer relationships. While parents stated specific concerns and expectations for their child, they communicated the least likelihood to intervene in this area.

**Peer and social relationships.** Parents wanted their children with chronic illness to have friends. They wanted them to be included in activities in school, in extra-curricular activities, and in other ways that typically-developing children interact with other children. They also regularly expressed that having friends and “being normal” was something their children wanted.

He wants to be able to run around and play like all the other boys and girls but, well, you know. (Justin’s mom)

**Knowledge.** An important way to help their child with chronic illness to be accepted and to normalize relationships with peers was to dispel misperceptions and myths which could lead to fear or avoidance, even bullying. Some parents did this through directly to teachers in parent-teacher conferences or to administrators. One parent went directly to the source, and spoke to her child’s peers to provide information and answer questions.

I went in and I spoke the preschoolers because not that really many of them understood. And I explained to them that Kevin is sick and explained why he is sick and explained what cancer blood looks like versus what regular blood looks like using like red hots, and marshmallows, and skittles to make up the blood. (Kevin’s mom)

**Peer awareness of differences (positive).** Peer knowledge about the child’s chronic illness was seen as important. However, more than the knowledge, the awareness and actual response of the peers to those differences, both health as well as necessary accommodations, were the most impactful to peer relationships. Parents expressed situations in which peer awareness of differences had been positive or, at minimum, had not created any further barriers for their child with chronic illness. Unfortunately, not all peer responses were constructive. Some varied, year-to-year, and others changed as new children joined the class and as friendships shifted.



I think that we are very lucky that she can verbalize. She can verbalize very well, so at this point it has not affected her socially. She has never been at a point where her peers were ever aware of the accidents that she was having at school. (Mary's mom)

And explain that she doesn't have the same filtration system why she eats differently and why she has to be careful if they are playing outside or in gym and just messing around, she has to be careful about not having something pressure against her chest and um so the kids but the kids have accepted her. I would say that the kids here have accepted her much more if they see her at Wal-Mart, they will come up to her and say hi Susie and start to talk to her. (Susie's mom)

The following is an example of a peer response which varied across time. Peer response (where to sit or with whom) may not have fully been within the control of the children, as it may have been dictated by school policy in some settings.

He has to sit at the peanut free table, which is very embarrassing to him. And in different years of his life sometimes a friend will join him who is not allergic, and sometimes he's eaten from kids from entirely different grades, which is also not very socially normal for him. So, there was a time, I think when he was in 3<sup>rd</sup> grade, when he was eating with kindergarteners with peanut allergies. And it just made me sad that that is your free time and you're not even with peers. (Bryan's mom)

Here a parent shared an example of a new classmate who changed the peer dynamic.

According to the description, this one child changed the peer interactions within the classroom for her daughter for several years. According to the parent, it was a misunderstanding, based on health accommodations.

When she got to about 3<sup>rd</sup> grade, and a new girl came, and then she started telling the other kids that Caroline could do whatever she wanted because she had cancer. But the kids never thought one thing about it. They were very supportive, and throughout the whole thing until that one... And now they're friends, they've gotten through it. But it was a rough couple of years to get through that but, I mean, for the most part it was fine. (Caroline's mom)

**Parents.** According to the parents of the children with chronic illness, it is not only the peers that need to be aware and understand, but also the parents of their peers. If the parents of the other children in the class are not knowledgeable, comfortable, or open to adapting or making

the environment safe for the child with chronic illness, peer relationships are more difficult to facilitate. Some parents were noted to be less open than their children.

I do see some parents aren't as willing to take her because they're afraid of what could happen. So you have some that are a little bit leery of that. You do have some kids that are real inquisitive. What's this? How's this? (Emily's mom)

**Self-esteem.** The continued development of self-esteem is a key issue for school-age children. Relationships with peers are a primary context in which aspects of self-esteem are explored and fostered. Parents expressed expectations related to their child and peers related to the impact on the self-esteem of the child with chronic illness.

**Self-confidence.** The child with chronic illness often had to deal with being different from peers, whether this difference was physically-visible or not. Parents expressed concern but also pride connected to when their child appeared to deal with stressors to their sense of self in a positive manner.

I think that there are times when it pulls on her self-confidence. But at this point, I haven't seen it become it hasn't become, she'll have periods of time with it but it has not become overwhelming part of her life. (Mary's mom)

She really has the attitude that God gave this to her for a reason. She never uses it as a crutch. I can't say never, but more times than not, won't. She'll go out of her way to educate than to deny it. It's part of who she is. (Emily's mom)

**Self-consciousness/fear/embarrassment.** Alternatively, and more frequently, parents expressed concern related to their child's sense of self-esteem. Parents most often related impact on the self-esteem of children with chronic illness to their visible physical differences or limitations or to the child's concern about being different from peers. Often there is an overlap between these two issues—the child is embarrassed about being different. The comments are, therefore, difficult to separate.

Some comments related to physical differences or limitations include:

It's very embarrassing to him so it does affect him when they're running the mile and when they're doing a lot of physical activities. (Bryan's mom)

He was scared too when it happened, when he has an asthma attack, he is really scared too so you know that why I wanted to come up with ways to prevent it beforehand so that he doesn't get to that point. Because he's kind of a sensitive kid so like if something like that happened during gym and he had an asthma attack and then he couldn't play or something especially if some of the kids made fun of him or something he would really take that to heart. (Justin's mom)

Some comments related to concern with being different include:

But the other kids at school, everyone is old enough now to start noticing that his glasses look different than everyone else's and so like it hurts if his feelings, he was telling me this morning, it hurts his feelings when kids say that his glasses are cracked and he has to keep explaining to them that they are not cracked that they are bifocals and that is the way they are supposed to be but that is something that bothers him so if he had more issues that prevented him from participating with other kids, I know that would be something that really, he would really take that to heart and that would bother him. (Justin's mom)

He is starting to get more self-conscious about because he's getting older. (Justin's mom)

He's embarrassed to tell the PE teacher if he needs his inhaler. He used his nebulizer once at school during the recess and that was several years ago and he's still traumatized that the other children would see him looking different. So he does not want to be different with anything. At parties I will send a separate snack for him but he usually doesn't eat anything because he's too embarrassed to have a snack that looks different. (Bryan's mom)

**Peer response.** As peer relationships are the context in which self-esteem is developing, peer response is an essential component. While not total, overall, parents reported higher levels of positive support and understanding among peers. Parents reported few examples of negative peer response, and those reported appeared to relate more to perception of the child with chronic illness than overt action of the peer, as with the first comment below.

Even when she would wear her brace to school sometimes, I wish I... I think she felt different in it. So she would, no I'll just do my night thing. But she tried it a few times and most of them were all, I think, they were just supportive. (Lizzie's mom)

She'd get her treatments on Fridays so she'd miss all morning and when she'd come to school, they would be excited she was back. And that made her feel pretty good. (Caroline's mom)

They were so excited to see her and they were so welcoming and they were doing everything ok on that end. She was still so afraid of what people would think, how they would treat her just getting back in that routine. So, it's just kind of that level of mild depression really, just trying to get back into a normal. (Lizzie's mom)

**Emotional support.** In the area of social and emotional development, parents identified emotional support as an area where schools and teachers could do more to assist children, both the child with chronic illness as well as their peers. With emotional support, parents felt that there would have been fewer negative incidents within peer relationships and healthier self-esteem.

One thing that would have been nice to have is a counselor maybe at school. Maybe to, for her, but also for the other kids to understand... But I guess in the situation where this one girl came and started that stuff, you know, helping the kids understand that it wasn't her choice. (Caroline's mom)

For the most part, for most of his life, he has been such a strong stoic boy about anything medical. But the older he gets, the more dramatic he gets. I think sometimes it becomes a question of, is this asthma or is this laziness? And, do you really need a breathing treatment or are you trying to get out of the run that your brother and I are doing? So I just think some of that plays into, are we going to manipulate the medical information or are we going to continue to be that great stoic kid that perseveres and does everything well? (Bryan's mom)

## **Behavior**

While not directly an area of development, behavior is connected to physical development and health, social and emotional development, and cognitive development and abilities. Parents clearly expressed expectations, as well as concerns, for their child with chronic illness related to behavior within in the classroom, in social situations, at home, and related to completing expected academic tasks. Behavior of the child with chronic illness, as addressed by

their parents, was specifically impacted by the child's ability to concentrate, self-regulate, and be independent.

**Concentration.** The ability to focus, or stay on-task, was indicated as a concern by several parents. For some of the children with chronic illness, it was related more directly to a primary diagnosis, such as ADHD, and for others it was an effect of medications or response to the need for medication, having low blood sugar.

**Self-expectation.** Parents first expressed a direct concern about the child's own ability to recognize if their difficulty concentrating was related to their chronic illness or to situations impacting their concentration.

She does struggle with the fact: I can't focus, I know I should be able to, I can't eat that and they can eat it. There are days when the food comes in and Mary looks at it and knows I can't eat that. And it's, you know, just in terms of being able to focus on her work, and not sitting in for recess because she can't get the assignment completed. (Mary's mom)

She'll miss something that she shows she knew. And then she's gets really mad. But if she's in a really good range, it's not as hard for her to make the connections. If you're in a high or a low (*blood sugar*), sometimes the connections aren't there and you have to think a little bit harder or go round and round. Is this right? You're not quite sure what's going on. (Emily's mom)

If she's in a low (*blood sugar*), her mind is foggy so she isn't able to participate quite as clearly. If she's in a high that puts her more in an anger type of, she gets kind of antsy, very agitated. (Emily's mom)

**Teacher-expectation.** Parents also considered it essential for teachers to both recognize and understand when the child's ability to concentrate was being impacted by their chronic illness, whether it was pain, a need for medication, or another issue. Parents next expressed that teachers needed to know how to appropriately address any potential medical issue and then to understand if other accommodations were needed and, if so, when and how to implement them.

Sometimes they'll just call me or they'll just see how she does but their expectations get a little bit lower when allergies are really bad because it's just really hard for her to concentrate. (Amy's mom)

I can give you all kinds of philosophy but that philosophy is not gonna be something I can actually translate into, 'Okay, I know this child can't focus.' I think we need more strategies. (Mary's mom)

**Self-regulation.** Related to concentration is the ability to self-regulate, or monitor and control behavior in a given situation. Children are expected to make many decisions each day and for a child with chronic illness, these decisions become more complex and the consequences may be more immediate and potentially more severe. Parents expressed strong feelings about the choices and the ability that children with chronic illness have to make good choices consistently.

A kid with ADD that the medicine isn't going to cure ADD, it's going to give them the ability to bring their game, their brain into the game that day but that child has to choose to make good choices. The medicine isn't going to make them. You are never going to get the ADD kid to quit the compulsive behaviors. (Mary's mom)

They've always brought they're lunches but in middle school you can pick ala carte items and he's been very, very good about resisting temptation and not doing things he shouldn't but that will be a whole new ballgame. You know if everybody's having muffins that day, that's gonna be a whole new thing for him. A whole new set of peer pressure. (Bryan's mom)

**Independence.** As children with chronic illness get older, they make more decisions on their own and become more independent. Parents expect that as their child with chronic illness is spending more time away from their parents, in school, with peers, participating in various sports and activities, they will need to take more responsibility for managing their own health.

He's come a long way on his own handling of this. He's getting much better at that. (Bryan's mom)

I've really started going at it from the angle of training him of knowing what to look for in himself so that the teacher didn't have to do anything and so he hopefully won't have to use it in class but his teacher was very responsive and she helped us with it and that situation (Justin's mom)

I also feel good to know that he is old enough to use the inhaler. I don't know if they would be able to use the nebulizer. (Justin's mom)

## **Cognitive Development**

While all areas of development are inter-related, cognitive development may be the area of development with the most obvious impact on outcomes for any child as a student, and certainly for the child with chronic illness as a student. Within cognitive development, parents were concerned about the impact of the chronic illness on both their child's ability to learn, or their aptitude, as well as their overall learning outcomes, or achievement. As parents focused on outcomes, they were concerned about academic progress, school participation, and social growth and experiences. School participation was discussed previously, under physical development, and social growth and experiences were discussed previously under social and emotional development.

**Ability/aptitude.** Parents had a range of expectations for their child with chronic illness related to ability to learn. One parent was clearly frustrated about the results of the education testing which had been performed. She did not believe her child's cognitive abilities were appropriately represented. The parent was not sure what other resources were available to her in this situation.

One of them is people think she is dumb because she doesn't speak. She doesn't speak; she doesn't speak clearly, but she understands. Some of the testing that has been done, they have listed her as mildly to moderately retarded. And I will not believe that, I will not believe that because of how quickly she picks it up not everything but some things. (Susie's mom)

Parents also expressed the need to balance academic goals with health goals. Parents indicated the importance of knowing the child's overall abilities and creating expectations which were beneficial to the child's long-term needs and not based on the educational system's

standards. Parents spoke about the need for life skills versus higher level math or science, for example.

Let's work on one step at a time and, as the adults, we forget to take in the health care needs. I think she more so because they are not necessarily, I don't want to say because they are not what you consider severe or as obvious, these are internal health care things. They are not ones like kids who have you know who may need, who are wheelchair bound or more obvious overt health care needs. Hers are a little more internal, a little more easily hidden, and you can forget about them. That I think she runs the other end and it's not that people under expect for her, it's almost that we put it so high that we forget to make accommodations. (Mary's mom)

One of thing we have noticed is that some simple math, 6<sup>th</sup> grade she should be able to do simple math. It's like a foreign language to her but then all of sudden not very long ago it was like a light bulb went on about addition. (Susie's mom)

I would like to see for instance instead of some of the science, in some of those areas where it's just so over her head to be able to teach her more of a life skill. I just don't think they are prepared to teach the life skills. (Susie's mom)

Finally, there were a few students which did not appear to have any noticeable impact on their cognitive abilities or academic outcomes, according to parents. These children were generally doing well throughout the illness and treatment.

Because she works really well independently and is able to navigate through the material, and they did offer if she needed some extra help with math or whatever to let them know. (Lizzie's mom)

**Achievement.** Parents also has expectations about their child's ability to achieve, or perform successfully in academic settings. Parents expressed concern at how their child's chronic illness may impact the expectations, or standards, to which their child was held. There were both positive and negative ramifications to having the chronic illness impact expectations related to achievement. Overall, parents wanted academic standards to be as "normal" as possible, with accommodations for health only.

We weren't sure if he was going to have to repeat school again because he had missed so much but when he entered school the teacher said he really did fine. She said you



wouldn't have known, had you not known the situation, that he had not really missed all of that schooling. So, he stepped right in. (Patrick's mom)

Academically she's done really well so I think she's really able, even if she's out a day or so, here and there, she's able to keep caught up. And we would take work with us even so that maybe she could work on some of it in the car or whatever. (Lizzie's mom)

We encouraged there should be the same expectations she should have to turn in her homework. In the past they were just glad if she brought it back. I don't think they ever corrected it. (Susie's mom)

### **Summary of Findings for Research Sub-Question b: What Academic and Social Expectations do Parents of Children with Chronic Illness Have for Their Child?**

The second sub-question focused on parents' expectations for their child with chronic illness. The themes identified related to parent's expectations for their child with chronic illness in each area of development identified on the concept map. The results were associated with physical development (physical activity, pain and symptom management, and school participation), social and emotional development (peer and social relationships, self-esteem, and emotional support), behavior (concentration, self-regulation, and independence), and cognitive development (aptitude/ability and achievement). Through each of these areas, as parents expressed their expectations for their child with chronic illness, they often opened the door to discussion of the supports which either are or which they believe should be provided for their child with chronic illness (research sub-question c).

### **Research Sub-Question c: What Supports do Parents of Children with Chronic Illness Perceive Are and/or Should Be Available at School?**

The third sub-question explored the supports parents both perceived were and those they believed should be available for their child with chronic illness at school (See Table 5). Again, themes related to each area of development detailed on the concept map: physical, social, behavioral, and cognitive. With physical development, themes focused on participation and

medical treatments. Within social and emotional development, themes focused on peer interactions, self-esteem, and emotional support. Again, behavior was included, and themes focused on self-care and independence. Within the area of cognitive development, themes focused on supporting academic outcomes, IEP or 504 plans, home schooling or tutors, and the need for or impact of extra work. A final area of support was advocacy. Parents perceived the need for advocacy related to issues of awareness and preparation for working with their child with a chronic illness.

One parent summarized the need for supports, as well as the need for advocacy, in working with her child with chronic illness this way, “Keep putting in the teachers face, ‘Do you remember this is what they struggle with this?’ Put that health care need right back under their nose and say let’s examine their expectations.” (Mary’s mom)

Table 5

*Research Sub-Question c: Summary of Perceived Supports Themes*

Primary Theme	Secondary Themes	Tertiary Themes
Physical Development	Environment	Environmental cleanliness Environmental contamination
	Medical treatment	Staff knowledge Staff resources Medical equipment Schedule Dietary issues
	Participation	Physical environment/structure School day participation Extra-curricular participation
Social and Emotional Development	Peer interaction	Knowledge provided Support provided for the child with chronic illness
	Self-esteem Emotional support	
Behavioral	Self-care Independence Concentration	
Cognitive	IEP 504 (or similar) plans No plan Home schooling/tutors	Instructional support provided Instructional support not provided
	Extra work	Positive Negative
Advocacy	Awareness Preparation	

## **Physical Development**

Physical development was the area which most clearly connected to the child's physical health, and therefore, related most directly to their chronic illness. Parents clearly expected schools to recognize and provide necessary supports to allow their child with chronic illness to be present and participate as fully as possible. The supports which parents discussed related directly to child's physical ability to be present at school or participate in events or activities. These supports included supports related to the environmental, medical, or health supports and overall ability to participate.

**Environment.** The first and most basic support discussed as necessary was an awareness of the overall environment, as related to the child's chronic illness. Not all parents had the same concerns but there was a common concern related to cleanliness.

***Environmental cleanliness.*** Parents of children with chronic illness frequently express concerns related to the safety of the environment for their child regarding exposure to illness, germs, and other infections. They expected the school, and specifically the classroom teacher, to support the maintenance of an appropriately-clean environment for their child. This was not always the case, as two opposing comments were expressed by the same parent.

Just simple things, like in the classroom, his class was very good about wiping down their desks and using hand sanitizer when they come in the classroom. Teaching the kids to cough into their elbow instead of into their hands. (Patrick's mom)

And it makes me cringe now, knowing that my child is in school with these children that have fevers and are throwing up. I don't know what you do about it but...Some parents don't have a choice so they send their kids. Education is the key but enforcement is also important. (Patrick's mom)

***Environmental contamination.*** Specific to the needs of certain children with chronic illness, parents expressed the need for the environment to be safe for their child as related to allergies or other health issues. Parents expressed an appreciation for supports which increased

awareness of their child's needs and communicated these needs, such as written lists. However, they also expressed a concern for the lack of communication and discouragement that school policy was inconsistent, which potentially created dangerous situations for their child.

They will have questions, where they have asked for a list of what she can't have, like we sent in a list of especially food. I can't give you everything but I can give her some of the chemicals, some of the things to look for in the food. And we gave her a safe candy list. Here is a safe candy that if that candy comes into the classroom, this is the stuff she can have. (Mary's mom)

For a long time they still served peanut butter in the cafeteria, now children can still bring it, but they're not serving it any longer. So that's something that has helped at least a little bit. (Bryan's mom)

Some years he has a peanut free classroom officially and they put a sign up and they take it very seriously and they communicate to parents. And other years the teacher doesn't even seem to know when I arrive for back to school night that he has serious allergies and asthma. So it is, it's just a hit or miss, probably depending on the teacher's personality and the office's craziness. (Bryan's mom)

**Medical treatment.** Supports for medical treatment relates to supports directly connected to the managing the child's chronic illness while they are at school or at school-sponsored events or activities. Children spend six to eight hours a day at school, and during this time, school staff are the adults primarily responsible for monitoring them. For a child with chronic illness, this may mean access to medications, medical equipment, and various health monitoring. In order to support their medical care, parents expect staff to have the knowledge and resources to provide care, medical equipment to be appropriately-stored and available, a schedule that supports their child's medical needs as well as other daily participation, and regulation of necessary dietary issues.

**Staff knowledge.** In order to provide support for the medical needs of the child with chronic illness at school, teachers and other school personnel needed to have the necessary knowledge about the individual child, the medical condition, and potential medical interventions

required. This related to issues of knowledge as well as attitude and, according to parents, sometimes, came down to whether appropriate training was provided.

They seem very attentive to her. They kind of know that if she's spacy, they'll ask her to test. They know that if she's getting kind of grouchy, to ask her to test. They've been really good about those things. (Emily's mom)

I would have to say their biggest struggle has been with not so much the asthma, not so much the Celiac, those have seemed, for whatever reason those are easier accommodations for teachers to make. I really think it's the ADD one that we struggle with. And I think that's where they have been the weakest. As really taking the time to understand the kids who struggle with that. And being able to make real adjustments, you know what I would consider real adjustments. As not just telling me that this is what she did today or she is doing these negative behaviors. Really, I can't do anything about it, I am not in the classroom, you fix it. What is going to work for you in the classroom? I mean I could come in and teach her, but that's not you know, just nitpicking the daylight out of her behavior isn't going to fix it. Figure out the left-handed kid needs left handed scissors before you tell me she can't cut. (Mary's mom)

I just feel like communication could be better. Training could be better. I'm a teacher myself in a different district and we have very little training on epi-pens or on inhalers or any of those things. And the truth is, if a child has a reaction, it's not gonna be a school nurse giving that medicine, it's going to be whoever is right there. (Bryan's mom)

They need the personnel to be trained so there's not the stigma of wrong information. Like I said, most her teachers have been very, very good about it. (Emily's mom)

**Staff resources.** Supporting the child's health needs at school also required not only teacher knowledge, but resources. Parents communicated the need for specific supports such as appropriate staff and communication plans, including documentation. Parents clearly expressed that appropriate supports in this area frequently influenced the ability of their child with chronic illness to participate in extra-curricular activities or attend school-sponsored field trips, which will be further discussed within the later section on participation.

Outside of school of school resources would be really nice. A nurse on hand. At least a trained coach. I don't even know if the coaches have been trained in the glucagon. We've talked, but I don't know if they would actually, physically be able to do it. (Emily's mom)

I like the support plan idea. I also think that, from my experience in another district as well, I get one sheet of paper that has the entire school's worth of medical concerns and it's supposed to go locked up and that's it. I think that that sort of document should be somewhere very obvious, we even have these google drives. And it should be something that we are all required to read and they can see that we have read it and checked it off and talked it with whoever we need to talk about it with, and gotten specific training. I just think that we need a lot more proactive. (Bryan's mom)

If it was something that needed one of us, they would contact us right away or take the appropriate medical steps. No many things that were needed for us, I don't think, because I think that what we are dealing with is minor enough compared to other families that I don't think that we would need more specific. (Justin's mom)

**Medical equipment.** Some children with chronic illness needed access to medical equipment, medication, or specific health-related items in order to attend school or participate in events or activities. Parents expressed that the school should provide a safe location for storage of materials as well as appropriate supervision to monitor child's need for or use of medical equipment.

Making sure that we have the nebulizer and their school secretary is actually trained as to be able to work with the kids who have the medical issues as like a nurse would, just as a nurse training. To be able to if she gets into distress to go to the office to get her medicine. (Mary's mom)

She needs nebulizer treatments and she has her own nebulizer things at school. The school Teachers and provides the storage for it. (Susie's mom)

She also has a suction machine that is kept at the office at school. She um she has an emergency bag that has an extra feeding tube, an extra trach tube. Whatever she might need including extra clothing, because sometimes her feeding valve leaks. They provide the space that she can take her food in and put it in a fridge in the nurse's office. (Susie's mom)

**Schedule.** Children with chronic health issues often need to take medication, complete treatments, or monitor various things (such as blood sugar) on a regular basis. Health-related issues often did not follow a standard academic schedule, allowing medical or health issues to be dealt with solely during lunch, free periods, or during transition time between classes. Because of this, parents expressed a need for support in creating a schedule with flexibility which

supported their child in meeting or monitoring their health needs within their daily school environment.

She has to take time out of class if she's low (blood sugar). She always has to have a friend or buddy walk her to class because if she would happen to go into a seizure there has to be somebody there to alert a staff member. (Emily's mom)

I mean, there was days she wasn't going to have her work because she was tired or didn't feel like it. And they understood that. So, they didn't penalize her or anything, they just let her catch-up and get her work done as she could. (Caroline's mom)

One of the things they have commented about is that, you know, very honestly, when she has to stay after to finish her homework and we go sit there and that's not our responsibility and the school knows that is not our responsibility but we are thankful that they do a good job in what they provide and we want what is best for her so we are willing to do that. I am not quite sure how they would deal with those things, I think they might, they might cave and give in to we can't do that otherwise but I think they've learned a lot about and they talk a lot about how they we are willing to step in and take up the slack that needs to be (Susie's mom)

***Dietary issues.*** As part of spending the full-day at school, most children eat lunch. For a child with chronic health concerns, this can be a more complicated issue, requiring accommodations related to the food. Specific allergy-related concerns were addressed above, in environmental contamination.

She has to have, she can't just eat the hot lunch. And if they are fixing her food for hot lunch hers has to be prepared separately from the rest or she just brings in her own food. We have special food that's in the classroom that she only can eat. (Mary's mom)

***Participation.*** The ability of the child with chronic illness to participate may be impacted by the physical environment as well as their health or physical condition. Parents expressed concern for participation during the traditional school day as well as for after-school activities, extra-curricular activities, and other events.

***Physical environment/structure.*** For some children, the actual physical structure or layout of the school could impact their ability to participate. Children with chronic illness often have limited physical stamina or need more direct adult monitoring, which is limited in some



locations. While they understood limited ability to change the environment in some situations, parents expected appropriate accommodations.

They did ask about stairs. She could by the time she went back, she could do stairs well. But she was very dizzy, so stairs were kind of scary. Currently they are putting in an elevator so they are becoming more handicap accessible ... but at this time there really was no other way. I don't know what we would have done if she couldn't get up the stairs. (Lizzie's mom)

**School day participation.** Parents expressed concern with missed class time as well as inability to fully participate in regularly-scheduled activities. Missed class time occurred due to the need for medical treatments, physical health responses (i.e. feelings of pain, tiredness), or extended time needed to complete tasks. Inability to fully-participate may relate to physical health (i.e. lack of stamina, risk of injury) or lack of presence due to the extended time needed to complete health or school tasks. Clearly this could become a circular issue. Parents of a child with chronic illness clearly expressed the need for adapted activities as a support.

Before her asthma was under control she was getting a sinus infection, she was not feeling well, she was having to be on, you know we were not, she was in the office missing class time because she was on the nebulizer. Having to do that or she was missing recess because that was the easiest time for the teachers to get her into the office so she won't miss class time. But then she was missing recess which is what she needs and it can sometimes take up to 15 minutes for the nebulizer treatment by the time you. So that is your recess period. So, I think you know that is something that we are still working on a balance. (Mary's mom)

By virtue of her time it takes her to do her medical things and her lack of stamina; things like sports and then her esophagus they are trying to rebuild is on top of the breast bone, so contact sports are not good, she can't do that. So those kinds of things are non-issues, they are just, they have adapted PE for her, so she does get some exercise. (Susie's mom) Finding alternatives for her to, some sort of social something maybe that some of the other kids could have done with her, instead of handing them all recess being out on the playground where there is the temptation and potential for tripping, falling, whatever. (Lizzie's mom)

Because the recess is a decent amount of time. Or maybe suggesting her and some of the kids can walk around the block, with a teacher even. You know, just getting them active without...because she needs her heart rate up but she can't do the typical things kids would do on the playground. (Lizzie's mom)

***Extra-curricular participation.*** The ability for participation in athletics, field or other class trips, and activities outside of the traditional classroom is another area where parents clearly expressed their concern. They expected their child with chronic illness to be able to participate. In order to do so safely, they felt appropriate supports were the responsibility of the school. They expressed that these needs were not clearly understood and met in all circumstances by the school. They expressed communication as essential and, again, a support need not fully met.

Athletically, they might have snacks on the bus. Well freshmen, of course, serve the lowest level so if there was nothing left they didn't eat. Not realizing that after a big meet, she needs to eat. So actually, if they wouldn't have anything left, if she wouldn't have brought something then she would not have had that extra. But we're always really prepared. We always send extra. (Emily's mom)

The teacher was very accommodating when I, one of the first days she went back to school they had a field trip to the capitol and to the zoo, and so I basically said she wants to go. (Lizzie's mom)

The class trip they took this year to Chicago, they assured me there would be a medical professional on tour with them. Person cancelled out. I didn't get a call to say there was not going to be medical on the trip. So that was a little concerning to me. So that right at the last minute before they left, the day before actually, we had to go through all of the procedures for what to do with the glucagon, what to do if she's low. And they kind of relied a lot on the other diabetic child to help each other and watch each other. (Emily's mom)

## **Social and Emotional Development**

Social and emotional development, while an area of concern for parents of a child with a chronic illness, was not an area in which they expressed strong expectations for supports within the school system or from the teacher. They were more likely to recognize supports that were available or had been provided than to identify needs.

**Peer interaction.** Peer interaction is an essential area for social and emotional development for school-age children. Therefore, parents are appreciative of situations, settings, and other supports which encourage positive peer relationships, or friendships, for their child with chronic illness.

**Knowledge provided.** Parents expressed appreciation when knowledge about their child's chronic illness was provided in a supportive manner. Education about the chronic illness or their child's specific needs improved their child's ability to participate safely in the school and to engage in peer relationships. Parents acknowledged support provided by the teacher as well as outside health providers and the need for knowledge to be provided to peers, classmates of peers, and other children in the school.

The teacher had made sure all the parents were aware. And it wasn't done in a, you know, the teacher even communicated with the other parents in the class and she obviously came to me for my permission. It was great because Mary felt a little less like it was 'I am or feel weird and different'. It was helping her to feel a little more normal, bringing some normality to what feels like you are different and sticking out. (Mary's mom)

Shelley came and did a presentation that first week back and that was nice. And Shelley sent a little letter. And I went down and watched her presentation. I think that was good for the kids because she brought in her little doll and the port and Patrick answered questions. (Patrick's mom)

And really, with peers, make sure they understand that this is not something they wished happened to them. This is just something they're going through. (Emily's mom)

One thing they did really well that I thought was nice, is that they even told all of the younger kids in the building, "Don't run up and grab her or hug her." Those things that these little kids might think, oh she's here, she's back, and they're excited to see her. And so it's sweet because they're bring nice but don't run over, or let her be at the back of the line so she's not getting bumped into. (Lizzie's mom)

**Support provided for the child with chronic illness.** Another area of peer interaction where parents acknowledged support was from the peers for their child with chronic illness. Here, they directly expressed appreciation for several specific examples of peer-initiated events

the parents described as showing the peers' care and some understanding of on-going health related issues.

They did a bake sale to go with it and they raised \$800 or a little bit more than \$800 and they are sending it to donate. (Kevin's mom)

They had started somethings called Caps for Caroline. They collected a \$1 and the kids could wear caps. All the money went to St. Jude. This is when she was going through treatment. And then they did Canes for Caroline and they sold candy canes at Christmas, and the same thing. (Caroline's mom)

**Self-esteem.** Self-esteem is an area in social and emotional development in which parents expressed some concern for their child with chronic illness. This led to the expressed need, or potential need, for support related to self-esteem.

Emily's never, she doesn't consider herself different. She's really positive about everything but I can see where if there's a time where you need to talk to somebody, there's not so much there for that. (Emily's mom)

It was almost hard for her to go back. She almost got, in a way, a level of depressed, where she got comfortable with where she'd stay up late because her days and nights were really mixed up. So she'd stay up late, sleep part of the day, and I think she just wasn't motivated, which just isn't like her. She'd just get up and go. So transitioning back to school was really, really hard. She felt like everybody was looking at her. I meant that's her age, she felt like. (Lizzie's mom)

**Emotional support.** Parents communicated a desire for the provision of emotional support, both for their child with chronic illness as well as for themselves. Emotional support was not something parents necessarily wanted to provide directly by the teacher or school, but parents recognized the need for access to resources.

It is the emotional part that is hard to describe. And I even told them, I think she's afraid to come back. I think she's afraid of what will happen. And then once she got there and it was going better and ok and she got with her friends again, she kind of forgot about all that. (Lizzie's mom)

I sought it out. I found people that I knew had kids that struggled with the same needs. With Celiac, the school secretary her daughter went through with that same specific need, she had already kind of paved the way so I benefited from someone who already went

ahead of me. But I talk with her and she put me in contact with organizations, whether it was online support groups, that help me get good information. (Mary's mom)

## **Behavior**

Behavior can have an impact on the ability of a child with chronic illness to participate successfully, make friends, or perform expected academic accomplishments. Parents communicated expectations for supports which would assist their child in achieving physical and health-related goals, social and peer relationship goals, and impact academic outcomes. These supports focused on supporting the ability of the child with chronic illness in the areas of self-care, independence, and concentration.

**Self-care.** The ability to learn to make decisions related to their own well-being is a normative function of childhood. For a child with chronic illness, decisions made are more frequent and often of higher consequence. Parents expressed the need for schools to provide supports for self-care, as many decisions are made while the child is at school. Parents also recognized that some schools were more actively supportive of self-care than others.

I feel like I'm hyper-vigilant. And at least he's at an age where he can help manage it himself more. No one's going to put something in his mouth that he doesn't know where it came from. (Bryan)

With other issues I know they help me kind of make sure that she is doing it right, writing a social story. I'm kind of wondering if I maybe I should go about that. (Amy's mom)  
She doesn't allow anybody to treat her different. I know that sounds like of odd. Her teachers don't seem, I mean they get a little bit grumpy if she's got to leave a lot. So their expectations are that she probably should be better controlled. Not understanding that the wind changes and diabetes can change, especially when you are a teenager. (Emily's mom)

We have to limit her or she overdoes it. So with her personality, if somebody said to her, "It's your turn. You're supposed to do that today." She just goes and does it. (Lizzie's mom)

**Independence.** Strongly related to self-care, was independence. When parents referred to independence, they expressed support goals related less to managing chronic health issues and more related to behavior management and transition for functional or life skill long-term goals for their child with chronic illness.

There again, she is 13 and they can't police her every move. You know, they can't follow her through the building. But she is still young enough that her decision making is not always going to be there. And she's so fragile, that I about had a heart attack. (Lizzie's mom)

I see the window closing so fast on her educational opportunities because at 13 she is so far behind and again I, we may be unrealistic but we think that someday she will be able to live on her own with possibly very little assistance. Well we are going to have to bump up this teaching her how to do it. I think that's their biggest deficit. (Susie)

But hers is a physical issue that you couldn't necessarily just see if she's walking around and functional. I think people almost forgot. Like the first day she was back at school (after her surgery) they had her do lunch duty. And it was just scraping trays but she had such little energy that it was just not necessarily to expend it. And I think she didn't speak up and say, "Oh, I don't really feel like doing it." (Lizzie's mom)

**Concentration.** For parents, supports discussed in the area of concentration related as much to behavior management as to cognitive development. However, parents clearly recognized that these concerns overlapped.

I think that will always be her struggle and even she notices it. 'I can't make my brain think, my brain is busy, I can't do this.' We are trying to get her teachers to let her type out stories, rather than having to painstakingly handwrite and cursive. You know, for a kid who is trying to focus, what do you want? Handwriting or a story. Pick one. At seven o'clock at night when the list of homework is an arm length, the ADD kid is not going and the ADD medicine probably wore off somewhere around three four o'clock by seven o'clock we are at the end. (Mary's mom)

## **Cognitive Development**

Cognitive development was the area of development where supports were most clearly provided for children with chronic illness and it was also the area in which the educational system was most likely to initiate supports. School systems, by law, have a variety of supports in

place for students. These supports were not available to those students with chronic illness who attended private schools. Few parents choose to take advantage of the supports available or felt that supports were made available in an appropriate time manner. Along with provision or availability of cognitive supports, parents acknowledged regularly that attitude of teachers or school personnel impacted their comfort and timing in accessing supports.

**IEP.** An individualized education plan (IEP) is perhaps one of the most-recognized supports for children in an academic setting. While supports may be written into an IEP in a variety of areas, parents clearly expressed the need for support related directly to health needs or academic support.

I think we were very intimidating because we had to have an IEP meeting very quickly, they are used to having the couple of teacher involved and, in her case, she had the nurse involved. The principal involved the guidance counselor would be involved, the social worker usually only one parent. Well for the first IEP meeting for Susie, um there were 23 people there...The room was so full and they are used to having IEP meeting last 15 – 20 minutes. We finally called an end to the meeting at 2 ½ hours. So think that they were pretty intimidated by the whole, but they dealt well with it. (Susie)

She is way behind, and they what did is they were to alter the curriculum to her IEP to meet her needs, and that sort of has been done. (Susie)

The school, we obviously had his IEP meeting and we explained to them if you are using playdough, he uses a brand new container. He doesn't use something that 5 other children have already used, sneezed on, spit on, put in their mouth. You can clean tables, you can't clean playdough. Then we also told them that we're not sure how often you're cleaning your toys, but with Kevin being in your classroom, at the end of each day, you either spray them down with Lysol and you wipe them down or it's just that he simply can't come here. His health comes first. (Kevin's mom)

**504 (or similar) plans.** Some parents recognized the need for some form of support plan even if their child did not have a more formal IEP. Parents referred to 504, or 504 type plans. This was an area in which parents expressed a need for a plan that supported communication and collaboration between the education and healthcare systems.

It's kind of like a 504 type of thing. It actually came from her pediatric endocrinologist. It just says that if she'd high or low, testing can be affected. She's allowed to go to the bathroom when she needs to. She needs to test when she can test. And then it has a guide that shows all the symptoms of a low and then you circle what her symptoms are. Same for the high. And then how to treat. (Emily's mom)

I've heard of other places that have really good medical plans, like a 504, and I like that idea. We don't do that. I know someone else who has a child with seizures and they're gonna have a plan soon. I like the idea that you'd sit down formally and talk to people and have that communication because that's never been an option. I fill out one paper at the beginning of the year, the doctor signs it, and I turn it in with all the meds and that's it. (Bryan)

**No plan.** In order to have an IEP, a child must meet certain criteria and not all children with chronic illness qualify for an IEP. It is also important to note that not all parents had or wanted an IEP, 504, or other similar plan. One parent specifically noted that her child with chronic illness could have had an IEP, but that she did not need it. Another parent, while they did not yet have any plans in place, specifically mentioned needing a health plan.

We probably could have gotten her one (an IEP) but she didn't need it. It didn't really affect her learning so she didn't really need any special services. We were really lucky. (Caroline's mom)

And we still at this point don't have a health plan made up for him. Which needs to be done and I reminded our principal again at the end of the year that a health plan needs to be made. (Patrick's mom)

**Home schooling/tutors.** When discussing cognitive development or academic outcomes, the majority of the parents referred to home schooling or the use of tutors as a support. The provision of learning support outside of the tradition class environment was generally considered a benefit, to both cognitive as well as health outcomes.

When he was going to school versus his at home schooling, he was a lot more sick. Let's just put it that way. (Kevin's mom)



***Instructional support provided.*** Parent desire for support for home school or tutoring was met in a variety of ways. According to parents, children with chronic illness may be unable to attend school because of their own health or in order to avoid illness contamination in the environment, when peers were ill. Home schooling was provided by the classroom teacher or other tutor, as well including other services such as occupational therapy.

His main classroom teacher, she comes to the house for an hour each day during the school year for his at home. And then he receives speech and OT therapy. (Kevin's mom)

He literally was not there at all, but because he received homebound he had a teacher coming in. It was just an hour a day but that counted as his attendance. (Patrick's mom)

They have been helpful in setting up a tutor to come in if she can't go to school. At one point there was 2 ½ weeks where she didn't go to school because of the amount of illness in the school so they set up a tutor to come to the house and help her. (Susie)

Now that we are closer to the end, at the beginning of this school year or half way through we decided to do at home, it's called home bound schooling. Because he was missing...he missed about 65% of the school year because of all the times his counts were too low or there had been kids with the chicken pox or the flu that were going to the school and I said No. I'm going to take him out of the school because he's not going to be around that because those are deadly towards my child because he doesn't have it in him to fight those things off. So that's when we decided we were going to start doing this as home. (Kevin's mom)

***Instructional support not provided.*** When parents expressed that home schooling or tutor supports were not provided, it was often due to either refusal by the parent or timing. In one instance, the parent was a teacher and felt capable of meeting the child's educational needs, although the school offered tutors. In more than one other case, parents expressed that they wished services had been provided earlier in the illness or school year.

And so, me being a teacher at the school, it was easy for me to keep up with what she was missing and do work at home with her. We did not get a home tutor or anything. I just did it myself. (Caroline's mom)

Yeah, they were willing to bring her work to her if I wasn't at school that day or they tried to look into getting a tutor if we wanted it, but we chose not to. (Caroline's mom)

I honestly wish rather than waiting until the last 5 months of his treatment to be like it was okay to do home schooling versus when he started when he was 3 years old and he was missing 90% of the school year at that time, not thinking maybe this is something that we should do. I honestly think they waited too long to do the at home bound schooling because if he would have been on that home bound schooling sooner, I think he'd be progressing faster. Because since he's has had that home schooling he has progressed so much more. He works so much better with the teacher. (Kevin's mom)

**Extra work.** Parents also communicated a need for support for their child with chronic illness to receive support with extra work which may be needed to make-up missed class time due to medical appointments or treatments or extended time needed to complete class work. They specifically expressed the desire for support for extra work or time out of class in order for their child to stay on track academically.

**Positive.** Parents clearly expressed the support of the teacher and school system in assisting their child with chronic illness in meeting their academic requirements. Parents expressed that they, as the parent, as well as other family members, were expected to take responsibility for providing supervision and support for the child.

I said what happens to the normal kids? Well, they stay after and do their work. Okay, I will be at school and I will sit in the office to make sure she is safe while she completes her work. We think that is important for her development in many ways. She has to learn to be accountable for herself. (Susie)

Willingness to work with her if she needed extra help. They were more than happy to help her. Or they would come to the house and help her. (Caroline's mom)

They were really good with getting assignments to us. And actually a friend of ours, her good friend and her grandma, brought us assignments. So they got everything ready. (Lizzie's mom)

**Negative.** Parents expressed times in which they noted lack of support or places where they felt accommodations could have been made to assignments.

And for the most part over the past 4-5 years they have been really understanding about appointments. There was really only a couple of times, I remember one time she had a teacher who kind of didn't understand why she was going to miss part of the day. I suppose maybe they had something important going on in class. (Lizzie's mom)

Some of the assignments maybe could have been cut down a little bit. That maybe wasn't necessary, and maybe she already did. I guess I don't know what the other kids got. I guess I'd have to find that out in order to properly answer that, but it really felt like a lot. You know, when you see this whole pile, you think, does she need to do the entire thing? Could she just do maybe some of the math problems just to show she knows it and then move on? If you're reading a book, you've got to read the whole book, granted, but some of it maybe they could have cut it down a little bit. Because it really was kind of a lot. (Lizzie's mom)

## **Advocacy**

Advocacy is the final area identified as a support need by the parents who had a child with a chronic illness. Previously, under peer support, they identified some ways in which peers positively supported their child and acknowledged caring through activities which may often be identified as advocacy, such as fundraising or other awareness efforts. Advocacy, identified here, related more directly to teachers, administrators, and school systems. Parents identified a need to advocate for awareness and preparation in those professionals who would be working with their child with a chronic illness.

**Awareness.** Parents openly-expressed that teachers and schools were not aware of the needs of their child with chronic illness. They felt that an advocate was needed in order to support both their child as well as the education system in meeting their child's needs. Parents most often described that they needed to fill this role or that these needs would not be met—for their child or for the teachers. Additionally, advocacy, in order to promote awareness, was needed on a repeat basis. A one-time intervention was not sufficient.

I think initially, you know, you kind of feel like people initially are really understanding. And then they kind of forget. Because you get back and you look normal and look healthy. And so, you kind of forget that our family is still not back to normal. It's going to take us a long time, especially after a surgery. (Lizzie's mom)

You never truly know what they are going through if you're not going through it, so compassion. Be involved. Get to know them personally. Don't label them as "this is what they are". Because I don't like when you come up and say this is my diabetic

daughter. This is my Emily. This is her. What she has is just something that's happened to her. (Emily's mom)

They say, oh, ALL it's the best kind of cancer you can have. No part of cancer, no kind of cancer is a good cancer. Cancer sucks. There is no good part about it. A success rate may be the only okay thing about it, but it's never okay to actually have or be going through. ... Yeah. Yeah. That's what everyone would tell me when they found out he had cancer. You got the best kind of cancer. I said, Really? What part of he got cancer do you think is okay? ... So what part of this is okay? None of it. ... You get it slapped on your plate and you deal with it. You work through it as best as you can and you deal with it. One day at a time. Obviously, not every step of the way is going to be easy. It's hell. I'm not gonna lie. It's hell. But, we're almost there. We're ready to be done. (Kevin's mom)

**Preparation.** Parents clearly communicated that the individual teachers and the larger school communities were not prepared to have their child with chronic illness in the classroom. Parents expressed the need for an advocate to prepare the people and the environment for their child. Also, this preparation was not needed as a one-time occurrence, but rather needed to occur at the initial diagnosis or entry of their child with chronic illness into the classroom and then be repeated as health needs or environmental changes occurred.

The school was really at a loss as to what to do. I would say I kind of took over. I work at the school so it was more me telling the school what they needed to do. (Patrick's mom)

I'm not sure if they would have pursued that if I hadn't really sent an email with a bunch of information or upcoming dates that we're going to be gone. I would give them maybe a week's notice that we're going to be gone and tell them ahead of time. I did even think to myself, if I didn't push, would they even have asked? And I don't know. (Lizzie's mom)

At the start of the year I have that form I have to fill out. I do try very hard not to be an obnoxious mother in regards to school. But every time there's a field trip, when I sign the permission slip, I say please bring this, this, and this with him. And the morning of, I do email them a reminder, because I know it gets crazy and busy and the idea that he would be off somewhere far from me and far from his medical supplies would not be a good situation. (Bryan)

### **Summary of Findings for Research Sub-Question c: What Supports do Parents of Children with Chronic Illness Perceive Are and/or Should Be Available at School?**

The third sub-question focused on the supports parents perceived were and should be available at school for their child with chronic illness. The themes identified related to support needs for the child with chronic illness in each area of development identified on the concept map. The results were associated with physical development (environment, medical treatment, and participation), social and emotional development (peer interaction, self-esteem, and emotional support), behavior (self-care, independence, and concentration), and cognitive development (IEP, 504 or similar plans, home schooling or tutor, and extra work). Advocacy was identified as an additional area of support need, with advocacy needed both for awareness and preparation. Through each of these areas, as parents expressed the supports needed for their child with chronic illness within the classroom or school environment, they discussed what was available, what was missing, and the impact of knowledge or attitude on decisions to provide supports.

## CHAPTER VI: FINDINGS AND RECOMMENDATIONS

Chapter VI is organized to provide the reader with a brief overview of the study followed by discussion of the findings, limitations of the study, and future directions for this line of research. The findings of primary interests were in the areas of communication, physical development, social and emotional development, behavior, cognitive development, and advocacy. The main findings are presented in order guided by the presentation in the results. Communication findings represent concerns related to teacher knowledge, skills, and attitudes, as well as the amount and valence of communication. Communication-related comments were reviewed with respect to A-IIRS scores to determine if the overall intrusiveness of the illness on family life impacted parent-teacher communication. Findings in the area of physical development related to the environment, pain and symptom management, supports for participation, staff knowledge and ability once again, and physical structure (of the building, etc.). Findings related to social and emotional development related to peer relationships, or having friends, peer supportiveness, accuracy of information, and self-esteem. Behavioral findings focused on not making assumptions about that health was the cause of behaviors, being aware of long-term impact, and independence versus over-protectiveness towards a child with a chronic illness. Findings in cognitive development stated there was an impact depending on whether the teacher or school was prepared for having the child with chronic illness in the class. Parents were least confident in this area and yet expected the most of teachers in this area. There were also the most supports provided in the area of cognitive development. Finally, findings connected to advocacy indicated the need to promote awareness and education and to increase preparation. Much of this falls to the parent of the child with chronic illness and an advocate would be beneficial.

## **Statement of the Problem**

Nearly 20% of school-ages children have a chronic illness, with 2% experiencing a severe chronic illness (Shaw & McCabe, 2008). Regardless of the fact that this represents one in five children, relatively little research has been done to explore how having chronic illness impacts the child as a student. It is widely acknowledged that illness, in general, impacts development, but there is a need to better understand the impact of chronic illness, particularly as advancements in medical research lead to children with special health care needs (CSHCN), including children with chronic illness, living longer and reaching school age and beyond (Shaw & McCabe, 2008). They are entering classrooms, thus impacting their peers, teachers, and families. The goal of this research was to understand the experience of communication between home and school for the parents of a child with child with chronic illness. Also examined, were the parental academic and social expectations for their child at school and the educational supports they perceived were or should be available.

## **Methodology**

This research project was a phenomenological study using semi-structured interviews as the primary method of data collection. The goal was exploration and understanding of participant experiences as there is no single, objective truth (Patton, 1990). The participants of the study were parents who had a child with a chronic illness. Although both mothers and fathers were recruited, all final participants were mothers. A combination of purposive and snowball sampling were used to identify participants. At the start of the interview, participants provided demographic information and completed the A-IIRS, a measure of the degree of illness intrusion in their life. This was used to gain perspective on range of chronic illness represented during data analysis. Finally, participants answered the semi-structured research questions, using

an open-format with follow-up probes used for additional information or clarification as needed. Research questions asked about communication with the child's teacher, the parental academic and social expectations for the child with chronic illness, and supports the parent perceived were or should be available for their child with chronic illness at school. A final open-ended question allowed parents to share any additional information they felt was relevant to the current research which had not already been asked about or shared. All interviews were recorded and transcribed.

### **Summary of Data Analysis**

Initial data analysis used on descriptive and provisional coding to identify emerging themes (Miles et al., 2014). A pilot study was completed. Second-cycle coding identified emerging patterns and constant comparison of coding and themes resulted in the creation and revision of a concept map. Results of the pilot study refined the interview questions. Similar cycles of coding, identification of themes, and constant comparison were utilized throughout the remainder of the research study. The concept map was foundational as a visual representation and guide for identifying, organizing, and presenting themes as they emerged throughout the remainder of the research study.

### **Overview of Results**

Results focused on the phenomenological experience of parents who had a child with chronic illness in communicating with their child's teacher or school. Guided by the research questions, results were primarily organized into three sections: communication, expectations parents have for their children, and supports parents perceived were or should be available for their child at school. Themes related to communication concerned process of communication (method, timing, content, and valence) as well as the content of the communication (child-related issues and teacher-related concerns). Themes in both parental expectations and perceived



supports covered the full range of development, with the addition of behavior as a strongly-related category. A summary of themes for parental expectations was organized by major area of development: physical (physical activity, pain and symptom management, and school participation), social and emotional (peer and social relationships, self-esteem, and emotional support), behavior (concentration, self-regulation, and independence), and cognitive (aptitude and achievement). A summary of themes related to supports parents perceived as available or expected to be provided was organized by major area of development: physical (focused on participation and medical treatments), social and emotional (peer interactions, self-esteem, and emotional support), behavior (self-care and independence), and cognitive (supporting academic outcomes, IEP or 504 plans, home schooling or tutors, the impact of extra work and advocacy). Although some additional themes occurred, it was interesting to note how closely the themes in the final research study followed the initial patterns and themes which emerged in the initial pilot study.

### **Findings**

The results reported presented few surprises, as they were largely aligned with development, the theoretical foundations of family system theory and ecological systems, and previous research related to working with children with chronic illness or communication between parents and educators as presented in “Chapter II: Review of Related Literature”. However, certain findings merited more in-depth discussion to highlight the essentially unique phenomenological experience of the 10 parents of children with chronic illness as represented in this research (See Table 6).

Table 6

*Summary of Findings*

Primary Theme	Secondary Themes	Tertiary Themes
Communication	Expect communication	Health of the child School performance or needs Classroom management/scheduling
	Diagnosis specific concerns	Teacher knowledge, skills, attitude Administration & other personnel
	Valence of communication	Not related to A-IIRS
Physical Development	Environment	**Strongest area of concern--health Cleanliness & safety Teacher knowledge & attitude
	Materials & equipment	Teacher knowledge, skills, training Availability—location & storage
	Structure of building	
Social and Emotional Development	Peer relationships	**Most important outcome for parents (after health) Least intervention in this area
	Teacher	Training needed
Behavior	Appropriate expectations Timeline for impact	**Major area of expectation Late term effects Assumed impact not related to chronic illness
	Cognitive Development	**Area of lowest confidence for parents **Coincides with area of highest confidence & skill for teachers

*Table continues*

Advocacy	Parent vs. teacher goals	Academic vs. life skills
	Individualized support or instruction	
	Awareness & preparation	Enhanced role for parent of child with chronic illness
	Typical role for parent	Case advocacy vs. class advocacy

*End Table*

### **Communication**

The child-related issues in the content of communication were not unexpected. Parents expected to be communicated with about their child's health and to be communicated with about their child's performance or needs at school in addition to issues connected to classroom organization (schedule or special events). However, communication related to teacher concerns included a wide range of issues concerning teacher knowledge, skills, and attitudes toward working with children with chronic illness. As found in Shaw & McCabe (2008), teacher knowledge was addressed often as a diagnosis-specific issue, such as the concern that the teacher had never had a child with a specific diagnosis in their classroom or that they generalized knowledge from a previous child to all children who had diabetes. Teachers who reported feeling competent and informed in working with students with chronic illnesses are the minority (Nabors et al., 2008). Parents expressed specific concerns related to knowledge about physical needs and impact of their child's specific illness.

This concern was not limited to teachers. Parents expressed a lack of knowledge or preparation from the administration or school system. They felt they, as parents, were largely responsible for providing information and training, similar to findings from the literature (Anderson, 2009; Oeseburg et al., 2010). They also expressed concern that when information

was provided, it was not appropriately communicated to other personnel (i.e. other teachers) which impacted child safety. This is a concern as parents are considered outsiders to both the education and medical systems. They were expected to manage knowledge and communication within an educational system which they were often not included.

Knowledge clearly impacts skill and parents were concerned about the ability of school personnel to provide appropriate care to meet their child's medical needs. Brook and Galili (2004) reported that the presence of a child with chronic illness in the classroom correlated with higher levels of teacher knowledge. This finding was corroborated across the literature, emphasizing the connection between both knowledge and also skills (Gartin & Murdick, 2009; Nabors et al., 2008; Shaw & McCabe, 2008). From recognizing signs of an asthma attack to proper use of an epi-pen, parents were unsure of teacher's ability to care for their child. Without the knowledge or the skills, who would make sure their child's needs were met and that they came home safely at the end of the school day?

The third part of the trifecta is attitude. A teacher who has the knowledge and the skill must be willing to use it. Parents felt that school policy, at times, did not support parents and teachers. Materials had to be locked in a specified location which may be far from the student or where it was needed. Liability concern may lead teachers to be reluctant to be involved. Olson et al. (2004) identified positive attitudes about children with chronic illness in the classroom, matching the information provided by parents interviewed. While the majority of teachers expressed a positive attitude toward having children with chronic illness in the classroom, it was an additional stressor for the child, peers, parents, and teachers.

Communication was generally more positive in tone with three times more positive comments than negative; additionally, there were approximately an equal amount of positive and

neutral comments. Overall, 45.55% of comments related to communication were rated as positive. Interestingly, all ten parents made at least one positive communication-related comment and eight made multiple positive comments. When considering communication between parents and teachers related to expectations and supports, having nearly half of all communication rated as positive was unexpected. The largest number of positive comments were made in the areas of communication from school to family and the quality of school communication. While parents and other professionals identified multiple issues of concern about children with chronic illness in the classroom, overall, most seem to feel positively about this aspect. This is an important finding related to children with chronic illness in the classroom and may be a helpful foundation upon which to build relationships for further improving communication and building skills or impacting attitudes, of parents or teachers.

Considering the valence of communication-related comments, comparison was made to the overall intrusiveness of the illness on family life applying the A-IIRS. The parent with the highest A-IIRS scores and a parent with a moderate A-IIRS score made the largest number of positive comments related to communication. The next most frequent numbers of comments were made by parents with both the lowest A-IIRS score and three with moderate A-IIRS scores. This appears to suggest that positivity in communication is not correlated to degree of illness intrusiveness. Another factor commonly explored in parent expectation is timing since diagnosis; this was not found to be related to overall valence of communication-related comments.

Slightly fewer communication-related comments were neutral, with 41.58% of all comments. Neutral comments were primarily related to managing the process of

communication, such as method or timing. The majority of comments were made in the areas of both communication from school to family and communication from family to school.

The parent who had the highest A-IIRS score also made the highest number of neutral comments. The parent with lowest A-IIRS score and two with moderate A-IIRS scores made frequent neutral comments. The fewest neutral comments were made by a parent with a moderate A-IIRS score. Again, there does not appear to be an impact between degree of illness intrusiveness and valence of communication.

Only 13.86% of all comments connected to communication were rated as negative. Only six of the ten parents made any negative comment related to communication. Negative comments were primarily about the quality of school communication. No other category had multiple negative comments.

The majority of negative comments were made by families with moderate A-IIRS scores, indicating illness intrusiveness on the family. While the family with the lowest A-IIRS score made only one negative comment, the family with the highest A-IIRS score made no negative comments. This indicated that illness intrusiveness does not have a strong association with negativity of communication.

Overall, there was no substantial relational evident between valence of communication related comments and degree of illness intrusiveness. This is surprising as one might expect a parent with a higher degree of illness intrusiveness, and therefore a higher A-IIRS score, to have greater expectations and therefore potentially more negative interactions with teachers. This was not evident in the experience of the parents in the current research study. Open and respectful communication between home and educators will allow students with chronic illness to receive

the best education with the best chance for optimal learning outcomes (Bobo, Kaup, et al., 2011; Bobo, Wyckoff, et. al, 2011; Erickson et al., 2006).

### **Physical Development**

While physical development was the area seen as most directly related to developmental impact for a child with chronic illness, it was also the area of strongest concern for parents as many of their safety concerns were contained within this category. The cleanliness of the environment was a major concern for numerous parents. It was also a concern which was misunderstood, ignored, or denigrated by individual teachers or school systems. This indicated a shocking lack of knowledge regarding the health implications of exposure to germs or certain substances, in the case of allergies, some children with chronic illness face. The actual environment was a potential danger to the children. Serious education is needed in this area. Parents must not only provide the necessary information but be respected and taken seriously. Parents are the most knowledgeable individuals regarding the overall development and health of a child (Anderson, 2009; Oeseburg et al., 2010). Once the information is available, it must be acted upon appropriately and the education environment must support the teacher or other professionals in providing necessary safeguards (encouraging handwashing, peanut-free zones, etc.).

Children with chronic illness also need to be supported in meeting their individual health needs in the school environment. Some children need to monitor blood glucose levels, others may need to have access to breathing treatments, still others may need medication for pain management. Teachers are not healthcare professionals and therefore may lack the knowledge or willingness to support children with these needs. Clay et al. (2004) stated that educators are ill-prepared to deal with issues of chronic illness in schools, further reporting that 59% reported

receiving no academic training and 64% reported no on-the-job training for dealing with issues of chronic illness, while 43% felt moderately to very responsible for dealing with issues of chronic illness. This is not much of a change over the findings by Becker et. Al (1996) in which half of all respondents received basic first aid, CPR, and universal precaution training but over 75% had no training in procedures to meet the needs specific to the students in their classrooms. School policy may also limit teacher ability. At the same time that teachers may be limited in their knowledge or ability to support children with chronic illness in their classroom, it is essential for both the health of the child as well as the active participation of the child in the class for the child with chronic illness to be healthy, in order to be present with the ability concentrate cognitively and socially. This is not possible if the child is having difficulty with pain, breathing, or other symptoms which impact the child's ability to be either physically present and/or cognitively attentive.

Most interesting, parents were especially concerned about the teacher's ability to manage the health of a child with chronic illness not in a typical school day or in a standard classroom, but when there were special events or changes in the daily schedule. Obringer and Coffey (2008) stated that educators needed to be aware of the medications a child was taking and knowledgeable about the side effects of common medications for a diagnosis, such as asthma, cerebral palsy, or seizures. Field trips, participation in extra-curricular activities, and sports caused changes in daily routines which increased risk factors for management of children's health needs. Teachers need to keep track of specific details and document any side effects that impact student's academic progress as well as their participation outside of the classroom. These concerns linked to communication, parental expectations for their child's physical development (health, participation, safety), and expected or available supports. For example, if the epi-pen



was stored in the school office, what if it was locked during after school events? If children went on field trips, who was responsible for knowing which children could have certain snacks or needed to check blood sugar? Parents considered these situations as opportunities for their child to be as “normal” as possible but also as situations with higher risk for negative outcomes for their child with chronic illness.

While there were expressed concerns related to staff knowledge and school attitude, there were also issues expressed that were connected to the actual physical structure or environment of the school or class setting. Parents identified that it was important to focus on issues that were controllable because there were factors such as stairs in the building or length of hallways and distance between classes that were out of the control of the parent and the school personnel. In these situations, the only possibility was to create an accommodation, if the child had an official plan, or to otherwise hope for flexibility and communication working with the teacher or other appropriate school staff.

### **Social and Emotional Development**

With the exception of health, friends were more important than any other outcome for parents of a child with chronic illness. At the same time, parents were least likely to intervene in this area of development. Parents expressed the need for peers to have accurate knowledge about the impact of the illness to dispel misperceptions and myths. Parents were more often the source of this information than teachers. It became clear that parents were a vital source of information for most everyone interacting with their child with chronic illness. It is critical to recognize this added stressor as a responsibility for parents, which requires their need to have both have current, accurate information and also to be able to communicate in a way effective for specific audiences. This is not training or a skill that all parents have. According to the NSCH (2009/10),

parents who have a child with chronic illness experience a variety of challenges including increased levels of stress, decreased health, and feelings of inadequacy and self-doubt regarding their parenting skills.

While peer relationships and interactions were perceived as more often supportive overall, emotional support and peer interactions were identified as an area in which teachers could provide more support. This is perhaps not surprising when considering friendship was rated as higher in importance than cognitive or behavioral outcomes by parents, even in an educational setting. Research recognized the school setting was central for peer interaction, support, and socialization, and peers were vital in establishing self-esteem and identity (King et al., 2010; Nabors et al., 2008). Teachers focus primarily on cognitive function and tend to focus on peer interactions, or social development, only in instances where there is an identified deficit or interference with classroom management. Parents and teachers do not equally rate the importance of promoting peer relationships, nor do teacher education programs consistently provide concentrated training in intervention for social and emotional development, in the opinion of the parents.

Training in social and emotional learning (SEL) is a new area of study for teacher education programs in preservice education (Schonert-Reichel, 2017). In teacher education programs there are four topics related to SEL—social development, emotional development, behavior management, and abuse and neglect. Research performed by Schonert-Reichel (2017) analyzed teacher preparation programs representing 30% of all US colleges that offer teacher education coursework, looking at course requirements and competencies covered. Of the programs reviewed, more than two-thirds required at least one course on topics in SEL, with behavior management cited more frequently. About one-fourth of programs, 26.9%, required a

course in social development, while one-fifth required two courses, and one program required three courses. Only 16.9% of programs required a course in emotional development. Interestingly, courses in development were most often taught outside of the education department. Textbooks, therefore, contained virtually no application of development to classroom situation, leaving teachers to create their own examples and practices. Research findings indicated that few programs covered all SEL competencies. In fact, only 13% of programs had at least one course that included relationship skills. The other four competencies (decision-making, self-management, social awareness, and self-awareness) were between 1-7% (Schonert-Reichel, 2017). Who, then, should provide this support expected by parents for their child with chronic illness? School social workers are available but not to manage these issues on daily basis.

The 2017 survey of School Social Work students reported that 7% of new social work graduates are working in school settings. Previously, Fisher (2010) estimated that there were 17,797 school social workers providing related services to children and youth ages 3 to 21 under IDEA. As the data only covers those school social workers in the U.S working with special education students, the accuracy of the report remains questionable. Fisher (2010) speculated that although at least 95% of school social workers may be working with special education students there are many who do not hold responsibilities in this area. It is difficult to ascertain an accurate number of how many school social workers are currently practicing because although 60% of state departments of education certify or license school social workers, as not all of them produce an annual census of school social workers (Fisher, 2010). In spite of the vague data available, the 2017 edition of the Occupational Outlook Handbook (Bureau of Labor statistic U.S. Department of Labor, 2018) reported 16% growth for the school social work profession.

## **Behavior**

As previously mentioned, behavior is not technically an area of development. And yet, it was a major area of expectation for parents who had a child with chronic illness and area for supports. A foremost concern of parents was that behavioral expectations not automatically be relegated to cause and effect related to the chronic illness--outcomes or treatments. Educators of a child with chronic illness have a further tendency to assume that when the child with chronic illness is experiencing a decreased ability to focus, limited mobility, verbal or memory delays, or difficulties with peer interactions, it is always due to their illness or treatment (Sexson & Madan-Swain, 1993; Shaw & McCabe, 2008). While chronic illness clearly had the ability to impact behavior in a wide range of ways and over an extended period, the assumption that health was the principle factor was detrimental in determining appropriate expectations or effective plans for behavior management. On-going assessment is needed in order to make accurate, evidence-based decisions related to student behavior management or instruction, particularly following diagnosis or changes in medication or treatment. For the student with chronic illness, this information may be supplemented with developmental assessments completed by healthcare professionals, school social workers, psychologists, or other professionals (Sexson & Madan-Swain, 1993).

Timeline for behavioral impact was a concern. Most parents expressed that teachers, as well as others, were understanding and accepting of outcomes immediately following diagnosis and during active treatment. However, relatively few understood the potential long-term consequences of chronic illness management. According to the literature, teachers may be unaware of the specific areas of long-term and significant impact of chronic illness on academic performance as well as in other areas of development such as behavior (Gartin & Murdick, 2009;

Nabors et al., 2008; Shaw & McCabe, 2008). Parents in the current research were concerned that medications, chemotherapy, and missed class were just the start of the list of treatments which have not only immediate, or short-term, but possible long-term impact on behavior. The abilities to concentrate and self-regulate, language, and memory may be impacted as medications or treatments interfere with brain development or function. Currie (2005) also stated that educational staff may misattribute learning issues to disability, motivation, or other explanations rather than understanding that the etiology of learning issues was related to medical treatment. Children with chronic illness may require supports in school beyond the end of treatment to manage specific individual issues.

As children with chronic illness continue to receive supports to learn to manage behavior as well as their health, they can struggle with gaining independence. While this is a developmentally-appropriate concern, there are added stressors for children with chronic illness and parents, as well as other adults in their lives, are often over-protective. Parents may additionally be reluctant to allow an ill child to participate in group activities, contributing to the perception that the child is vulnerable or incapable (Anderson, 2009; Currie, 2005; Sexson & Madan-Swain, 1993). Children with chronic illness have a dual presence of more adults than other children their own age as they have more experience with medical procedures, pain management, and making complex health decisions. Alternately, they are more-childlike in being watched closely, not allowed many freedoms, and having all aspects of their lives more carefully-monitored to a later age than typical. Both of these are exacerbated by spending more time in the presence of adults than other children. Correlating to both Anderson (2009) and Webb (2009), it is essential to normalize childhood as much as possible, allowing children to be children, playing with peers, and having as typical of a childhood as their health allows. School

is considered a “normal” setting for children, a concept highly valued by parents of a child with chronic illness.

### **Cognitive Development**

While cognitive development was the area of lowest confidence for parents, they did have goals for their child and expectations for the teacher and school system. In most situations these high expectations coincided with the confidence and skill teachers have in the area of cognitive development, their primary area of professional skill. This correlated with literature results that indicated that although most educators reported feeling secure in meeting the academic needs of children with chronic illness, they lacked confidence in meeting psychosocial needs of these same students with chronic illness (Nabors et al., 2008; Shaw & McCabe, 2008). When expectations did not align, either the parental expectations for the child with chronic illness differed from the specific expectations of the teacher or the teacher lacked confidence, related to knowledge or skill, in working with children with chronic illness.

Some parents desired life skills or a reduced academic course load for their child with chronic illness. They stated that school was important but not as important as other areas, such as peer interactions, family time, or health needs. Parents felt teachers focused more on purely academic outcomes. In meeting cognitive function goals, attendance, completion of work, and medication or symptom management were noted as issues which directly interfered. For children with chronic illness, increased absences and decreased ability to concentrate combine to create an additional risk to the student’s learning outcomes (Sexson & Madan-Swain, 1993; Shiu, 2001). These issues required support from the teacher and school.

Supports designed to individualize instruction and maximize student learning can only be provided when educators have the necessary information about a specific child (Badger, 2008;

Shaw & McCabe, 2008). IEP or 504 plans were needed, based on the degree of accommodation or length of time accommodation would be needed. According to the literature, clearly written goals and strategies in the student's IEP or 504 plans are valuable in establishing expectations (Robinson & Summers, 2012). Parents in the current research noted that most supports were provided, however, the timing was later than what parents preferred or defined as most beneficial. According to West et al. (2013), educators are less willing to implement accommodations that were perceived to be burdensome. Of the supports not provided, parents noted a number of issues including lack of understanding from the school, lack of interest from the family, and lack of availability in the necessary time frame.

### **Advocacy**

Advocacy was a finding added under the concept of supports perceived or expected to be provided. Parents primarily perceived advocacy as needed in the areas of awareness and preparation for having a child with chronic illness in the classroom, or in the school. Anderson (2009) reported that parents perceived they are acknowledged as experts, but also felt that teachers should be better educated about the impact of chronic illness on their child. As previously discussed, teachers were not seen as prepared to have children with chronic illness in their class. The first step in the process was awareness that the child with chronic illness had special needs, potentially in every area of development, and that each child's needs must be identified based on individual health circumstances—diagnoses, treatment, medications, etc. This awareness was seen as necessary for the teachers, school systems, peers, and parents of peers. The parent's perspective is a more thorough, comprehensive, developmental impact should be understood by educators and health care professionals alike (Oeseburg et al., 2010; Sexson & Madan-Swain, 1993). Parents of the child with chronic illness often felt responsible to

be their child's advocate in the education setting as well as in the healthcare setting and in every other setting where the child with chronic illness existed or spent time.

Being an advocate often meant providing education for working with own their child with chronic illness, case advocacy, and sometimes for the larger population of children with chronic illness or special health care needs, class advocacy. Many educators are ill-prepared to deal with issues of chronic illness in the schools (Clay et al., 2004). Parents emphasized that the role of advocate and educator was ongoing, as the role of the child grew and changed from one classroom to another, adding new sports or extra-curricular activities, or staff changed, or health conditions progressed. Having relevant knowledge and training would allow the teacher to provide individualized instruction that recognizes the strengths and concerns of each student, as related to their chronic illness, their treatment, prognosis, and developmental information (Gartin & Murdick, 2009; Nabors et al., 2008; Shaw & McCabe, 2008). The role of advocate, although not atypical for a parent, was more complex for the parent of a child with chronic illness when adding the layer of healthcare concerns. These concerns had the added meaningfulness of impacting the child's well-being and, therefore, often took precedence over other roles or responsibilities for the parent, affecting other family members and career. Advocacy was an essential role, yet not a role that came naturally to all parents. In this role, parents were often expected to communication and expedite collaboration among multiple professionals, perhaps across multiple settings. These multi-disciplinary meetings often required information from the parent and yet the parent had little to no power in the logistical planning or control of meetings. Outcomes of conferences might impact supports or services available to the child. Parents clearly communicated a potential to feel overwhelmed and frustrated. Advocacy was a role



expected of parents and yet one in which they have little power. Advocacy is, therefore, an area to consider the role of the professional in supporting the family of the child with chronic illness.

### **Limitations**

The current research included interviews with 10 parents who had a child with a chronic illness. While the research was qualitative and intended to be phenomenological and represent parent experience, it may be considered a limitation that only 10 parent experiences are represented. In assessing previous research with parents of children with chronic illness, the experiences of 10 participants is expected to be adequate for “saturation in thematic areas” (Fischer, 2001, p. 345).

Additionally, all 10 of the parents interviewed were mothers. Several fathers expressed interest in participating, but were unable to be scheduled during the data collection period. This is essential to note, as each parent may fill a different role in the family system. Mothers may be more hands-on caregivers and fathers may be more financially supportive. Mothers are more frequently present during communication with various educational and healthcare professionals due to these differing roles and responsibilities (Anderson, 2009; Kerr & Bowen, 1988)

The sampling methodology may have led to a sample which was not representative of the general experience of a parent of a child with chronic illness. The pilot study used purposive sampling, with purposive and snowball sampling used to recruit the remainder of the research participants. Parents who volunteered, nominated other parents, and agreed to participate in research related to communication may differ in important aspects from the larger population of parents who have a child with a chronic illness.

The topic or nature of the study may have limited participation, either in general willingness to participate or in openness of communication. Asking questions related to health,

child outcomes, communication with education system, and overall family systems may be considered sensitive. Although parents were assured of confidentiality, encouraged to schedule interviews at a time and location of their choice, and assumed to be truthful, it is possible that some parents declined to participate or withheld information due to feelings of discomfort or ambiguity. Parents who have a child with a chronic illness experience increased levels of stress, decreased health, and feelings of inadequacy and self-doubt regarding their parenting skills. The stress and health issues may lead to less availability to participate in the research whereas the feelings of inadequacy may lead to less willingness to participate in the research.

Another possible limitation related to the importance of communication is the need to incorporate multiple participants and perspectives. During the current research, only the experience and perspective of the parent was explored. This limits the understanding of the relationship between the parents of a child with chronic illness in communicating with their child's teacher (or other education or healthcare professionals), as the teacher's experience and perspective were not part of the current research. A one-sided assessment is considered a limitation of this work.

Generalization of findings emerging from qualitative research is a final limitation. Qualitative research does not seek to generalize (Denzin & Lincoln, 2005). There is no expectation that the 10 cases in the current study represent the experiences, expectation, and beliefs of all parents who have a child with a chronic illness. The goal was greater insight, which may be transferrable to other settings, and help to provide better understanding of a complex situation.

## Recommendations

In order to meet both the health and the educational needs of students in educational settings, parents and educators need to communicate openly, clearly, and regularly. The student is the one who ultimately pays the price for lack of communication. There are several recommendations that may increase the understanding and sharing of information. The first is training and education. There are some pieces in place in teacher preparation programs (Nabors et al., 2008; Sexson & Madan-Swain, 1993). From the start of their education, all teachers should be provided with training on the effects of illness and hospitalization on a child's ability to learn and develop. Teachers should be educated about both the short-term and long-term impact of chronic illness on students' cognitive, social, emotional, and physical development. Some specific high incidence illnesses should be part of their training. As part of ongoing continuing education and training, teachers should become more informed about specific health-related issues, diagnoses, treatment, and prognosis of the individual students within their classrooms. It would be impossible for any educator to keep current with all medical knowledge. This is the role of the PCP and current medical information must be provided by or through the parent. Educators need to know how to access relevant medical information, when they should be getting more education, and why it is important. Alternatively, parents should be supported in how to effectively work with school personnel to enhance learning for students with chronic illness and know their rights. They should be provided some form of training or education to enhance their understanding of the rights their child with chronic illness has within the educational system.

A second recommendation would be to have a liaison, or advocacy, position (Nabors et al., 2008; Shaw & McCabe, 2008). Parents are often put in the position of being the go-between

and translating or communicating between school and healthcare staff. This can put parents in a position of explaining to both sides issues and decisions that are potentially beyond the parents' comfort level and understanding (Anderson, 2009; Oeseburg et al., 2010). A liaison could be an advocate who is educated on how both professional worlds process information and function. Decisions can be made more efficiently and more accurately. Several logistical possibilities exist for a liaison position. The liaison may be an individual or it may be a team. The liaison may be appointed as needed, by referral, or it may be an on-going position used as a resource without necessitating a full case referral.

A final recommendation is for administration to be educated about the impact of chronic illness and the importance of communication and collaboration between education and parents of children with chronic illness (Currie, 2005; Kaffenberger, 2006; Shaw et al., 2004). Policies, funding, and personnel decisions should be made that support the education of all children and this includes those with a chronic illness. Data related to school attendance and academic performance may be used to support the need to provide support and transition or school reentry services for children who are chronically ill in the education setting. Students with a chronic illness may be eligible for educational services or accommodations under IDEA or section 504. The support that students receive increases their chances for academic success and a return to normalcy. This knowledge will allow administrators and policy makers to be aware of the needs of the students in their schools and make available appropriate resources.

### **Future Research**

As communication is a dynamic process, future research may explore communication from the perspective of the educator as well as that of the PCP. Teachers' knowledge of the impact of illness on student ability to learn may be compared to parent knowledge as well as the

knowledge of healthcare providers. Researchers may explore differences in perceptions as well as how differences are attributed to either acute or chronic illness. Researchers may also explore the link between knowledge and practice. Does understanding that illness affects learning translate into educational practice in the classroom? With the increase in the number of children with a chronic illness in the classroom, researchers may investigate the difference between the knowledge and comfort of general education teachers and special education teachers. How confident are teachers about their preparation and knowledge to work with students with a chronic illness? There are numerous issues to look at in the connection with having a student with a chronic illness in the classroom and the impact on learning since the population of children with a chronic illness in the classroom is growing. Collaboration between education and healthcare settings will provide improved understanding and better communication. This will allow for all professionals to provide the best care for the student based on accurate, complete, and current data.

Finally, the experience and perspective of the child with chronic illness personally should not be ignored. What do these children have to say? What do they want to share about their health and education? How is their knowledge and attitude important, both about their illness as well as their expectations for inclusion, achievement, and supports? What perceptions do they have about their peers, teachers, PCPs, and families? How much do they know about their own health and its impact on their education? What are their goals and how do we, as professionals, support achievement of these goals?

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## APPENDIX A: QUESTIONS FOR INTERVIEW

1. Tell me about your child. How old is he/she? (make a note if the child is male/female)
2. How would you describe your child's ethnic background?
  - White-Non-Hispanic
  - Black-Non-Hispanic
  - Asian/Pacific Islander
  - Native People
  - Hispanic
  - Multiple Ethnic Backgrounds
  - Other (specify)
3. Tell me about the family members that live in your home.
4. What grade in school is your child in?  
What is the name of your child's school?  
What town is it in?  
Approximately how many children attend your child's school?
5. Describe your child's special health condition.
  - What, if any, special medical interventions or considerations does your child need that other children the same age, without any special health conditions, do not need?
6. Tell me how your child's special health care needs affect him/her at school.
  - May follow up/ probe about behavior, peer relationships, school performance.
  -
7. Are there some particular things that your child's school does very well in terms of meeting the support needs of your family and your child?
  - May follow up/probe as to why parent perceives it as a strength.
8. Are there some particular things that your child's school does poorly in terms of meeting the support needs of your family and your child?  
May follow up/probe as to why parent perceives it as a weakness.
9. Describe what supports are and what supports should be available at school for your child with special health care needs.
  - May follow up/probe regarding whether educators have been consistent from year to year, or if some years the educators were better than other years. If such a discrepancy exists, will follow up/probe regarding whether the parents believe that the discrepancy was due to characteristics of the child (e.g., he was sick more often) or characteristics of the educators.
10. How prepared did you feel teachers were to work with your child with special health care needs?

- May follow up/ probe about educator competency and preparation to meet a child's physical needs and medical care needs, in contrast to educator competency and preparation to meet a child's social, academic, and needs other than physical/medical.
11. Can you describe how having a special health care need might affect people's expectations for your child?
- May follow up/ probe about expectations of parents, other family members, educators, peers, and others (e.g., neighbors).
  - May follow up/ probe about behavior, peer relationships, school performance.
12. Tell me about the communication you have with your child's teacher and other educators?
- Do feel the communication between home and school meets the needs of your child and you as a parent?
  - If not, what, if anything, could be done to improve it?
  - May follow up/probe to ask about frequency of communication, desired forms/ methods of communication, desired topics for communication.
13. In addition to communication, are there other ways that teachers or the school supports your involvement as a parent in your child's education, or in some way supports the family as a whole?
- May follow up/probe to determine the nature of these parent/family supports, and if these are provided to all families or are unique because of the special needs of the parent's child.
14. What else would you like to add that I have not asked?



## APPENDIX B: PARENT PARTICIPANT INFORMED CONSENT FORM

I, \_\_\_\_\_, agree to participate in the research project that will be conducted by Keri Edwards, doctoral student, and Dr. James R. Thompson, faculty member of the Department of Special Education at Illinois State University. I understand that my participation in this study is entirely voluntary. I can withdraw my consent to participate at any time without penalty.

The purpose of this research is to investigate the perspectives of parents of children with special health care needs regarding their desire and understanding for supports needed for their child at school. I will be asked to answer questions about this in a 60-minute interview that will be audio-recorded. I understand that I may refuse to answer any question and/or may withdraw from the study at any time.

The findings of this research project may assist educators in developing further professional opportunities and in making decisions in developing future programming and supports for students/children with special health care needs. There is a potential risk to my confidentiality. All necessary precautions will be taken to ensure my complete confidentiality. My interview will be audio taped by the interviewer, Keri Edwards. She will destroy the audio recording as soon as she is done transcribing the interview, which will be within two weeks of the interview. When she transcribes the audio recording, she will use a code name for everyone and everything that is mentioned during the interview. That is, she will not use my real name, she will not use anyone else's real name (e.g., a teacher's real name who I might mention), and she will not use any organization or building's real name (e.g., the name of my child's school). Keri Edwards will assign a code name for all written and verbal reports that emerge from her interviews with parents, including her interview with me. If I find the questions and interview to be psychologically distressing, I can end the interview and withdraw from the study at any time.

Only the two researchers, Dr. James Thompson and Keri Edwards, will have access to the master list containing my real name and corresponding code name. Keri Edwards will store all the interview data under lock and key. Written documents will be shredded 5 years after any written reports are published or disseminated, and transcription files will be erased 5 years after any written reports are published or disseminated. The benefits of understanding the perspectives of parents of children with special health care needs may lead to professional development for teachers that can improve the supports that schools provide to children with special health care needs.

Keri Edwards will answer my questions about the research, either now or during the study. I may contact Keri Edwards by cell phone XXXXX or email at XXXXX or Dr. James R. Thompson at XXXXX or email at XXXXX. If you have any questions about your rights as a subject/participant in this research, or if you feel you or your child have been placed at risk, you can contact the Research Ethics & Compliance Office at Illinois State University at (309) 438- 2529 or [rec@ilstu.edu](mailto:rec@ilstu.edu).

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Signature of Participant

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Printed Name of Participant

APPENDIX C: ADAPTED ILLNESS INTRUSIVENESS RATING SCALE  
(adapted from Devins, 2010)

The following items ask about how much your child’s healthcare need and/or its treatment impact different aspects of your child’s life and your family life. PLEASE CIRCLE THE NUMBER THAT BEST DESCRIBES THE CURRENT SITUATION. If an item is not applicable, please circle the number one (1) to indicate that this aspect of life is not affected very much. Please do not leave any item unanswered. Thank you.

*How much does your child’s healthcare and/or its treatment impact his or her:*

		Not Very Much							Very Much
Health	Physical, mental, and social well-being	1	2	3	4	5	6	7	
Diet	The things your child eats and drinks	1	2	3	4	5	6	7	
School Participation	School attendance or other activities that impact your child’s ability to participate in school	1	2	3	4	5	6	7	
School Learning	Activities related to acquiring knowledge and/or skills while attending school	1	2	3	4	5	6	7	
Active Recreation	Activities such as sports	1	2	3	4	5	6	7	
Passive Recreation	Activities such as reading or listening to music	1	2	3	4	5	6	7	
Relationship with Peers	Interactions with friends and/or classmates	1	2	3	4	5	6	7	
Self-Expression	Ability to communicate his/her thoughts, feelings, or ideas	1	2	3	4	5	6	7	
Family Financial Situation	Impact on family resources (primarily economic)	1	2	3	4	5	6	7	
Family Stress	Response to impact on family resources	1	2	3	4	5	6	7	

## APPENDIX D: RECRUITMENT E-MAIL

Dear \_\_\_\_\_,

I am writing to you to see if you would consider being interviewed regarding your perspectives as a parent of a child with special health care needs. Specifically, I am interested in learning about your understanding of the supports your child needs and what supports you believe your child's educators should provide. The interview will take approximately 60-minutes and will be audio-recorded.

Please understand that your participation in this study is entirely voluntary. It is totally up to you whether you participate. If you choose to participate, you can refuse to answer any question and can choose to withdraw from the study at any time. The questions that I will be asking are:

1. Tell me about your child. How old is he/she? What grade in school is he/she in? Approximately how many children attend your child's school?
2. Describe your child's special health condition. What, if any, special medical interventions or considerations does your child need that other children the same age, without any special health conditions, do not need?
3. Tell me about the communication you have with your child's teacher and other educators? Do feel the communication between home and school meets the needs of your child and you as a parent? If not, what, if anything, could be done to improve it?
4. In addition to communication, are there other ways that teachers or the school supports your involvement as a parent in your child's education, or in some way supports the family as a whole?
5. Tell me how your child's special health care needs affect him/her at school.
6. Can you describe how having a special health care need might affect people's expectations for your child?
7. How prepared did you feel teachers were to work with you child with special health care needs?
8. Describe what supports are and what supports should be available at school for your child with special health care needs.

I intend to interview at least four parents. Findings from my interviews may be shared in publications or presentations at professional conferences. However, no individual's name or other identifying information will be shared.

This study has been approved by the Illinois State University Institutional Review Board. If you have any questions about your rights as a subject/participant in this research, or if you feel you have been placed at risk, you can contact the Research Ethics & Compliance Office at Illinois State University at (309) 438- 8451.

Thank you for your consideration of this request and please do not hesitate to contact me if you would like more information. All of my contact information is listed below. I look forward to hearing back from you regarding your availability to participate in the study. If you are interested and available to participate, I will need to review a consent form to you. If you choose to provide consent to be interviewed, I would then be able to proceed to conduct the interview.

Sincerely,  
Keri Edwards  
Doctoral Student  
Department of Special Education  
Illinois State University -MC 5910  
Normal, IL 61790-5910  
XXXXX

APPENDIX E: DATA ACCOUNTING LOG

	Initial Contact/ Participant interested	Interview date	Location	Interview transcribed	Interview coded	Coding confirmed with 2 <sup>nd</sup> reviewer	Interview confirmed with participant
Mary	1/13/13	2/7/13	Family home	3/13/13	4/13/13	5/20/13	6/15/15
Susie	2/13/13	4/14/13	Family home	4/13/13	4/13/13	5/20/13	2/11/15
Justin	3/13/13	5/10/13	Researcher office	5/13/13	5/13/13 Recoded 10/13- 14/15	5/20/13	2/16/15
Amy	3/4/15 5/21/15	5/27/15	Researcher office	6/16/15	9/19/15	10/16/15	6/18/15
Kevin	6/21/15	6/12/15	Clinic	6/16/15	9/16/15	10/17/15	
Caroline	6/12/15	6/12/15	Clinic	6/22/15	10/5/15	10/17/15	
Patrick	6/12/15	6/12/15	Clinic	6/17/15	10/9/15	10/17/15	
Bryan	5/21/15	6/17/15	Coffee shop	7/20/15	10/16/15	11/13/15	
Lizzie	5/21/15	6/29/15	Home	7/22/15	10/23/15	11/13/15	10/5/15
Kelli	6/12/15	7/1/15	Participant office	7/23/15	10/24/15	11/13/15	10/15/15

APPENDIX F: RESEARCH PARTICIPANT INFORMATION

PART 1

	Mary	Susie	Justin	Amy	Kevin
<b>Child Demographics</b>					
Gender	F	F	M	F	M
Age	10	13	8	10	6
Grade	4	6	1	4	Pre-K (second year)
SHCN (special health care need)	ADD; allergy induced asthma; celiac disease; urological issues	no esophagus; tracheotomy; gastrostomy tube; developmental delay	asthma; glasses (bifocals)	allergies; asthma	ALL; autism spectrum disorder
<b>Family Demographics</b>					
Adapted IIRS Score (7-70)	42	70	14	28	37
Parents	married	married	married	Divorced; mom remarried	married
Siblings Age	11, 8	32, 31, 30	Only child	8	2 ½
<b>School Demographics</b>					
Public/Private	private	public	public	public	public
Class Size	14	21	22	20	11
School Size	135	400	500	200	400

PART 2

	<b>Caroline</b>	<b>Patrick</b>	<b>Bryan</b>	<b>Lizzie</b>	<b>Emily</b>
<b>Child Demographics</b>					
Gender	F	M	M	F	F
Age	13	7	10	13	15
Grade	7	1	4	7	9
SHCN (special health care need)	Leukemia (in remission)	ALL	allergies; asthma	scoliosis	diabetic- type I
<b>Family Demographics</b>					
Adapted IIRS Score (7-70)	39	42	28	41	40
Parents	married	married	divorced	married	married
Siblings Age	7, 10	11, 17	11 ½	3 ½, 10	11
<b>School Demographics</b>					
Public/Private	private	public	public	private	private
Class Size	22	23	22	10	58
School Size	200	470	500	100	225

APPENDIX G: PARENT PERSPECTIVES ON THE SUPPORT NEEDS OF CHILDREN  
WITH CHRONIC ILLNESS: CODING MATRIX

<b>Category/Pattern</b>	<b>Code</b>	<b>Description/Definition</b>
<b>Demographics</b>	<b>Dem</b>	
	Fam	Family
	FamDem	Child/Family Demographics
		Ethnicity
		Marital status of parents
		# of children (in family, in home)
		Birth order of child, if reported
		Age of child
		Gender of child
	Sch	School
	SchDem	School Demographics
	PCP	Primary Health Care Provider
	PCPDem	PCHP Demographics
<b>Collaboration &amp; Communication</b>		topic: dx, health, tx, meds, attendance, performance
	ComFamSch	Family to School Communication
	ComSchFam	School to Family Communication
	ComFamPCP	family to PCHP Communication
	ComPCPFam	PHCP to Family Communication
	ComPCPSch	PHCP to School Communication
	ComSch	Communication within the school
	ComSchQual	School Communication Quality
	ComQual	Communication Quality
	SchTrn	School/Teacher training or education
	SchExp	School/teacher expectations
	SchKnow	School/teacher knowledge or understanding
	FamExp	Family expectations
	FamKnow	Family knowledge
	SocExp	Peer (or community) expectations
	SocKnow	Peer Knowledge or understanding
<b>Child's Functioning</b>	<b>ChFx</b>	
	ChFxPhy	Child's Functioning, Physical
	ChFxSoc	Child's Functioning, Social
	ChFxBeh	Child's Functioning, Behavioral



	ChFxCog	Child's Functioning, Cognitive
<b>Support Needs</b>	<b>SupNd</b>	
	SupNdPhy	Support Needs, Physical
	SupNdSoc	Support Needs, Social
	SupNdBeh	Support Needs, Behavioral
	SupNdCog	Support Needs, Cognitive
<b>Supports Provided</b>	<b>SupPr</b>	
	SupPrPhys	Supports Provided, Physical
	SupPrSoc	Supports Provided, Social
	SupPrBeh	Supports Provided, Behavioral
	SupPrCog	Supports Provided, Cognitive
<b>Outcomes</b>	<b>Out--</b>	
	OutAc	Outcomes, Academic Progress
	OutSchPart	Outcomes, School Participation
	OutSoc	Outcomes, Social Growth

APPENDIX H: CONSTRUCT MATRIX: COLLABORATION & COMMUNICATION

	Supporting Quotes	SHCN	Age	Grade	A-IIRS Score
<b>Mary</b>					
ComFamSch	<p>with the ADD is working with her teachers to be able to understand what ADD is</p> <p>So once I made the teacher aware of it, the teacher then was noticed it, she could then zero in on when it was happening.</p>	ADD; allergy induced asthma; celiac's disease; urologic issues	10	4	42
ComSchFam	<p>their teachers are very good at keeping us informed of any changes um and</p> <p>they can communicate back to the health care providers</p> <p>They let me know when they see changes or struggles that they are having</p> <p>they will have questions, where they have asked for a list of what she can't have, like we sent in a list of especially food</p>	ADD; allergy induced asthma; celiac's disease; urologic issues	10	4	42
ComFamPHCP		ADD; allergy induced asthma; celiac's disease; urologic issues	10	4	42
ComPHCPFam	The doctors have also been really good with giving us information to pass on to the teachers	ADD; allergy induced asthma; celiac's disease; urologic issues	10	4	42

ComPHCPSch	<p>her pediatric urologist has letter that goes to her teachers</p> <p>our health care provider has given us checklists that the teachers can use then to help evaluate in classroom behaviors</p>	ADD; allergy induced asthma; celiac's disease; urologic issues	10	4	42
ComSch	the teacher even communicated with the other parents in the class, um and she obviously came to me for my permission.	ADD; allergy induced asthma; celiac's disease; urologic issues	10	4	42
ComSchQual	<p>Some teachers have been more receptive to understanding some of the needs and some have been a little bit more I don't want to say resistant but some of them don't necessarily understand and so or they have misinformation themselves and they are not always as open to understanding some of the new information</p> <p>we do benefit it from being a smaller school because I can talk with our cafeteria person and her and I talked about, and she will come up to me and show me the box that the food came in and we screen it for her.</p> <p>I can say if you talk to the third grade teacher, he was really successful at getting her to get the work done.</p>	ADD; allergy induced asthma; celiac's disease; urologic issues	10	4	42
ComQual	I can read about what a child with ADD is like but you don't actually until you, no two kids are the same, no two treatments are the same.	ADD; allergy induced asthma; celiac's disease; urologic issues	10	4	42
Susie					
ComFamSch	We did an orientation about Susie and her difficulties and some of her	no esophagus;	13	6	70

	<p>personality things with the teachers, the teaching assistant, and with her main classroom teacher because in this class they then leave the classroom for science social studies.</p> <p>There are times when I send a note back saying you know she was just too tired last night that we didn't get the homework done and the teachers are understanding about that.</p> <p>And then also when we have conference we make it clear, you still need to expect her to do homework.</p>	tracheotomy; gastrostomy tube; developmental delay			
ComSchFam	<p>And they called me in to tell me she didn't get her work done, we don't know what to do with this. Partly because the nurse goes home at 3:30 and the nurse needs to be in the building when she was there. So they communicated with me, we don't know how you want to handle this, and I said what happens with normal kids, well they stay after and do their work, Okay, I will be at school and I will sit in the office to make sure she completes her work.</p> <p>This small school works very well to call and talk to the teacher or the nurse on the phone.</p> <p>They called me to say we really don't think she should be here because she doesn't need to catch these things (if staff of students called in sick).</p>	no esophagus; tracheotomy; gastrostomy tube; developmental delay	13	6	70
ComFamPHCP		no esophagus; tracheotomy; gastrostomy tube; developmental delay	13	6	70

ComPHCPFam		no esophagus; tracheotomy; gastrostomy tube; developmental delay	13	6	70
ComPHCPSch		no esophagus; tracheotomy; gastrostomy tube; developmental delay	13	6	70
ComSch	Then the nurse will find the time to tell the teacher.	no esophagus; tracheotomy; gastrostomy tube; developmental delay	13	6	70
ComSchQual	<p>Pretty much anything we ask to alter that they have commented, I think the school has learned a lot from this experience.</p> <p>They talk about how we are willing to step in and take up the slack that needs to be.</p>	no esophagus; tracheotomy; gastrostomy tube; developmental delay	13	6	70
ComQual	<p>I think we were very intimidated because we had to have an IEP meeting very quickly. They are used to having a couple of teachers involved and in her case she had the nurse involved, the principal involved, the guidance counselor would be involved, the social worker, and usually one parent. Well, for her first IEP meeting there were 23 people there.</p> <p>The usual IEP meeting lasts 15-20 minutes. We finally called an end to the meeting at 2 ½ hours.</p>	no esophagus; tracheotomy; gastrostomy tube; developmental delay	13	6	70

<b>Justin</b>					
ComFamSch	<p>I did communicate with his teachers and staff to make sure that they were aware and everything</p> <p>I sent a note to his teacher</p> <p>so I have to update that information again but this next year school year.</p> <p>that will definitely be something I make sure the teacher is aware of and um from the very beginning</p> <p>that's why I sent the note to school to let her know.</p> <p>I've always communicated with teachers, it's always something that we've had to keep watching a he is starting to get more self-conscience about because he's getting older</p> <p>So we have probably to do a lot more communication with teachers and stuff back than with that as we were getting things figured out maybe even with the asthma right</p>	Glasses; neb tx and/or inhaler	8	1	14
ComSchFam	<p>what she would do is she would communicate back or she would put a note in his bag with the inhaler when he brought it home if he had to use it at school that day</p> <p>made me feel a lot better when she sent that note home because like during a couple month of period when he was doing worse with it, I was always checking my phone</p> <p>they would contact us right away or take the appropriate medical steps.</p>	Glasses; neb tx and/or inhaler	8	1	14
ComFamPHCP		Glasses; neb tx and/or inhaler	8	1	14

ComPHCPFam		Glasses; neb tx and/or inhaler	8	1	14
ComPHCPSch		Glasses; neb tx and/or inhaler	8	1	14
ComSch		Glasses; neb tx and/or inhaler	8	1	14
ComSchQual		Glasses; neb tx and/or inhaler	8	1	14
ComQual	<p>we sort of have had a proactive approach so I won't have to keep sending the note to school every day. After I sent her the note and told her, here's what I think is going on,</p> <p>she totally understood what we were doing</p> <p>our particular school they do a very good job with parent contact in general they have always been communicating with us</p> <p>things like being able to communicate with parents whether it be conferences or anything or being able to doing something after school hours</p>	Glasses; neb tx and/or inhaler	8	1	14
<b>Amy</b>					
ComFamSch	<p>I came up to the school to let them know. I talked with the nurse in the office and I talked with her teacher.</p> <p>I communicated with her special ed teacher the most.</p> <p>We have a daily communicator that comes home and sometimes through email.</p>	allergies; asthma	10	4	28

	When I told them about the food allergies, they were surprised because if they would have items with peanuts in them she would just say I don't like it				
ComSchFam	<p>Sometimes they'll call me to see if I want her to stay there and just work through the day or take her home.</p> <p>She came to school and they wrote me a note letting me know could you bring it (medicine) back tomorrow. So they are very visual and they are letting me know that she didn't have her medicine today and could bring it back for tomorrow.</p> <p>Actually, I think sometimes phone calls work better for me. Just because every once in a while it will be just really busy and I don't read the communicator as much as like I should.</p> <p>There is a newsletter that is sent home and it is also sent electronically. Sometimes the teacher will send notes about certain events that the kids are going to be involved in, like the whole class was in the talent show.</p>	allergies; asthma	10	4	28
ComFamPHCP	And there are times I take her to the doctor and the doctor is like "oh, she's fine". Well, there's \$25 down the drain.	allergies; asthma	10	4	28
ComPHCPFam	I was given one (form) by her allergist...	allergies; asthma	10	4	28
ComPHCPSch		allergies; asthma	10	4	28
ComSch	I was given one (allergy form) by her allergist, but they (the school) wanted me to fill out a more specific form that all the nurses in the district and familiar with to get information.	allergies; asthma	10	4	28



ComSchQual	Do the teachers think I'm not doing my job? When I get that phone call, "She's not feeling well." And I feel like what they're saying... I mean, they are really nice, but in the back of their heads I know they're thinking, "I know you saw what she looked like this morning and you sent her to school this way?" It's like, a lot of thought went into this, do I want her to miss another day of school?	allergies; asthma	10	4	28
ComQual	I liked that- that they had a specific form.  Yes, the communication between home and school generally meets my needs.  So phone calls are the best.	allergies; asthma	10	4	28
<b>Kevin</b>					
ComFamSch	We text a lot.  We explained to them if you are using playdough, he uses a brand new container. He doesn't use something that 5 other children have already used, sneezed on, spit on, put in their mouth. You can clean tables, you can't clean playdough.  We also told them that we're not sure how often you're cleaning your toys, but with Kevin being in your classroom, at the end of day, you spray them down with Lysol and you wipe them down or it's just that he simply can't come here. His health comes first.	ALL; autism spectrum disorder	6	PreK -2nd year	37
ComSchFam	I wasn't always told exactly when other kids were sick. It was always after the fact.  They always call me when other children school had pneumonia or stuff like that.	ALL; autism spectrum disorder	6	PreK -2nd year	37

	<p>We (Mom and Teachers) have each other's phone numbers. Other than that, when he was going to school I would hear from all of his teachers daily.</p> <p>They did call me on certain circumstances like at the beginning of the school day if they had call ins.</p>				
ComFamPHCP	I have talked to her doctor about this as well, I wonder if she is using her inhaler properly.	ALL; autism spectrum disorder	6	PreK -2nd year	37
ComPHCPFam		ALL; autism spectrum disorder	6	PreK -2nd year	37
ComPHCPSch		ALL; autism spectrum disorder	6	PreK -2nd year	37
ComSch		ALL; autism spectrum disorder	6	PreK -2nd year	37
ComSchQual	<p>It's pretty good for the most part.</p> <p>I honestly thing the communication is a lot better now that we are doing it at home.</p> <p>Obviously there were times when they weren't as good at communicating as they should have been.</p>	ALL; autism spectrum disorder	6	PreK -2nd year	37
ComQual		ALL; autism spectrum disorder	6	PreK -2nd year	37
<b>Caroline</b>					
ComFamSch	<p>Usually communicated just directly with the teacher.</p> <p>Yes, usually verbal communication, yeah.</p> <p>Another thing that speaks of our modern communication is that I was texting with her teacher. I would text her updates and communicate.</p>	Leukemia (in remission)	13	7	39

ComSchFam	<p>The secretary would communicate with me if need and that kind of stuff.</p> <p>I mean if I wasn't there that day, then phone communication. Not a whole lot of emailing goes on.</p> <p>When we were in the hospital they skyped with her.</p> <p>I do have to say that her regular full time teacher who has her most of the day said to me, "Will you go to the doctor, will you please bring me a list of what she can't do?"...And I am glad she did reach out to me.</p>	Leukemia (in remission)	13	7	39
ComFamPHCP		Leukemia (in remission)	13	7	39
ComPHCPFam		Leukemia (in remission)	13	7	39
ComPHCPSch	<p>And so I would say most of the time the communication got transferred. And we asked everyone to share that.</p>	Leukemia (in remission)	13	7	39
ComSch	<p>We have gotten into different modes of communication with texting, facebook, emails.</p> <p>And one thing they did really well that I thought was nice, is that they even told all of the younger kids in the building, "Don't run up and grab her or hug her." Those are things that these kids might think, oh she's here, she's back, and they're excited to see her. And it so sweet.</p>	Leukemia (in remission)	13	7	39
ComSchQual	<p>You know, 10 years ago, you wouldn't have had that instant communication, so that has been something they did really well. And it was a tool we had to make work.</p>	Leukemia (in remission)	13	7	39
ComQual		Leukemia (in remission)	13	7	39

<b>Patrick</b>					
ComFamSch	Well, I talk to the teacher a lot. I talk to her a lot and then I would see her every day before and after school.	ALL	7	1	42
ComSchFam		ALL	7	1	42
ComFamPHCP		ALL	7	1	42
ComPHCPFam	Like in Memphis they told us if he needs help for her (school nurse) not to have him go to her office but she needs to come to him because there are so many germs in her office.	ALL	7	1	42
ComPHCPSch	And (they) came and did a presentation that first week back and it was nice. And (they) sent a little letter....I think that is was good for the kids because she brought in her doll and answered questions	ALL	7	1	42
ComSch		ALL	7	1	42
ComSchQual		ALL	7	1	42
ComQual	Yes, we communicate verbally most often.	ALL	7	1	42
<b>Bryan</b>					
ComFamSch	But every time there's a field trip, when I sign the permission slip, I say please bring this, this, and this with him. And the morning of, I do email them a reminder, because I know it gets crazy and busy and the idea that he would be off somewhere far from me and far from his medical supplies would not be a good situation.  I communicate with the office and the teacher mostly. I try to send things to both just as a back-up plan so that at least 2 people in the school know what I'm trying to communicate.	allergies; asthma	10	4	28
ComSchFam	And she (nurse) actually called me and said, "we don't have what you're supposed to have (Benadryl)."	allergies; asthma	10	4	28
ComFamPHCP		allergies; asthma	10	4	28

ComPHCPFam		allergies; asthma	10	4	28
ComPHCPSch	If we have a new issue, then I have the doctor write a note and send that to the school.	allergies; asthma	10	4	28
ComSch	If you don't understand the what the signals are or when to call for help, or what to do, valuable time is lost when something should be happening....And those are the kinds of conversations that I would like to have more of. Do you know what I mean? If he's doing this, you need to tell him to go use his inhaler whether he wants to or not.	allergies; asthma	10	4	28
ComSchQual	<p>I love the quality control, I was so excited that someone was actually paying attention that Bryan needs this available and we have to have it and so I believe they're getting better.</p> <p>I don't think that most people get it that if he eats peanuts, he will most likely have anaphylactic shock and could die. So that is something that I don't feel like we've gotten across very well.</p> <p>And so that is my current experience is that I'm going to have to be a lot more assertive with the staff because if they're not reading the papers that I have to fill out for them then I don't know how to (communicate clearer), you know, what I mean.</p> <p>(Previous school experience) When they (paramedics) arrived they said he would have 15 more minutes or he would have died because of the swelling. And so they said to me, my relevant piece here, they said to me afterwards, you never told us how serious his allergy was.</p>	allergies; asthma	10	4	28

ComQual		allergies; asthma	10	4	28
<b>Lizzie</b>					
ComFamSch	I'm not sure if they (school) would have pursued that if I hadn't sent an email with a bunch of information or upcoming dates that we're going to be gone.  We used text messaging, email. Mostly text and email, very few phone calls.  I would text her every few days with update and when she was in the hospital I would probably (communicate) close to daily, just kind of letting them know because they were all worried about her and how things were going.	scoliosis	13	7	41
ComSchFam	We used text messaging, email. Mostly text and email, very few phone calls.	scoliosis	13	7	41
ComFamPHCP		scoliosis	13	7	41
ComPHCPFam		scoliosis	13	7	41
ComPHCPSch		scoliosis	13	7	41
ComSch		scoliosis	13	7	41
ComSchQual	Actually, most of the time yes if one person was told it (information), it got transferred to other staff and teachers in the school.	scoliosis	13	7	41
ComQual		scoliosis	13	7	41
<b>Emily</b>					
ComFamSch					
ComSchFam	Email. The nurse will call me, usually very seldom talk to her through email, unless it's something that is coming up, like the school trip type of thing. Otherwise, teachers if they have a question they usually wait until conferences.	diabetic-type I	15	9	40
ComFamPHCP		diabetic-type I	15	9	40
ComPHCPFam		diabetic-type I	15	9	40

ComPHCPSch	And the pediatric office that she goes to, the endocrinologist, prints out a discharge paper that goes directly to the school, It tell them what her ratio are, what to do if she high, if she ketones how much to give her. All of the information to contact them.  If they want to know something specific, Erin (nurse) knows she has the permission to call.	diabetic-type I	15	9	40
ComSch		diabetic-type I	15	9	40
ComSchQual	She (nurse, Erin) is very good about calling me if there's any chance that something's going on.	diabetic-type I	15	9	40
ComQual		diabetic-type I	15	9	40

End matrix

APPENDIX I: CASE-LEVEL DISPLAY FOR PARTIALLY ORDERED META MATRIX

	Collaboration & Communication	Child's Functioning	Support Needs	Supports Provided	Outcomes
Mary	<p>with the ADD is working with her teachers to be able to understand what ADD is</p> <p>her pediatric urologist has letter that goes to her teachers</p> <p>home visits initially before school starts so at that time we will make the teacher aware of the situations that they have and um encourage them to talk with previous teachers that have had success in helping her especially with the attention deficit</p> <p>The doctors have also been really good with giving us information to pass on to the teachers and so as um either at parent teacher conferences or we can request and their teachers are very good at keeping us informed of any changes um and then our health care provider has given us checklists that the teachers can use then to help evaluate in classroom behaviors or things that they can use so that they can communicate back to the health care providers</p>	<p>urological issues that have caused her to have trouble with accidents both bladder and um bowel</p> <p>about six months ago she was diagnosed with celiac's disease.</p> <p>severe allergy induced asthma</p> <p>Mary is very comfortable in her own skin,</p> <p>she does struggle with the fact, I can't focus, I know I should be able to, I can't eat that and they can eat it.</p> <p>she can verbalize very well</p>	<p>different dietary restrictions; modified schedule in terms of being able to, like with the urologic issues being to work with some of the um how to help her um be able to be successful and not have accidents</p> <p>She could get together with kids, she went and had lunch with another person who had already had to go through the same struggles, who went through the depression of the loss of, it's like, it's like going through, it's the stages of grief and I didn't realize that I was unprepared as a parent.</p> <p>No doctor told me, watch your kid for depression, my kid would eat anything, she refused to eat for two weeks barely because she hated the fact she could not have what she wanted.</p> <p>giving work so the kids can do it get it done at their pace. Giving them extra time if</p>	<p>hot lunch hers has to be prepared separately from the rest or she just brings in her own food</p> <p>have special food that's in the classroom that she only can eat</p> <p>we have the nebulizer and their school secretary is actually trained as to be able to work with the kids who have the medical issues as like a nurse would</p> <p>she's got a couple of friends that know she can't have certain things. So when they brought in Christmas, her mom decided it was going to be a gluten free Christmas party, and they made the whole room.</p> <p>We are good at the big, but the actual boots on the ground how do I work with Johnny. Because what worked with Johnny, won't work with Suzie, won't work with Mary.</p>	<p>just in terms of being able to focus on her work, and not, I mean sitting in for recess because she can't get the assignment completed.</p> <p>she can verbalize very well</p> <p>at this point its hasn't affected socially, she has never been at a point where her peers were ever aware of the accidents that she was having at school.</p>



	<p>Some teachers have been more receptive to understanding some of the needs and some have been a little bit more I don't want to say resistant but some of them don't necessarily understand and so or they have misinformation themselves and they are not always as open to understanding some of the new information</p> <p>there is no good things she can hand her teacher and say this is what ADD is, this is what Celiac's is, this is what it isn't.</p> <p>**multiple mentions of desire for better information to share with teacher</p> <p>They let me know when they see changes or struggles that they are having</p> <p>they will have questions, where they have asked for a list of what she can't have, like we sent in a list of especially food</p> <p>So once I made the teacher aware of it, the teacher then was noticed it, she could then zero in on when it was happening.</p>		<p>they miss so they can get it done and get it done well.</p>	<p>You know and every kid, Mary she has her own little mix of health care needs which is not the same as the kids sitting next to her. Who may have a different mix.</p> <p>She's the only one that has ever looked at it as this is not something to fix, it's to help Mary be a better Mary. So if getting her on that schedule, bathroom schedule making sure she has the right foods, making sure she can wiggle in her seat or have something to help her focus. Um if that's helps Mary be a better Mary, then let's do it.</p> <p>You know they were having tater tots and they didn't know if Mary could have them. It was a quick and easy, ask me, let's find out if you know when I pay for her lunches, they know what the menu is so they can say hey the truck came In do you want to take a look and see</p> <p>As really taking the time to understand the</p>	
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<p>the teacher even communicated with the other parents in the class, um and she obviously came to me for my permission.</p> <p>I can read about what a child with ADD is like but you don't actually until you, no two kids are the same, no two treatments are the same.</p> <p>We are good at the big, but the actual boots on the ground how do I work with Johnny. Because what worked with Johnny, won't work with Suzie, won't work with Mary. You know and every kid, Mary she has her own little mix of health care needs which is not the same as the kids sitting next to her. Who may have a different mix.</p> <p>we do benefit it from being a smaller school because I can talk with our cafeteria person and her and I talked about, and she will come up to me and show me the box that the food came in and we screen it for her.</p> <p>I can say if you talk to the third grade teacher, he was really successful at getting her to get the work done.</p>			<p>kids who struggle with that. And being able to make real adjustments, you know what I would consider real adjustments. As not just telling me that this is what she did today or she is doing these negative behaviors.</p> <p>Really I can't do anything about it, I am not in the classroom, you fix it. What is going to work for you in the classroom? I mean I could come in and teach her, but that's not you know, just nitpicking the daylight out of her behavior isn't going to fix it. Figure out the left handed kid needs left handed scissors before you tell me she can't cut.</p>	
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<p>Susie</p>	<p>We did an orientation about Susie and her difficulties and some of her personality things with the teachers, the teaching assistant, and with her main classroom teacher because in this class they then leave the classroom for science social studies.</p> <p>There are times when I send a note back saying you know she was just too tired last night that we didn't get the homework done and the teachers are understanding about that</p> <p>So they communicated with me, we don't know how you want to handle this, and I said what happens with normal kids, well they stay after and do their work, Okay, I will be at school and I will sit in</p>	<p>She has a feeding tube since she has no esophagus, she has had a tracheotomy to help um so she can inhale without always inhaling her secretions and due to the fact that she has um always had an adult with her, okay that is why I think she has the development delays.</p>	<p>Unable to attend school unless a nurse is present in the building</p> <p>there should be the same expectations she should have to turn in her homework um in the past they were just glad if she brought it back.</p> <p>people think she is dumb because she doesn't speak. She doesn't speak, she doesn't speak clearly but she understands.</p> <p>I would like to see for instance instead of some of the science, in some of those areas where it's just so over her head to be able to um teach her more of a life skill.</p> <p>She needs nebulizer treatments</p>	<p>she needs door to door transportation, so they have sent, it's a minivan that they take kids to special programs in.</p> <p>we went into the classroom we took her teaching bear which has a trach and a feeding tube and explained why Susie is different and some needs that she has,</p> <p>they have adapted PE for her, so she does get some exercise.</p> <p>they have been helpful in setting up a tutor to come in if she can't go to school.</p> <p>she has her own nebulizer things at school</p> <p>She also has a suction machine that is kept at the office at</p>	<p>then all of sudden, not very long ago it was like a light bulb went on about addition. Now she still doesn't get subtraction and money is just totally foreign to her but I think that the other thing is that when she was in the public schools in Minneapolis because of her difficulties there were not expectations of her. Um we encouraged we, there should be the same expectations she should have to turn in her homework um in the past they were just glad if she brought it back.</p>
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	<p>the office to make sure she completes her work.</p> <p>This small school works very well to call and talk to the teacher or the nurse on the phone.</p> <p>They called me to say we really don't think she should be here because she doesn't need to catch these things (if staff of students called in sick).</p>			<p>school. She um she has an emergency bag that has an extra feeding tube, an extra trach tube. Whatever she might need including extra clothing, because sometimes her feeding valve leaks. They provide the space that she can take her food in and put it in a fridge in the nurse's office. Um and medications and then the nurse watches her do things and makes sure that's it, kind of like the nebulizer.</p> <p>They are not good about providing somebody for that. They are never good at providing someone for her. Have a history of not providing a replacement for her.</p>	
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				the secretaries, I think are the ones they have kind of backed off and kind off and went and they have not attempted to do anything for Susie and I am quite happy with that.	
Justin	<p>I did communicate with his teachers and staff to make sure that they were aware and everything</p> <p>I sent a note to his teacher</p> <p>what she would do is she would communicate back or she would put a note in his bag with the inhaler when he brought it home if he had to use it at school that day</p> <p>we sort of have had a proactive approach so I won't have to keep sending the note to school every day. After I sent her the note and told her, here's what I think is going on,</p> <p>so I have to update that information again but this next year school year.</p> <p>made me feel a lot better when she sent</p>	<p>he has asthma</p> <p>good to know that he is old enough to use the inhaler</p> <p>really having problems with it instead of playing with the other kids, he would chose an activity that was, he would choice reading or coloring or something like that instead of running with the other kids.</p> <p>I don't want him to just sit out so that's when I had suggested that he needed to use it as a preventative right before he went there and so that he could keep participating so it wouldn't keep him from other things</p>	<p>he would have to use the inhaler while he was at school</p> <p>we went through a two month period where I had him use the nebulizer before he went to school to kind of prevent, that had been recommended by the doctors,</p> <p>training him of knowing what to look for in himself</p> <p>affects him when he is doing more active things. So like P.E. or going out at recess or the after school program.</p> <p>something that bothers him so if he had more issues that prevented him from participating with other kids</p>	<p>his teacher was very responsive and she helped us with it and that situation</p> <p>I don't know if they would be able to use the nebulizer.</p> <p>they would contact us right away or take the appropriate medical steps.</p>	<p>he is starting to get more self-conscience about because he's getting older</p>

<p>that note home because like during a couple month of period when he was doing worse with it, I was always checking my phone</p> <p>she totally understood what we were doing</p> <p>they would contact us right away or take the appropriate medical steps.</p> <p>that will definitely be something I make sure the teacher is aware of and um from the very beginning</p> <p>that's why I sent the note to school to let her know.</p> <p>our particular school they do a very good job with parent contact in general</p> <p>they have always been communicating with us</p> <p>things like being able to communicate with parents whether it be conferences or anything or being able to doing something after school hours</p> <p>I've always communicated with teachers, it's always something that we've had to keep watching a he is starting to get more self-conscience</p>	<p>He's got friends that can't do certain things</p> <p>he was scared too when it happened, when he has an asthma attack, he is really scared too</p> <p>then um he couldn't play or something especially if some of the kids made fun of him or something he would really take that to heart so...</p> <p>He wears bifocal glasses</p> <p>it hurts if his feelings, he was telling me this morning, it hurts his feelings when kids say that his glasses are cracked and he has to keep explaining to them that they are not cracked that they are bifocals</p>			
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	<p>about because he's getting older</p> <p>So we have probably to do a lot more communication with teachers and stuff back than with that as we were getting things figured out maybe even with the asthma right</p>				
Amy	<p>"Sometime they'll (school) call me to see if I want her to stay at school and just work through the day or take her home."</p> <p>"I was given an allergy form by her allergist, but they (school nurse) wanted them (her allergist) to fill out a more specific form that all the nurses in the school district are familiar with to get information."</p> <p>"She came to school and they (school nurse) wrote me a note letting me know if I could bring it (medicine) back for tomorrow."</p> <p>"I talked with the nurse in the office and talked with her teacher."</p> <p>"(asked who he/she talks to most at the school) Her special ed teacher."</p> <p>"We have a daily communicator that comes home and sometime through email."</p>	<p>"She has high functioning Autism, food allergies, seasonal allergies, and Asthma."</p> <p>"Amy has certain peanut allergies and also has shellfish allergies."</p> <p>"And then with the Asthmas they have this medicine that she takes before she does gym or a lot of physical exercise and she takes that to school with her."</p> <p>"I mean she is never like rude or mean, but she's just less willing to talk."</p>	<p>"Yes, it's an Inhaler."</p> <p>"At home it seems to be really bad we'll do the nebulizer, that seems to work best and then she takes daily allergy pills at home."</p> <p>"She has to take Flonase."</p> <p>"(goes to the doctor) 2-3 times every 6 months."</p> <p>"I don't know if she's breathing it (inhaler) in."</p> <p>"(Asked to describe other support needed at school) Other than maybe a possible social story to kind of give her understanding with the allergies and understanding that allergies are here but that doesn't mean that I should go home, you know, when the pollen count is really high."</p>	<p>"She is in 2 different classes. In her special services class there is about 7 kids and when she takes general ed courses there are about 20 kids in there including her and 2 other kids from the special services class."</p>	

	<p>“There is a newsletter that is sent home and it is also sent electronically.”</p> <p>“Actually, I think sometimes phone calls work better for me.”</p>				
Kevin	<p>“I wasn’t always told exactly when other kids were sick, it was after the fact.”</p> <p>“They (school) always called me when other child re in the school had pneumonia or serious stuff like that.”</p> <p>“(when asked about communication quality of school) It’s pretty good for the most part.”</p> <p>“We text a lot.”</p> <p>“When he was going to school I would hear from his teachers daily. I honestly think the communication is a lot better not that we are doing it at home.”</p>	<p>“He has ALL (acute lymphoblastic leukemia).”</p> <p>“Typical 5 year old boy, other than having a few learning delays.”</p> <p>“He will be repeating preschool.”</p> <p>“He goes once a year for a check-up for his Autism diagnosis.”</p> <p>“His ANC isn’t always, which is like his fighting virus and everything, isn’t always as high as like yours or mine. Which means if it’s like low, he isn’t going to have it in him to fight off those viruses which makes him miss quite a bit of school.”</p> <p>“He missed about 65% of the school year because of all the time his counts were too low or there had been kids with the chicken pox or the flu that were</p>	<p>“I’m going to take him out of the school (and do home schooling) because he’s not going to be around that (viruses and germs) because those are deadly towards my child because he doesn’t have it in him to fight those things off.”</p>	<p>“He is in the special education pre-k.”</p> <p>“We come to the clinic for treatment every Friday.”</p> <p>“They (school) met the needs of keeping the classroom clean.”</p> <p>“His main classroom teacher, she comes to the house for an hour each day during the school year for his tat home schooling. He receives speech and OT therapy as well.”</p>	<p>“I honestly think they waited too long to do the at home bound schooling because if he would have been on that home bound schooling sooner, I think he’d be progressing faster. Because since he’s had had that he home schooling he has progressed so much more.”</p>



		<p>going to the school.”</p> <p>“The school, we obviously had his IEP meeting and we explained to them if you are using playdough, he uses a brand new container. He doesn’t use something that 5 other children have already used, sneezed on, spit on, put in their mouth.”</p> <p>“They call it “chemo brain” and basically it fogs your memory.”</p>			
Caroline	<p>“The teachers were all very supportive, sending work home, letting me do the tests at home, and that kind of thing.”</p> <p>“The secretary would communicate with me if need and that kind of stuff.”</p> <p>“(when asked who she communicates with most often at school) Usually just directly with the teacher. If I needed to with the principal.”</p> <p>“(when asked the type of communication used) Usually verbal, yeah.”</p>	<p>“She was diagnosed with Leukemia when she was 6. At this point she is 5 years out of treatment.”</p> <p>“She’s a really strong student so I think that helped.”</p> <p>“The kids never thought one thing about it. They were very supportive, and through the whole thing until that one, and now they’re friends.”</p> <p>“It didn’t really affect her learning, she didn’t really need any special services. We were really lucky.”</p>	<p>“One thing that would have been nice to have is a counselor maybe at school. Maybe to, not so much for her, but for the other kids to understand.”</p>	<p>“I tutored (mom) her myself as I am a teacher at the school.”</p> <p>“The teachers needed to do was make sure everything was clean there was hand sanitizer, and the kids were washing their hands, that kind of things, and they were all really good about it.”</p>	
Patrick	<p>“Well, I talked to the teacher a lot.”</p>	<p>“He just got to school for the time in April. So,</p>	<p>“Yeah, he literally was not there (school) at all.”</p>	<p>“We were in Memphis for very intense</p>	

		<p>it was difficult, he literally could not leave the house other than to go to the doctor's appointment until he got to go to school in April."</p> <p>He was diagnosed last July with ALL."</p> <p>"It was good to finally get to interact with other kids and to be able to concentrate on something other than his illness."</p> <p>"She (teacher) said you wouldn't have known, had you not known the situation, that he had not really missed all of that schooling. So, he stepped right in."</p>	<p>"(when asked if school does anything poorly in meeting child's needs) I wouldn't say poorly, I just wouldn't say they (school) understood the severity of it all."</p>	<p>treatments through November, And then now that were on maintenance he receives chemo a pill at home every night. He receives IV treatments every Friday here at St. Jude and then once a month he also receives a dose of steroid which are really tough on his little body."</p> <p>"But because he received homebound he had a teacher coming in. It was just an hour a day but that counted as his attendance."</p>	
Bryan	<p>"She (school nurse) actually called me and said, we don't have what you're supposed to have. So that led me to believe that all those other years probably no one was looking at my stuff and reading everything I had written and double checking me."</p> <p>"It's not a great communication system. I don't think that most people get it that if he eats peanuts, he will most likely have anaphylactic shock and could die. SO this is something I</p>	<p>"He's just as very active boy."</p> <p>"He's good in school and he loves learning and he gets excited about it."</p> <p>"Bryan has asthma and he very serious allergies. He is allergic to peanuts and tree nuts and he has had anaphylactic reactions before that he almost died from so it's something that we take very, very seriously."</p>	<p>"He takes medicine every day. He has to carry an epi-pen and inhaler and Benadryl everywhere he goes."</p> <p>"He goes for allergy shots every moth and sees an allergists."</p> <p>"I've heard of other places that have really good medical plans, like 504, and I like that idea. We don't do that."</p> <p>"I like the support plan idea, I also think that, from</p>		

	<p>don't feel like we've gotten across very well."</p> <p>"I feel like communication could be better."</p> <p>"At the start of the school year I have that form I have to fill out."</p> <p>"I have the doctor write a note and send that to the school."</p> <p>"(When asked who she communicates with most often) The office and the teacher."</p>	<p>"(when asked if child's special health care needs affect him at school" But it's very embarrassing to him so it does affect him when they're running the mile and why they're doing a lot of physical activities."</p> <p>"He has to sit at the peanut free table, which is embarrassing to him. And it just makes me sad that that this is your free time and you're not even with peers."</p>	<p>my experience in another district as well, I get one sheet of paper that has the entire school's worth of medical concerns and it's supposed to go locked up and that's it. I think that sort of document should be somewhere very obvious, we even have these google drives."</p>		
Lizzie	<p>"They (teachers) were really good with getting assignment to us."</p> <p>"Another thing that probably speaks of our modern communication is I was testing with her teacher. I would text her updates and communicate."</p> <p>"I would give them (school) a week's notice that we're going to be gone and tell them ahead of time."</p> <p>"(When asked if information gets transformed to all school staff usually? Actually most of the time yes."</p> <p>"We used text messages and email (to communicate)."</p>	<p>"She is very independent, she is also shy sometimes around people she doesn't know well. It take her a little bit to get to know them."</p> <p>"At age 9 we discovered she had scoliosis. So the next step was bracing."</p> <p>"I think she had more pain that she told anyone. Because she said when she was in the hospital, and probably on pain medication, she said I didn't tell anybody my back hurt because I didn't want to have surgery. So I think there was a lot of time that she was masking</p>	<p>"Finding alternative for her to, some sort of social something maybe that some of the other kids could have done with her, instead of handing them all recess being out on the playground where there is the temptation and potential for tripping, falling, whatever."</p> <p>"Yeah, most of the things that are mentioned are just making accommodations or providing an alternative activity for her."</p> <p>"There wasn't really a formal attempt to gather information for her, It was really</p>	<p>"They (school) did offer if she needed some extra help with math or whatever to let them know."</p> <p>"Accommodations were provided by her teacher, like allowing me to go on the field trip to the capital and to the zoo."</p>	

		<p>the pain that we weren't aware of.”</p> <p>“Academically, she's done really well so I think she's really able even if she's out a day or so, here and there, she's able to keep caught up.”</p> <p>“Actually, I think our particular group that she's with have been very supportive. We were lucky that we had kids that were really supportive.”</p> <p>“Her special need is a physical issue that you couldn't necessarily just see if she's walking around and functional at school. But after she was back at school (from her surgery) she was on lunch duty, which expended all of her energy she had. But she did not speak up.”</p> <p>“She almost got, in a way, a level of depressed, where she got comfortable with where she'd stay up late because her day and nights were really mixed up.”</p>	<p>me pushing it on them or bringing it up at a conference. So I don't even know if they would have brought it up if I didn't ever say anything.”</p> <p>“But that's an example of things that, on their end, if someone had a condition like this or similar, maybe setting up a meeting, even if it's a phone interview just to set up those accommodations that were needed, like a second set of books.”</p>		
Emily	<p>“Erin is the nurse there, She is very good about calling me if there's any chance that something's going</p>	<p>“He has Type 1 diabetes and wears a pump that tells him his glucose levels at all times.”</p>	<p>“She does 8 pokes a day usually. Finger sticks. And with the pump it's an every 2 day site change.”</p>	<p>“They (school) make sure she is pretty on target for testing. And they (school) do giver her time</p>	

	<p>on. She's probably my main primary contact."</p> <p>"The class trip they took to Chicago this year, they assured me there would be a medical professional on tour with them. The person canceled out and I didn't get a call to say there was not going to be a medical professional on the trip. So that was a little concerning to me."</p> <p>"Email, or the nurse always calls me, Erin's always vocal. The teachers and I very seldomly talk usually just through email."</p> <p>"The pediatric office and the endocrinologist print out a discharge paper that goes directly to the school. It tells them what her ratios are, what do if she is high, if she has ketones how much to give her, All of the information to contact them. They (Doctors) can be contacted at any point. St. Eds is really good about that. If they (school) want to know something specific, Erin knows she has permission to call."</p>	<p>"If you're in a high or low, sometime the connections aren't there and you have to think a little bit harder or go round and round."</p> <p>"She'd rather be an educator about it (her diabetes) than to have people (peers) be misinformed."</p>	<p>"(when asked how often she needs to see her doctor) every 3 months."</p> <p>"It affects her like she has to take time out of class if she's low. If she's in a low, her mind is foggy so she isn't able to participate quite as clearly. If she's in a high that puts her more in an anger type of, she gets kind of antsy, very agitated."</p> <p>"She needs to eat even after a big meet. So athletically they might have snack on the bus so that they make sure she has something to eat."</p> <p>"I think even the resource of having someone for them (kids) to talk to."</p>	<p>between classes if she needs extra time. They (school) allow her to have juice and extra snacks in her locker, instead of trying to go all the way back to the nurse's office first."</p> <p>"She was allowed to keep stuff in her locker so she doesn't have to be out of class time so much. "</p>	
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End matrix

APPENDIX J: CASE-ORDERED DESCRIPTIVE MATRIX: SUPPORT NEEDS

Support Needs				
	Physical	Social	Behavioral	Cognitive
<b>Mary</b>	Dietary restrictions  modified schedule	Lunch with peers	Depression  Refusal to eat	Extra time needed to complete classwork
<b>Susie</b>	Tracheotomy, feeding tube  Passy-Muir valve for speaking  Needs to leave room to cough (based on secretions)  Nebulizer treatments; suction machine	Assistance for peers to understand her when speaking—realize she isn't dumb  Embarrassed about coughing and secretion in front of peers  Assistance to make environment more socially acceptable	Gets very crabby and unreasonably demanding when exposed to dairy or soy	IEP  Does not perform well in math  More life skills versus advanced science
<b>Justin</b>	Glasses; nebulizer treatments and/or inhaler	Encouragement to interact with peers  sensitivity to peer teasing	Awareness of fears related to asthma attacks	Need for support in ways to explain bifocals to peers
<b>Amy</b>	Inhaler  Nebulizer  Allergy pills  Flonase  Doctor visits (2-3 times / 6 months)  Proper supervision giving meds	Quiet in interactions with peers		Social story board to help her understand her condition

<b>Kevin</b>	Chemo at clinic  Oral chemo at home  Clean environment		IEP	Special education classes  “chemo brain” fogs your memory  IEP
<b>Caroline</b>	Clean environment	Support for relationships with peers  Counselor—to help with peer understanding	Need all to wash hands frequently  Not send ill peers to school	Accommodations for illness related needs (tired, attention span, etc.)
<b>Patrick</b>	Chemo at clinic  Oral chemo  Clean environment  Lots of steps at school—difficult due to lack of strength  PE adapted, also due to lack of strength & port  Need frequent snacks or breaks to regain strength	Peer interactions	Need for peers to wash hands & to stay home when ill  Can’t drink from water fountain  Should not go to nurse’s office—she should go to him	Homebound for months—missed months of attending school  Staff need a better understanding
<b>Bryan</b>	Epi-pen  Inhaler  Benadryl  Adapted PE, if having trouble breathing (due to temperature or allergens)	Assistance with peer interactions, especially at lunch (has had to eat with much younger children)  Assistance dealing with peer pressure	Assistance to ask for help (PE, etc.) when needed  504	Need more awareness of child’s health concerns for all staff

<b>Lizzie</b>	Back brace 12-16 hours a day  Adapted activity	Providing alternative activities during gym that can be done with other peers  Peer support	Needs monitoring to make safe choices	Meeting between parents and staff to help provide better understanding about condition  Schoolwork to do when missing class (appointments, etc.)
<b>Emily</b>	CGM Pump to test blood sugar  Nurse/Trained physical therapist on team  Breaks throughout the day when blood sugar is low	Needs someone to walk with her to class (in case of seizure)  Needs support for peer interactions and education	Regular eating schedules	
<b>Supports Provided</b>				
	<b>Physical</b>	<b>Social</b>	<b>Behavioral</b>	<b>Cognitive</b>
<b>Mary</b>	Lunch prepared separately or brings lunch  Special food in classroom  Nebulizer at school for treatments	Friends & parents who adapted to gluten free holiday events	Provided with a schedule	
<b>Susie</b>	Nurse present to attend school  Space provided for medical equipment and treatment as needed (nebs, etc.)  Transportation	Carries cup for secretions		Placed in 6 <sup>th</sup> grade versus higher grade (typical for age)  Adjustments to homework expectations based on medical needs



	Adapted PE to get some exercise			
<b>Justin</b>	Nebulizer treatments	Awareness of choosing solitary activities		
<b>Amy</b>	Nurse- dispenses needed medicines	Autism Awareness Day		Special Ed services
<b>Kevin</b>	Chemo at clinic and at home  OT/PT	Educational for peers		Special Ed services  Homebound schooling  Tutoring- extra help
<b>Caroline</b>		Held fundraisers at school- raise awareness	<i>Teacher did NOT do well encouraging peers to stay home</i>	Teachers sent work home, allowed test to be taken at home (if needed)  Allowed extended time to complete assignments
<b>Patrick</b>	Chemo at clinic and at home  Only back at school for short time (close to end of year) so did well with PE, few changes needed  Parent works at school—so she has his meds	Gets along well with peers	<i>Teacher did NOT do well encouraging peers to stay home</i>	Homebound- one-on one teaching  Child life came and spoke to class to help them understand better
<b>Bryan</b>	Allergy shots  Nurse- dispenses needed medicines  Adapted PE			

	Peanut-free lunch table			
<b>Lizzie</b>	Accommodations for PE, recess  Accommodations to participate in field trips	Accommodations other than missing out on activities  Provided information to peers related to safe behavioral interactions	<i>Poor expectations related to ability to make decisions (monkey bars, shooting baskets)</i>	Tutoring- extra help  Provided assignments as needed to complete at home—but where overwhelming in the amount when in hospital  Second set of books for home to reduce need to carry heavy weight
<b>Emily</b>	Extra time for transitions  Provided with a locker for snacks		Allowed to test blood sugar whenever needed  Set up signal with coached for when needs assistance	

End matrix

APPENDIX K: CONTRAST TABLE: COLLABORATION & COMMUNICATION

	Mary	Justin	Susie	Amy	Kevin	Caroline	Patrick	Bryan	Lizzie	Emily
ComFam Sch	N N	NNN N NNN	N+N	NN+-	+NN	NN+	+	NN	- NN	
ComSch Fam	+N+ N	+++	N++	N+-N	- +++	NN++		+	N	N
ComFam PHCP				-	N					
ComPCP Fam	+			N			N			
ComPCP Sch	++					+	+	N		NN
ComSch	+		+	+		N+		N		
ComSch Qual	- - ++		++	-	++ -	+		+ - - -	+	+
Com Qual	-	++++ +	- NN	++N			N			
Positive 45.55%	8	8	6	5	6	6	2	2	1	1
Negative 13.86%	3	0	1	4	2	0	0	3	1	0
Neutral 41.58%	4	7	5	6	3	5	2	4	3	3
Total	15	15	12	15	11	11	4	9	5	4

Valence of Communication

(+) = positive comment

(-) = negative comment

N = neutral comment