

Fall 12-16-2016

Parents' Perceptions Regarding the Special Education Classification of Other Health Impairment (OHI)

Michael C. Norman
University of New Orleans, New Orleans, mcnorman@uno.edu

Follow this and additional works at: <https://scholarworks.uno.edu/td>



Part of the [Disability and Equity in Education Commons](#), and the [Special Education and Teaching Commons](#)

Recommended Citation

Norman, Michael C., "Parents' Perceptions Regarding the Special Education Classification of Other Health Impairment (OHI)" (2016). *University of New Orleans Theses and Dissertations*. 2265.
<https://scholarworks.uno.edu/td/2265>

This Dissertation is protected by copyright and/or related rights. It has been brought to you by ScholarWorks@UNO with permission from the rights-holder(s). You are free to use this Dissertation in any way that is permitted by the copyright and related rights legislation that applies to your use. For other uses you need to obtain permission from the rights-holder(s) directly, unless additional rights are indicated by a Creative Commons license in the record and/or on the work itself.

This Dissertation has been accepted for inclusion in University of New Orleans Theses and Dissertations by an authorized administrator of ScholarWorks@UNO. For more information, please contact scholarworks@uno.edu.

Parents' Perceptions Regarding the Special Education Classification of
Other Health Impairment (OHI)

A Dissertation

Submitted to the Graduate Faculty of the
University of New Orleans
in partial fulfillment of the
Requirements for the degree of

Doctor of Philosophy
in
Special Education

by

Michael Clark Norman

B.A. Nicholls State University 1972
M.C.D. L.S.U. Medical Center 1976

December 2016

ABSTRACT

Students identified by the special education classification *Other Health Impairment* (OHI) represent the third largest group of students receiving special education services in the United States. The special education services offered these students include both academic and health related supports. The delivery of these services is enhanced when a partnership exists between the primary stakeholders; the student, parents, the school personnel, and the medical personnel. The use of Family Centered Care principles in the delivery of these services supports and maintains the partnership.

Following the qualitative analysis of a series of interviews of parents whose children were classified as OHI, descriptive and inferential themes were derived from the interview data. These themes are discussed relative to the parents' belief that the classification provided;

1. access to appropriate special education and school-based health care allowing their children to achieve their maximum potential,
2. parental satisfaction with the special education and school-based health care services provided, and
3. the use of Family-Centered Care principles.

Key Words: special education, health impairment, OHI, family

TABLE OF CONTENTS

INTRODUCTION	1
Statement of the Problem.....	1
Relevant Definitions (<i>Federal Register</i> , 2006).....	1
Students with OHI.....	2
Parents of Students with OHI	4
Conceptual Framework.....	6
Research Questions	8
LITERATURE REVIEW	10
Standards of Practice for Professionals & Families.....	12
Council of Exceptional Children Standards.....	12
Division of Early Childhood Recommended Practices	13
Parent-Professional Interactions	16
Recommendations for Special Educators	16
Parent Perception of Professional/School Processes	18
Parent Satisfaction Related to Student’s Age	19
Parent Satisfaction Related to IEP	20
Parent Satisfaction Related to Other Health Impairment.....	21
Summary.....	23
METHODOLOGY	25
Participant Criteria and Recruitment	25
Sampling Procedures	26
Data Collection	28
Knowledge of the Setting.....	29
Knowledge of the Language and Jargon.....	29
Reciprocity	30
Confidentiality	30
The Interview Process.....	31
Interview Format.....	31
Recording of Interview	31
Interview Sequence.....	32
Note-taking	33
Notes on Analysis	33
Data Analysis	34

Data Reduction.....	34
Data Displays	35
Summary	35
RESULTS	37
Demographics	37
Description & Inferential Codes	38
Inferential Codes.....	39
Positive Experiences with Part C Services	39
Loss of Trust	40
Negative Emotional Responses.....	41
Lack of	42
Lack of Systemic Resources	43
Lack of Interpersonal Integrity	44
Lack of Communication between Health and Education Professionals	45
Confusion Regarding OHI Classification	46
Usefulness of School Health Services	47
Summary	47
DISCUSSION.....	48
Responses to Research Questions	48
Summary	54
Limitations of Study	55
Sample Size.....	55
Sampling Methodology & Diversity.....	55
Future Research	56
REFERENCES	58
Appendix A.....	65
Appendix C	69
VITA.....	70

INTRODUCTION

Statement of the Problem

Parents raising children with chronic or acute health problems are likely unaware of the special education services offered to these students when they are classified as *Other Health Impairment (OHI)* per the Individuals with Disabilities Education Act (IDEA), (*Federal Register, 2006*). Given the child's medical condition and the fact that the child is a matriculating student, the family and child are put "at the intersection of the health and education systems, which traditionally operate in separate realms with different policies and philosophies." (Thies 1999, Abstract ¶ 3). Providing education and related services for a student, that includes school health care for students with a disability, has brought the field of special education to an educational and medical crossroad which is complicated by numerous federal, state, and local laws in addition to judicial rulings and case law. (Skrtic, Harris, & Shriner, 2005)

Relevant Definitions (*Federal Register, 2006*)

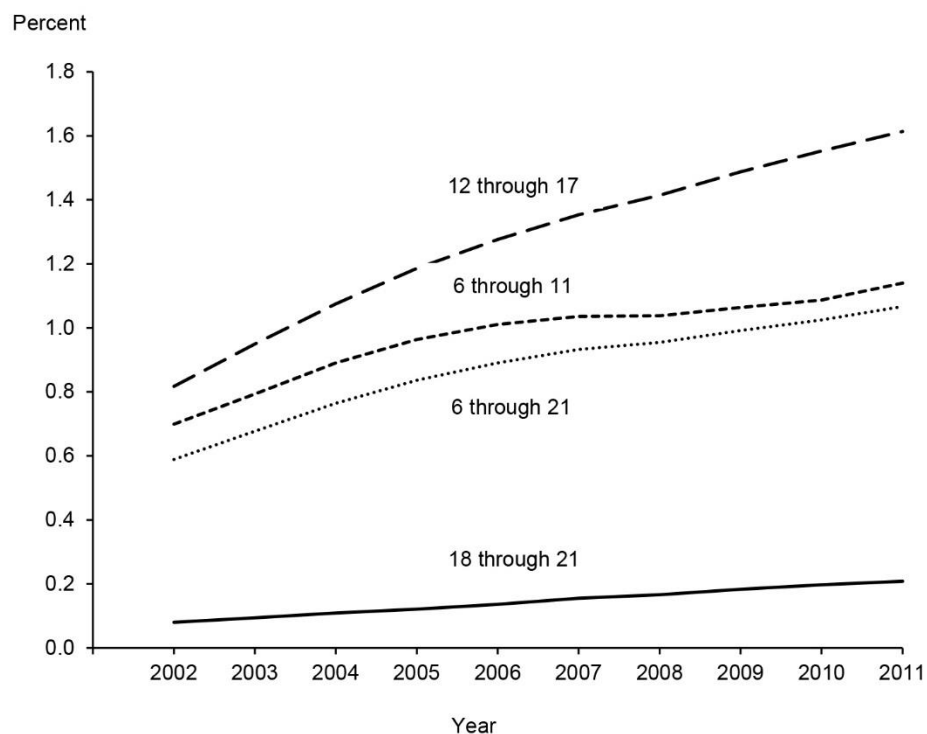
Per the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), (*Federal Register, 2006*) *Other Health Impairment* is defined as "having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment." The limited strength, vitality or alertness must be due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, epilepsy, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia and Tourette syndrome. The chronic or acute health problems must adversely affect a child's educational performance (*Federal Register, 2006*).

Students with OHI

During 1999-2000, 26% of children in early childhood special education (ECSE) received medication and 16% reportedly used medical equipment such as nebulizers and breathing monitors (DePaepe, Garrison-Kane, & Doelling, 2005).

According to the 35th Annual Report to Congress on the Implementation of Individuals with Disabilities Education Act 2013, the percentage of the resident population ages 6 through 21 years served under IDEA that was reported under the *Other Health Impairment* category represented 12.7% of the individuals eligible for service under Part B of IDEA. This category represented the third largest group of individuals served by IDEA at that time. Table 1 presents the increase in the number of children classified as *Other Health Impairment* (OHI) from 2007 to 2011 as represented by percentage of the United States population

Table 1 (U.S. Department of Education, 2014)



Education for Students with OHI

The special education rights conferred by IDEA are critical to children in the provision of Free and Appropriate Public Education (FAPE), the development and implementation of an individualized education program (IEP), providing placement in the least restrictive environment, assuring appropriate evaluation, assuring both parent and student participation and the provision of procedural safeguards. Regulations impose on school districts an obligation to provide appropriate education that meets the needs of children with disabilities such as OHI as well as the needs of children without disabilities. Other IDEA components include provisions not to segregate, to provide procedural protections, and to afford special rights in the student disciplinary process (Weber, 2011).

Health impairments can affect a student's educational performance, which in turn may result in the student qualifying for special education and related services. Three such related services include medical services, school health services, and school nurse services. Medical services include the services of a licensed physician to determine a student's medically related disability which is considered when qualifying the student for special education services. School health services and school nurse services allow students to receive a free and appropriate public education (FAPE) despite their medically related disability. Examples of such services might include special feeding and swallowing precautions, managing a tracheostomy, administering or dispensing medications, and managing chronic disease. Education and skills training may also be offered to teachers, paraprofessionals, and related service providers within the school setting (National Dissemination Center for Children with Disabilities, 2012).

Parents of Students with OHI

While considerable attention has been directed toward the identification and management of students classified as *Other Health Impairment* in the professional literature, limited research exists regarding the parents' perspective of the services provided to these individuals and families. The unique opportunity offered by IDEA to combine the efforts of professionals, with the experience and wisdom of parents, demands that we "hear" the voices of these parents as we strive to offer classification and interventions within special education.

Additionally, the inclusion of parents' perspective is an essential component of the Family-Centered Approach also known as Family-Centered Care. Family-Centered Care, like many other service delivery models, has origins in family systems theory. Family systems theory holds the parent-professional relationship paramount in service delivery (Dempsey & Keen, 2008). Family-Centered Care (most often described by a series of beliefs and/or principles rather than a definition) is, in general, a partnership approach to education /health care decision-making between the family and providers. As described by Kuo, D., Houtrow, A.M., Arango, P., Kuhlthau, K.a., Simmons, J.M. & Neff, J.M. (2012), Family-Centered Care involves five principles including information sharing, respect and honoring differences, partnership and collaboration, negotiation, and care in the context of the family and community. Table 2 provides a summary of these principles developed by governmental and professional agencies. Categories of Principles are listed on the left side of the table while determiners of each principle are detailed adjacent to the individual categories. These principles form the basis for the professional/family partnership – the highlight of Family Centered Care.

Table 2 Comparison of principles of family-centered care (Kuo, et al. [2012])

Categories of Principles	Maternal & Child Health Bureau (MCHB)	Institute for Patient-and Family-Centered Care (IPFCC)	American Academy of Pediatrics & IPFCC Joint Statement	Cronin/Shaller	Common Principles
Information sharing	Open and objective communication and information sharing	Information sharing: complete and unbiased information sharing that is “affirming and useful”	Sharing honest and unbiased information in ways “useful and affirming”	Free flow and accessibility of information	Open and objective information sharing between families and providers
Respect and honoring differences	All respect the skills and expertise brought to relationship Honors cultural diversity and family traditions	Dignity and respect: honor patient and family perspective and choice, including knowledge, values, beliefs, and cultural backgrounds	Respecting each child and his or her family Honoring racial, ethnic, cultural, and socioeconomic diversity, and its effect on families experience and perception of care	Respect for patient needs and preferences Sensitivity to nonmedical and spiritual dimensions	Mutual respect for family preferences, skills, and expertise Sensitivity to cultural and spiritual dimensions
Partnership and collaboration	Families and professionals work together in best interests of child and family, with child assuming a partnership role as s/he grows; there is an individual and developmental approach Partnership between families and professional is the foundation of FCC	Participation: patients and families encouraged and supported in participating in care and decision making at the level they choose	Collaborating with families at all levels of health care, in the care of child, professional education, policy making, and program development Support and facilitate choice about approaches to care and support Providing/ensuring formal and informal support for patient and family at all ages	Collaboration and team management Education/shared knowledge	Partnership and collaboration in decision making, meeting the needs, strengths, values, and abilities of all Decisions are made including families at the level they choose
Negotiation	Participants make decisions together There is a willingness to negotiate Trust is acknowledged as fundamental		Empowering families to discover their own strengths, build confidence, and make choices and decisions about their health	Involvement of family and friends	Partnership and collaboration between team members
Care in context of family & community	Develops policies, practices, and systems that are family-friendly/centered in all settings Recognizes importance of community-based services	Collaboration: patients and families include on an institution-wide basis on program development, implementation and evaluation, facility design and professional education	Flexibility in organization policies, procedures, and practices so services can be tailored to needs, beliefs, and cultural values of child and family		Incorporation of families at all levels of care, including encounter, institution, and policy settings

Conceptual Framework

Students classified as *Other Health Impairment* (OHI) represent the third largest group of individuals served by IDEA. To become classified as OHI, the student presents with limited strength, vitality, or alertness due to a chronic or acute health problem. The health problem must adversely affect the student's educational performance. Like all other special education categories, student's identified as OHI are entitled to a free, appropriate public education (FAPE) despite their medically related disability.

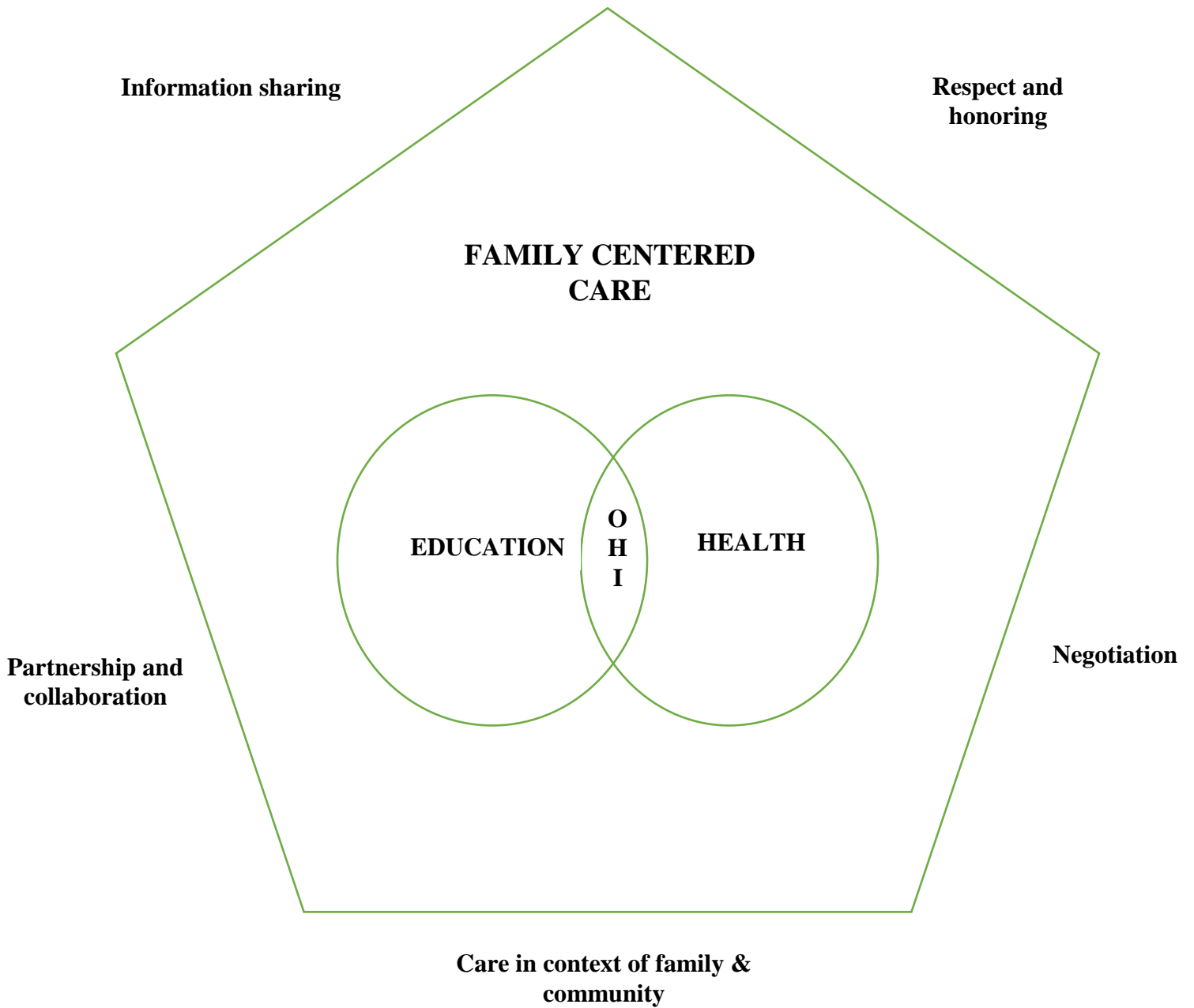
The principles of Family-Centered Care offer a framework for forming a partnership between the family, the medical provider, and the special educators when managing a student with a chronic/acute illness. These individuals are considered stake holders in the education and health care of the student. Important consider, when viewed across the lifespan, the family remains the one stakeholder that is consistent across the academic life of a student.

Recognizing the importance of the family as a primary stakeholder and as a lifelong stakeholder, the use of strategies to include the family as an equal partner in the planning and execution of a student's educational plan are essential. The use of Family Centered Care principles facilitate the appropriate inclusion of the student and family in this process.

Equally important with students classified as OHI, is direct and ongoing communication between caregivers within the medical and education communities. Historically, these two professional communities depart from different philosophies of care. However adoption of the use of Family Centered Care (also known in the medical community as Patient Centered Care) principles, in some medical and educational communities, has facilitated greater communication

between these two care communities. The following schematic is offered to assist in visualizing this project's conceptual framework.

Figure 1: Conceptual Framework Schematic



Research Questions

In an effort to expand the literature to include the perspective of parents, to determine the use of Family-Centered Care principles with students classified as OHI, and to view the influence of Family-Centered Care principles, this study was undertaken. Families with students classified as OHI and receiving special education services and/or accommodations/modifications as specified by IDEA were interviewed until information obtained began to be redundant. The interviews addressed the following research questions:

1. To what extent do parents perceive the classification of *Other Health Impairment* has provided their child access to appropriate special education and school-based health care to achieve their maximum potential?
2. How do parents perceive that they are satisfied with special education and school-based health care services provided to their child with the classification of OHI?
3. How does the use of Family-Centered Care principles influence parent satisfaction with OHI classification?

The implementation scenario described above is consistent with constructivist qualitative research "...which portrays a world in which reality is socially constructed, complex, and ever changing." (Glesne 1999). Through multiple comparative analyses of the data, concepts and hypotheses are discovered allowing for generation of theories that offer explanations and predictions. This inductive approach is known as Grounded Theory design. (Glesne, 1999)

Researcher Assumptions:

1. OHI classification does not provide sufficient access to special education & school health care services.

2. Parents of students classified as OHI are unsatisfied with special education & school health care services.
3. The use of Family Centered Care principles enhance parent satisfaction with OHI classification.

Summary

Students identified by the special education classification *Other Health Impairment* (OHI) represent the third largest group of students receiving special education services nationwide. The special education services offered these students include both academic and health related supports. The delivery of these services is enhanced when a partnership exists between the primary stakeholders; the parents, the school personnel and the medical personnel. The use of Family Centered Care principles in the delivery of these services supports and maintains the partnership.

LITERATURE REVIEW

On the heels of the Great Society programs championed by President Lyndon Johnson in the 1960's, the U.S. Congress, in 1975, passed the Education for All Handicapped Children's Act (PL 94-142) – both a grants statute and a civil rights statute. This law mandated the core guarantees that continue to undergird the delivery of special education services in the United States today. These core guarantees include Free and Appropriate Public Education (FAPE), Least Restrictive Environment (LRE), non-biased assessment procedures, Individual Educational Plan (IEP), and guaranteed due process rights for parents.

In 1990, the Education for all Handicapped Act Amendments were renamed from the Education for All Handicapped Children's Act to the Individuals with Disabilities Education Act (IDEA). Subsequent reauthorization and amendments to IDEA were completed in 1997 (PL 105-17) and 2004 (PL 108-446). The category “*Other Health Impairment*” (*OHI*) has been considered a category of special education since the original legislation of 1975.

The definition of *OHI* includes examples of types of conditions that may limit a child's educational performance. A variety of health conditions may qualify a child under *OHI*. Those conditions that are most often found under *OHI* are defined in Table 1. Also included are the potential impacts on a child's in-school performance.

Table 3
Examples of *OHI*

Illness/Condition	Description	Impact	Source
Asthma	A chronic lung condition characterized by inflammation, obstruction, and increased sensitivity of airways	Acute &/or Chronic, Limited vitality, Limited alertness	DePaepe, P., Garrison-Kane, L., & Doelling, J., 2005
Attention Deficit Disorder or Attention Deficit Hyperactivity Disorder	A chronic neurologic/psychiatric disorder resulting in children experiencing difficulties in behaviors crucial to academic success	Chronic, Limited alertness	DuPaul & Stoner, 2003
Diabetes	A chronic disorder in which the body fails to produce insulin, a hormone needed for the body to process sugar (glucose) obtained from ingested food.	Acute & Chronic, limited vitality, limited alertness, decreased psychomotor speed.	DePaepe, P., Garrison-Kane, L., & Doelling, J., 2005 Schwartz, Axelrad, & Anderson, 2014
Epilepsy	A chronic neurologic condition resulting in seizure activity that is considered chronic in nature.	Acute & Chronic, limited vitality, limited alertness	DePaepe, P., Garrison-Kane, L., & Doelling, J., 2005
Pediatric heart disease	A term used to describe several different heart conditions in children. The most common type of pediatric heart disease is congenital, meaning that children are born with it.	Acute & Chronic, limited strength, limited vitality, and limited alertness.	The Society of Thoracic Surgeons, 2002
Hemophilia	A rare bleeding disorder in which the blood doesn't clot normally and teach them how to exercise safely.	Acute & Chronic, limited strength, limited vitality	(National Heart, Lung, & Blood Institute [n.d.]
Lead poisoning or lead exposure	Lead poisoning is one of the most common preventable poisonings of childhood. Data from the Center for Disease Control (CDC) show that 6% of all children ages 1-2 years and 11% of black (non-Hispanic) children ages 1-5 years have blood lead levels in the toxic range .	Chronic, limited strength, limited vitality, limited alertness	American Academy of Child & Adolescent Psychiatry, 2012
Leukemia	A form of cancer that starts in blood-forming tissue such as the bone marrow and causes large numbers of blood cells to be produced and enter the bloodstream.	Acute & Chronic, limited strength, limited vitality, limited alertness	National Cancer Institute [n.d.]
Nephritis	A kidney disorder that occurs when one or both of a person's kidneys are inflamed.	Acute & Chronic, limited strength, limited vitality, limited alertness.	National Dissemination Center for Children with Disabilities (2012)
Rheumatic fever	A disease that develops as a complication of untreated or poorly treated strep throat or scarlet fever.	Acute & Chronic, limited strength, limited vitality, limited alertness.	NDCCD, 2012
Sickle cell disease	An inherited blood disorder, also known as sickle cell anemia and/or sickle-hemoglobin C disease, in which defective, sickle-shaped red blood cells fail to carry adequate oxygen to tissues in the body	Acute & Chronic, limited strength, limited vitality, limited alertness.	Key, DeNoon, & Boyles, 1999, p. 16 DePaepe, P., Garrison-Kane, L., & Doelling, J., 2005
Tourette's syndrome	A neurobiological disorder characterized by tics (involuntary, rapid, sudden movements) and/or vocal outbursts that occur repeatedly.	Chronic, limited alertness.	NDCCD, 2012

The list of qualifying conditions is illustrative rather than exhaustive and the portion of the IDEA regulations stating “...and adversely affects a child’s educational performance.” (Fed. Reg., 2006) must be considered before a student can be found eligible for any classification under *Other Health Impairment*. In her 2002 article *Eligibility under IDEA for Other Health Impaired Children*, page 12, Kara Grice offered a series of questions school officials may use when determining special education eligibility for *Other Health Impairment*. These questions follow:

1. Does the student have a chronic or acute health problem?
2. Does the student have limited strength, vitality or alertness? If not, does he or she have heightened alertness to general environmental stimuli?
3. If so, does the student’s limited strength, vitality, or limited alertness reduce his or her alertness in the educational environment? Or does the child’s heightened alertness to the surrounding environment limit his or her alertness to the educational environment? If so, is the limited, or heightened, alertness due to a chronic or acute health problem?
4. If so, is the student’s educational performance adversely affected by the limited alertness?
5. Finally, if so, does the disability create a need for special education services?

Standards of Practice for Professionals & Families

In addition to the guidance provided special education programs by federal, state, and local laws, regulations, and policies, special education professionals can be guided by ethical principles and recommended practices generated by professional organizations. The Council of Exceptional Children (CEC) and the Division of Early Childhood (DEC) within CEC have developed standards and recommended practices.

Council of Exceptional Children Standards

As the recognized leader for special education professionals, the Council for Exceptional Children (CEC, 2010) has developed standards, ethics, practices and guidelines to ensure that individuals with exceptionalities have access to well-prepared, career-oriented special educators. Of particular note to the area of discussion are certain ethical principles that address the

profession's and professional's interaction with students presenting with exceptionalities and their families. The CEC's *Special Education Professional Ethical, Practice Standard 4* addresses the importance of practicing collegially with others when providing services. Given the multiple service providers addressing the needs of students classified as OHI, collegiality among these providers is essential for successful collaboration. Practice Standard 5 addresses the importance of family-based service provision. Not only is this considered "Best Practice" but it also follows the mandate of IDEA. The emphasis of Practice Standard 7 is holding the physical and psychological safety of the individual paramount. Students classified as OHI present with precarious health requiring the professions working with the student to be vigilant regarding the student's ongoing health needs and considerations. Practice Standard 8 encompasses the "do no harm" mantra embraced by services providers. The standard also assists in defining the limits of professionals' practice with the student. Familiarity and convenience may encourage special educators to provide services outside their respective scopes of practice with children classified OHI. This standard emphasizes that the wellbeing of the student is dependent on adherence to the boundaries of each professionals' training. Practice Standard 9 reinforces that ethical practice embodies adherence to laws, regulations and policies related to the provision of services to students holding the *OHI* classification.

Division of Early Childhood Recommended Practices

The Division for Early Childhood (DEC, 2014) of the Council of Exceptional Children (CEC) has formulated recommended practices for practitioners and families to provide guidance in ways to improve learning outcomes and promote the development of young children, birth through eight years of age, who have or are at-risk for developmental delays or disabilities. By

highlighting practices known to result in better outcomes for children with disabilities, their families, and the personnel serving them, the DEC attempts to integrate principles anchored in research to the practices in schools, classrooms, and homes. These practices have been divided into seven topic areas and include specific guidance germane to this discussion. The practices recommended for topic areas relevant to the classification of OHI are summarized below and information regarding nurturing parent participation and satisfaction is also included.

Leadership: Individuals classified as OHI may require the services of a diverse group of providers. Leadership demonstrated by the special educator will be an essential part of bringing these diverse professionals together as a team. By assuring shared decision making with practitioners and families and by using data to examine the effectiveness of services and supports, multiple disciplines and the family can work together as a team.

Assessment: Correlating the effects of health, behavior, development and cognition present a challenge for families of children classified as OHI. By identifying and respecting family preferences for assessment and working as a team with the family to gather assessment information, assessment results will be understandable and useful to families.

Environment: Natural, accessible and inclusive environments promote access to and participation in learning for the child classified as OHI. Inclusion of access to assistive technology and opportunities for movement and regular exercise are essential to improve and maintain wellness for the child with chronic/acute health problems.

Family: As with children presenting with other disabilities, students with health impairments come from a variety of cultural, linguistic, and socio-economic backgrounds. Sensitivity to the family's culture and the changing life circumstances often experienced by students with health impairments is essential in establishing a partnership with families.

Instruction: Each child classified as OHI has strengths, preferences, and interests. By engaging the child in active learning, the child becomes adaptive, competent, and socially connected thereby promoting learning in natural and inclusive environments. Given the likelihood that the child classified as OHI will have multiple professional service providers, facilitating positive adult-child interactions designed to promote child learning and development are recommended

Teaming and Collaboration: The individual needs of children classified as OHI requires that supports and services provided meet those unique needs of both the child and the family. Exchanges of expertise, knowledge, and information between the child's multiple caregivers builds team capacity and allows for joint problem solving, planning and implementing interventions, community-based services, and other informal and formal resources. The identification of one practitioner from the team to serve as the primary liaison between the family and other team members is a recommended practice.

Transitions: Children classified as OHI may experience exacerbation and/or diminution of their health problems. With the changes in the health problems, transitions regarding educational and health services may be necessary. These transitions may include hospital to home, school to hospital, and Part C to Part B services. The team of caregivers must support successful adjustment and positive outcomes during these periods of transition for both the child and family.

The discussed practice standards and recommended practices are important because they provide guidelines for the provision of services to children and families. Additionally, these standards/practices should be reflected in the narratives of parents when interviewed regarding

their perceptions of access and satisfaction with the special education and school health care services provided to their children.

Parent-Professional Interactions

Families' involvement with and participation in the identification and management of students with special needs has been a cornerstone of the delivery of special education services since the passage of PL 94-142 in 1975. Often the health problems associated with children classified with OHI require a lifetime of support and adaptations. The parent, as the team member present across the lifespan, is essential in providing present and future service providers the history of the child's educational successes and failures. Therefore, nurturing positive parent-professional interactions will be an essential part of the child's educational experience. As described by Summers, J., Hoffman, L., Margquis, J., Turnbull, A., Poston, D., & Nelson, L., 2005, "measures of family-centered practice tend to measure the degree to which parents perceive the processes by which services have been delivered, that is, whether the professionals have been caring or facilitative of family empowerment."

Recommendations for Special Educators

In 1998 Pruitt and her colleagues outlined a series of concerns their research with parents brought to light. Also included were recommendations for establishing parent and educator decision making partnerships. The following recommendations were included by Pruitt:

1. Special educators must listen to parents' contributions concerning their children's needs, as well as family issues and concerns. As the one constant in their children's lives, parents have valuable information to offer professionals. Although parents may lack professional training, they can still make good judgments regarding educational planning and instruction. Parents must feel that their contributions are heard and validated. Families want professionals to be supportive and nonjudgmental as they strive to deal with the day-to-day parenting of their children with special needs. Teachers are admonished to listen and consider all contributions without prejudice.

2. Special educators must determine concrete strategies to improve the quality and quantity of communication with families. Just as educators need to listen carefully, they also need to monitor their verbal and written interactions with families to ensure that communication is kept at a level of mutual respect. Parents request that educators speak to them as they would speak to an equal or a friend, rather than in a dominating manner, and without implying intolerance. In addition, regular communication from school, such as written notes, journals, informational meetings, and phone calls detailing successes as well as concerns, should be established. Educators must enable families to feel comfortable in contacting the school with relevant information regarding home or related service situations that may affect student performance.
3. Special educators must be sensitive to the needs of the families, not just those of the students they serve. Parents encourage educators to "walk a mile in their shoes" and, as much as possible, to imagine how they might feel if they were parenting a child with special needs. Parents also exhort educators to recognize that every student they serve is a child in a unique family structure. By being aware of family issues, educators can be a key resource in tailoring school services as well as providing information about community services. Educators must monitor their advice and consultation to fit individual families and their needs while building their own knowledge of available supports.
4. Special educators must continue to increase their knowledge about disabilities. Educators should strive to be lifelong learners in their field. Parents ask that educators who are serving students diagnosed with disabilities with which they have limited or no familiarity seek additional information. By doing so, the educators are more adequately prepared to effectively address the complexities of those students' needs.
5. Special educators must respectfully accommodate individual needs of students. It is equally important to listen to the students' as well as the families' contributions regarding the educational process. Parents request that educators provide a supportive and nurturing environment that fosters self-awareness and healthy esteem. Educators are advised to help students to understand their own strengths and needs and thereby to be advocates for necessary accommodations. By doing so, educators allow students to be risk takers and partners in the educational process.
6. Special educators must improve the Individualized Education Plan process to be more receptive to family issues. Because the IEP process is the one mandated interaction between school and family, it must reflect to the fullest degree the potential for strong collaborative relationships. Parents ask that educators be responsive to them and regard their contributions as viable options for curricular and instructional services. Parents want to perceive themselves as equal partners in a team striving for the same goals. Educators are encouraged to select service patterns and develop instructional goals collaboratively with families so as not to give the impression that the family has no recourse.

Educators must be willing to acknowledge that parents should have equitable, collaborative roles because they possess critical information about their children, without which the educational process cannot be complete. Input from parents can provide information for school personnel about the child outside of the school setting.

Parent Perception of Professional/School Processes

Spann, Kohler and Soenksen (2003) examined parents' involvement and perception of special education services with a group of parents involved in a statewide support group. While the examination found that parents generally were satisfied with the quality of their children's special education services, nearly half of those parents interviewed believed that the schools were doing little or nothing to address their child's most pressing social or academic need.

As suggested by Stoner, j., Bock, S., Thompson, J., Angell, M., Heyl, B., & Rowley, E. (2005), although IDEA's provisions are straightforward and fundamental, attitudinal and implementation complexities often deter the law's well-intended focus. Recognizing the lack of investigative literature regarding the interaction between parents and education professions, these authors studied the influences on parents' interactions with professionals, their experiences when interacting with education professionals, and their roles and relationships with education professionals. The study targeted parents of children with autism spectrum disorders. In this study, the authors found that during the struggle to obtain a diagnosis for their children, parents adopted a pattern of behavior and a sense of distrust with medical professionals which continued and influenced the parent's interactions with educational professionals. The parents also became educated regarding their child's diagnosis and developed an "external problem-focused behavior" (focusing energy on child's diagnosis) to attack the problems which became their primary coping strategy.

Parent Satisfaction Related to Student's Age

Further, Stoner et al (2005) found early intervention services (birth to three years) offered to families with children on the autism spectrum were perceived as positive because they provided additional self-education and support for external problem-focused behaviors. However, the parents reported that entering school-based special education was traumatic, confusing, and complicated. The feelings of confusion resulted in intensified parental concerns and fostered attitudes of dissatisfaction with the special education system. When attempts at obtaining services for their children were unsuccessful, the parents' trust with the educational professional was reduced. The lack of trust resulted in the parents need for frequent, open, and honest communication between the parents and teachers. These negative experiences resulted in parents feeling educational professionals were untrustworthy even when individual situations with their children improved.

The age of the child receiving special education services also influenced the parents' satisfaction with the services provided. The previously cited study by Leiter and Krauss (2004) revealed that parents of older children were less likely to be satisfied with the programming offered for their children. Additionally, Stoner et al (2005) reported parent satisfaction was greater with parents of children in Part C (zero to three years old) services of IDEA as compared to parents of children in Part B (three to twenty-one years old) services.

Using the Beach Center *Family-Professional Partnership Scale*, Summers et al (2005) assessed parent satisfaction with special education programming and found "parents of children ages 6 to 12 appear uniformly less satisfied than do parents of children ages 3 to 5, who also appear less satisfied than do parents of children birth to 3 years. Generally, as service plans move from "family-focused" to "child-focused" the general level of satisfaction with the service

plans decreased. An additional finding in the Leiter & Krauss (2004, p.143) study was that "...it is not simply participation but rather the nature and outcome of that participation that may shape parents' satisfaction with regard to their children's educational services." Factors such as parents' level of expectation, gender of student, and whether parents are seeking additional services influence the "nature and outcome of participation."

Parent Satisfaction Related to IEP

In a 2000 study, Garriot, P., Wandry, D., & Snyder, L. specifically looked at the development of Individualized Educational Plans from the perspective of the parents participating in the process. The study suggested that the "first indications" of parent-professional interactions in IEP meetings were becoming more interactive and collaborative. However, in general, parents remained "in the role of recipient of information rather than a provider..." (Garriott et al. Discussion ¶1). In fact, approximately 27% of the parents participating in the study indicated a somewhat adversarial relationship existed between themselves and the professionals. Further, these parents felt "devalued, disrespected and ostracized during the planning process...leading some parents to believe their input was perceived by the educators to be inconsequential or unimportant" (Garriott, 2000, Discussion ¶6).

Fish (2006) conducted a case study focusing on one family support group chapter regarding the development of the Individualized Education Program (IEP). He notes that the IEP has been the primary vehicle for directing and monitoring the components of a student's special education program including educational needs, goals and objectives, placement, evaluation criteria, present levels of educational performance, duration of programming and modifications. Findings from this study suggested parents did not perceive themselves as being

treated as equals among educators during IEP meetings, and parents believed that their input was not valued or welcomed by most educators. The parents participating in this study did not feel that the school personnel adequately implemented the student objectives agreed upon in the IEP meeting. Rather, the parents felt teachers saw the process as a “formality” rather than an opportunity to implement and adhere to objectives in order to facilitate positive outcomes for their students.

In a follow-up study with middle and upper middle class parents of children receiving special services, Fish (2008) found the majority of parents had positive perceptions of IEP meetings because educators acknowledged their input and treated the parents with respect. The parents emphasized the need for parents of children who receive special education services to be proactive during meetings by asking questions and making suggestions to the team. They also recommended that parents become educated in all aspects of the special education law and the IEP process in order to improve the outcomes of IEP meetings. In fact, parents felt that their understanding of the special education process was the number one factor impacting the outcomes for their children’s IEP meetings, and consequently, the type of services that they received.

Parent Satisfaction Related to Other Health Impairment

In 2002, Sharon Miles-Bonart examined the influence of several variables on parent satisfaction with Individual Education Programs (IEPs). These variable included professional etiquette, procedural factors, demographic factors, and child eligibility code factors. While all variables were found to significantly influence parent satisfaction with the IEP process. Interestingly, when child classification factors were explored, parents of children with physical/health impairments were generally the least satisfied with the IEP development. Miles-

Bonart, 2002 opined that the lesser satisfaction by this group of parents may be related to differences in perceived needs of the child by parents and school staff. Miles-Bonart suggested that parents may focus more on health/medical services as opposed to standard academic practices and that the educational relevance of these services may be interpreted differently by members of the IEP teams.

Deborah Fidler and John Lawson (2003) of Colorado State University completed a study to explore what parents wanted in school programming for students with specific etiologies including *Other Health Impairment*. Their findings suggested that parents supported the tailoring of educational programming to meet syndrome-specific needs of their child in terms of classroom instruction and services received. Parents believed that programming for students categorized as *Other Health Impairment* (by the nature of the category) should be designed to align instruction that is consistent with the students' health impairment.

Leiter & Krauss, 2004, used data from the National Health Interview Survey (1994-1995), a nationally representative survey of the U.S. noninstitutionalized civilian population, to investigate school-aged children who received special education services and whose parents requested additional related services for their children including services typically provided to students classified as OHI (e.g. medical services, nursing services, therapy services). Specifically, the information gathered included the characteristics of the children receiving the services, the characteristics of the parents who requested additional related services, the characteristics of children and parents who experienced barriers to receiving these services. How the experiences of requesting additional related services were associated with parents' satisfaction with special education services provided their children was detailed. The authors' data analysis found that both collaboration and conflict occurred when parents engaged in

advocating on behalf of their children. Within special education, parental participation involves taking part in planning for the child's educational program and advocating for more services if the parent believes they are necessary. Approximately 15% of the parents made claims for additional related services, with most (80%) of those parents reporting problems in obtaining the services. These results attest to the potential for collaboration to turn into conflict. In this study, parents of boys and older children were less likely to report being satisfied with the services provided by the schools. The combination of requesting additional services and having problems was related to parental dissatisfaction. Parents were 90% less likely to report being satisfied with special education services when they had requested additional services and experienced problems obtaining those services.

Summary

The definition of OHI includes examples of types of health conditions that may limit a child's educational performance. A variety of health conditions may qualify a child under OHI. The sequela of the child's health condition(s) become an over-riding component when planning and implementing the child's educational experience. Key to successful planning and implementation is the establishment and maintenance of positive parent-professional relationships. Educational statutes and regulations establish the parameters of the educator's role in providing services to a child classified as OHI and professional organizations and research guide the delivery of services to this group of children. Recommendations, including developing collegiality between service providers, offering family-based services, keeping physical and psychological safety of the learning paramount, adhering to laws, regulations and policies, and knowing and maintaining professional boundaries, appear across the literature related to special

education and school health services. However, parent satisfaction with these services remains equivocal.

To fulfil the vision and purpose of the IDEA, engagement, support and satisfaction of parents of the children served is essential. To that end, a clearer understanding of parents' perceptions regarding children classified as *OHI* may help guide the professions in their efforts to increasingly implement family-centered care.

METHODOLOGY

The literature regarding the efficacy/utility of the OHI classification in providing sufficient access to both special education and school health services is limited. Additionally, existing literature is ambiguous regarding parents' perception of satisfaction with special education services. Exploring the families' perceptions of the OHI classification will aid in informing all stakeholders regarding the efficacy/utility of the classification and the influence of family-centered care principles.

Implementation of this investigation took place in a state in the southern region of the U.S. The parent participants were interviewed using questions and prompts preselected and designed to verify their experiences with the use of Family-Centered Care principles. Obtained data was analyzed using data reduction, data displays, and conclusion drawing. Data Analysis determined parents' perceptions of special education services, satisfaction of OHI classification and influences of Family-Centered Care principles on parent satisfactions. Results detailed these perceptions, levels of satisfaction and the influences. Theories supporting the source of the parent participants' responses were suggested.

Participant Criteria and Recruitment

Given the study's purpose of determining parents' perceptions of the *Other Health Impairment* category, criterion for participation was a parent of a student from 3 to 21 years old who has or had the OHI classification or accommodations via his or her school district. It was anticipated that some children would carry classifications in addition to OHI. While such participants would be acceptable for participation in the study, an effort was made to include data specifically related to the OHI classification. Ten (10) parent participants, referred by a parental advocacy agency, were identified whose children all carried the classification of OHI.

Sampling Procedures

Convenience sampling was used to select the sites and participants for this study.

Creswell 2002 defines purposeful sampling as “...a procedure in which researchers intentionally select individuals and sites to learn or understand the central phenomenon.” Participants from one state in the south, where the researcher lived and worked, were identified. Communities of differing population and sizes were included in an effort to provide study participants from urban, suburban and rural environments. By including participants from diverse geographic areas and school districts, the data collected had greater generalization across the broader population of students with OHI.

Sampling provided ethnic and cultural variety, therefore, sensitivity to the cultural diversity of the families became a necessary component of the sampling procedures. As noted by Kalyanpur et al (2000), families from diverse cultures may practice different parenting styles and hold different beliefs about child development and disability. Additionally, the parents’ culture and experience may shape their perception of the special educational system. These families may or may not have had access to or understanding about information and resources, awareness of their rights, the avenues for participation, and for redress. For example, given the influences of their cultures, some families may have chosen not to participate in the active decision-making process of the IEP development. Recognizing that implicit institutional and personal beliefs affected the potential for collaboration as much as did explicit practices (Olivos, 2009), care was taken to create a comfortable, trusting relationship with the participants and to project an accepting attitude toward the informants. The participating families were encouraged to self-select the time and venue of the interviews and the interviews were conducted in a

relaxed, conversational style. Additionally, families were assured that all identifying information (names of interviewee, student, school, school system, and city) would be eliminated from the reporting process and that a copy of the report generated from the interview would be made available to them.

Network sampling (Glesne, 1999, adapted from Patton 1990) was used to locate likely participants within communities from which participants were actually drawn. Through the researcher's network of academic and professional relationships, potential participants were identified. Additionally, parent groups representing several specific health impairments were used to identify families interested in participating in the research project. Letters were sent to special education colleagues, physicians, and education/health leaders seeking referrals of families with children holding the classification of *Other Health Impairment*. Additionally, parental advocacy groups (i.e. local chapters of Family Helping Families) were solicited in an effort to recruit participants.

Following identification of the potential participants, an initial contact was made with the families via email or telephone. A time, date, and place was determined for the interview. Parents were given a brief synopsis of the research project and a consent form (see Appendix A) that included required information -- the purpose of the research study, the interview procedures that were used to obtain data, the benefits for the participants' involvement, and the assurance of confidentiality of all data collected. The potential participants were asked to review the information provided and to sign the Consent Form. As an additional incentive for participation, the participants were offered a \$100.00 gift card for their time and participation.

Data Collection

Data collection began in August of 2015. Data was gathered via a face-to-face interview process. Qualitative methods are supported by the interpretivist paradigm (also referred to as Constructivist, Glesne, 1999) which portrays a world in which reality is socially constructed, complex and ever changing. Social realities are constructed by the participants in those social settings (Glesne 1999). Consequently, this study used interviews with parents of children classified as *Other Health Impairment* to begin to understand the parents' social realities.

Interviews or, "conversations with a purpose" (Burgess, 1984), involve the art of asking questions and listening. Unstructured, one-on-one interviews are effective ways to gain perspectives of participants in their own terms (Creswell, 2002). Thus, this method was especially suited to the goal of learning about the perceptions of parents whose children are categorized as presenting with *Other Health Impairment*.

Like most research methods, interviewing offers both benefits and challenges. Collecting a large amount of information related to the research question(s) as perceived by the interviewees is an obvious benefit of the interview method. The unstructured, one-on-one interviews completed for this study allowed the interviewees to describe in detail their experiences having a student classified with OHI. The rich detail offers the researcher opportunities to more fully understand the interviewee's point-of-view or socially constructed reality. Another benefit of interviewing is the ability to return to the interviewee at a later date to seek clarification and/or additional information.

Glense (1999, p. 96) advises "In qualitative research, rapport is a distance reducing, anxiety-quieting, trust-building mechanism that primarily serves the interest of the researcher." Establishing and maintaining rapport can become a challenge associated with the interviewing.

While a number of factors influence relationship building (rapport) with informants, four factors seem most pertinent to this study; knowledge of the setting, language, reciprocity, and assurances of confidentiality.

Knowledge of the Setting

Prior knowledge of educational settings or environments was an important consideration for this study. (Glesne [1999] states this knowledge demonstrates the interviewer's level of preparedness and adds to his/her credibility.) Knowledge about educational settings shared with the participant avoids the need for lengthy explanations (on topics not related to the research question) that could potentially disrupt the continuity of the discussion.

Having worked as a speech-language pathologist with children and adults with health impairments in school settings over a career spanning forty years, this researcher was knowledgeable regarding the challenges children with health impairment meet when attending school. In the summer of 2006 the researcher spent two months as a graduate intern in the Office of Special Education Programs (OSEP) within the U.S. Department of Education. The timing of this experience was particularly advantageous as that summer also saw the release of the regulations for the most recent reauthorization of IDEA. Much of OSEP's energy that summer was concentrated on distributing, introducing and interpreting the new regulations to professionals across the United States. Having the opportunity to participate in these activities allowed the researcher to become intimately familiar with the regulations.

Knowledge of the Language and Jargon

Like most professions, the field of special education has generated specific jargon and acronyms that can be confusing to someone unfamiliar with the profession. This can be a source of confusion both for the interviewer and the interviewee. This researcher has the advantage of

familiarity with the terms used by special education professions. Plus, having parented a child with special needs, the researcher was familiar with the potential concerns, fears, and frustrations parents face when interacting with the special education system. Armed with these two experiences the researcher was able to understand and translate the language and jargon of the profession with the research participants.

Reciprocity

Reciprocity, the mutual exchange of effort, includes the time the informant gives to the research project and their willingness to share information with the researcher. In return, the researcher offers participants the opportunity to express their feelings, to be heard by an engaged and accepting listener, and to feel valued for their contribution to research knowledge in the field of special education. Participants in this study also received a gratuity in the form of a \$100.00 gift card.

Confidentiality

Each participant received the assurance of anonymity, another building block in rapport building. The quality of an interview is dependent on gaining honest responses to questions that may be sensitive. Participants might be hesitant to respond as willingly and openly without the promise of confidentiality. Confidentiality was discussed with participant in the initial letter of invitation (Appendix C), the telephone conversations arranging the interview, the preliminary conversation prior to the actual interview, and again when explaining the informed consent. The informed consent outlines measures used to insure confidentiality: pseudonyms used in place of participants' and school/school districts' names in the written report; the names and roles of persons with access to privileged information; and the assurance that notes, forms, and materials

would be housed in a secured place. All participants signed the formal consent following the explanation of these confidential safeguards.

The Interview Process

Interview Format

Parents of children categorized as *Other Health Impairment* were interviewed. The interview process was initiated with an explanation of the project followed by the presentation of the informed consent information and the signing of the informed consent forms. The interviews typically lasted between 45-60 minutes. All interviews were conducted in-person at locations convenient to the participants. These locations included their homes, their offices, or convenient community locations.

Recording of Interview

The interviews were recorded using a Sony IC Recorder, Model ICD-PX333. Recording the interviews eliminated the need for ongoing note-taking that may have been distracting for the participants. Recording the interviews also allowed the interviewer to focus full attention on the participant and what they are reporting.

The recordings were transcribed verbatim. The recordings and transcriptions provided hard data that added to the trustworthiness or reliability of the study. The recordings remained a constant source of information regarding the interviews. The prosodic aspects of the interviewee's presentation also added meaning beyond the words spoken. A professional transcription service was used to transcribe the interview recordings. The transcription service agreed to adhere to the rules of confidentiality embraced by the participants.

To verify the accuracy of the transcribed recordings, each transcription was read while listening to the recorded interview. During this replay, the prosodic features of the interviewee's

presentation were noted on the interview transcripts – pauses, changes in pitch indicating emphasis, rushes of speech, emotionality, and other potentially relevant features.

The recording instrument automatically labeled each interview as the recording took place. Additionally, the recordings were dated and coded as discussed by Glesne (1999). The labeled data was repeated on the Interview Protocol (Appendix B). The Interview Protocol format was developed following the illustrated protocol featured in Creswell (2002). The protocol contained identifying demographic information, a description of the research project (including the purpose of the study, the sources of the data being collected, how the data would be used, the confidentiality standards, and how long the interview will take), along with planned questions to be used during the interview.

Interview Sequence

Each interview began with a brief overview of the study. The intention was to put the interviewee at ease and help establish a relationship of trust and willingness to share.

The interview process was semi-structured and included a series of open-ended prompts (Glesne, 1999). Interview prompts were designed to stimulate discussion and were formulated using “parent friendly” language (see Appendix B). The questions were designed to elicit narratives about the students classified as *Other Health Impairment*. The researcher anticipated that the parent interviewee would include in these interviews information that illustrated their perception regarding the utility of the classification category as it relates to their child, as well as satisfaction with their ability to access services for their child. The researcher’s goal was to elicit the parent’s perceptions without having to directly ask them to speak regarding their perceptions.

Throughout the interviews an attempt was made to remain attentive to gathering information and exploring experiences, perceptions, and satisfaction regarding the utility of the

Other Health Impairment category. When it appeared that the interviewee had more information to share, probing questions were used to elicit additional information from the parent.

Information concerning the use of family-centered care principles was gleaned by the parents' descriptions of their interactions with education and medical professionals.

Two verification procedures suggested by Creswell (as cited in Glesne ,1999) were used to increase the trustworthiness of the data. These procedures included multiple sites and clarification of researcher bias. The multiple sites represented multiple schools, school districts, and geographic regions within the state. The researcher bias regarding the research questions was determined and clearly stated prior to the initiation of the data collection. Continuous reflection on the researcher's subjectivity was applied during the data collection, data analysis, and formulation of results in an effort to eliminate the effects of the researcher bias.

Note-taking

Glesne (1999) discusses the importance of keeping an account of every interview/interviewee and suggests potential note-taking topics. Following the interviews, topics including questions that required elaboration, questions that were less effective, start and stop times of interview, and special circumstances that affected the quality of the interview and proved helpful were noted to aid in planning for subsequent interviews. These notations stimulated reflection, analysis and insight during data analysis and were used in this study.

Notes on Analysis

Consistent with grounded theory design, the process of analysis began following the first interview. With the first listening of the recording of the interview anticipated themes emerged. Some themes were confirmed by subsequent interviews while some fell away as more prominent and consistent themes emerged across the interviews. Several summation type questions were

included in the interview (i.e. “What was the most positive experience for your child classified as *Other Health Impairment?*”). These questions allowed the interviewee to summarize the most important considerations and helped formulate themes. A consistent coding device (nodes – a container for related material allowing for emergence of patterns and ideas [NVIVO 10]) were used to code similar themes across all interviews.

Data Analysis

Qualitative data analysis uses an inductive approach to generate concepts and hypotheses from the existing data (Vaughn, et al 1996). The analysis of the data collected during the participant interviews began with the planning of the research project, continued into the interviews with the participants, and was organized by nodes, themes, or hypothesis. Miles and Huberman (1994) define analysis as consisting of three concurrent flows of activity: data reduction, data display, and conclusion drawing/verification.

Data Reduction

Data reduction refers to the process of selecting, focusing, simplifying, abstracting, and transforming the data that appear in written-up field notes or transcriptions (Miles & Huberman, 1994). Data reduction was a part of the data analysis process. Each decision to include or exclude a piece of data was an analytic choice. The data was, however, maintained within the context in which it occurred. This process was aided by the use of *NVIVO-10* software. The *NVIVO-10* software allow for coding of the data into nodes which are linked to the original transcripts. The data can be viewed in total or in more abbreviated node form. The software provides an array of options for capturing and displaying the data. Thus, *NVIVO-10* software establishes a “checks and balances” system similar to interrater reliability.

The present study used participant interviews as a data gathering device. Notes completed after the individual interviews were inserted into the transcripts to more fully develop the context of the participants' words.

Each page of the interview transcripts were identified by data source, page number, and code types. The chunks of data extracted from the transcripts were coded allowing for tracing data back to the original data source more easily.

Data Displays

Using the qualitative analysis software (NVIVO) allowed for the development of various data displays. A data display is an “organized, compressed assembly of information that permits conclusion drawing and action” (Miles & Huberman, 1994). This required identification and extraction of meaningful units or nodes found in the words and actions of the participants that were related to the research questions. These passages or data chunks were examined repeatedly to determine more distinct patterns or themes as a base for larger categories of meaning. The data was displayed in several forms – Word Clouds, Tree Maps, and Matrix Coding schematics.

Summary

The proposed study described above was consistent with constructivist qualitative research, specifically grounded theory design. Using convenience sampling, ten families of individuals classified as *Other Health Impairment (OHI)* from varying geographic locations were interviewed concerning their perception and satisfaction with the classification. Questions were framed to reveal the use of Family-Centered Care. The interview data was analyzed using NVIVO software, data reduction, data displays, and conclusion drawing. Data analysis determined parents' perception of special education services, satisfaction of *OHI* classification

and influences of Parent Centered Care principles on parent satisfaction. Theories supporting the parents' perceptions, satisfaction, and influences were originated.

RESULTS

Demographics

Results of the study were determined using a systematic process. Ten parents of children classified with Other Health Impairment (OHI) by their Local Education Agency (LEA) were interviewed using an Interview Protocol (see Appendix B) containing a series of open-ended questions regarding the parents' experiences with the school system. Demographic information regarding the interviews are included in Table 4.

Table 4
Interviewee Demographic Information

Identification Number	Location of Interview	Relationship To Student	Age of Student	Medical Diagnosis supporting OHI	LEA Type	Total Time of Interview
01	Office of Parent	Mother	18 years	ADD*	Rural/ Public	66 minutes
02	Parent Home	Mother	17 years	ADHD*/OCD † Seizure Disorder*	Suburban/ Public	50 minutes
03	Parent Home	Mother	12 years	Orbeli Syndrome †	Suburban/ Public	55 minutes
04	Grand-Parent Home	Mother	13 years	Cri du Chat Syndrome †	Suburban/ Public	43 minutes
05	Retail Establishment	Mother	10 years	Autism *, ADHD*	Suburban/ Public	36 minutes
06	Retail Establishment	Father	8 years	ADHD*	Suburban/ Private	28 minutes
07	Home Parent	Mother	11 years	Fragile X Syndrome †	Urban/ Public	44 minutes
08	Public Library	Mother	18 years	Asperger's Disorder †	Urban/ Public	54 minutes
09	University Library	Mother	9 years	Autism * Anxiety * Depression *	Suburban/ Public	67 minutes
10	School Chapel	Mother	10	Congenital Cytomegalovirus †	Suburban/ Public	50 minutes

*Condition specifically detailed in IDEA regulations

† Condition not specifically detailed in IDEA regulations

Definitions: Obsessive-Compulsive Disorder (OCD) - a common, chronic and long-lasting disorder in which a person has uncontrollable, reoccurring thoughts (*obsessions*) and behaviors (*compulsions*) that he or she feels the urge to repeat over and over. (National Institute of Mental Health, 2016)

Orbeli Syndrome - Deletion of the long arm of chromosome 13 with a wide spectrum of abnormalities, including retinoblastoma, mental and growth retardation, brain malformations, heart defects, distal limb deformities, and digestive, urogenital, and other abnormalities. (Whonamedit?, 1994-2016)

Cri du Chat Syndrome - Cri du chat (a French phrase that means "cry of the cat") syndrome is a group of symptoms that result when a piece of chromosomal material is missing (deleted) from a particular region on chromosome 5. Children born with this chromosomal deletion have a characteristic mewing cat-like cry as infants that is thought to be caused by abnormal development of the larynx (organ in the throat responsible for voice production). They also have unusual facial features, poor muscle tone (hypotonia), small head size (microcephaly), and mental retardation. (Encyclopedia of Children's Health, 2016)

Table 4 cont.

Fragile X Syndrome - a genetic condition that causes a range of developmental problems including learning disabilities and cognitive impairment. Usually, males are more severely affected by this disorder than females. Affected individuals usually have delayed development of speech and language by age 2. (National Institute of Health, 2016)

Asperger syndrome (AS) is an autism spectrum disorder (ASD), one of a distinct group of complex neurodevelopment disorders characterized by social impairment, communication difficulties, and restrictive, repetitive, and stereotyped patterns of behavior. (National Institute of Health, 2016)

Congenital Cytomegalovirus - a condition that can occur when an infant is infected with a virus called cytomegalovirus (CMV) before birth. Congenital means the condition is present at birth. (MedlinePlus Medical Encyclopedia, 2015)

The group of ten interviewees were predominately mothers (one father participant) whose children attended mostly public schools (one private school) within suburban, urban, and one rural school district. Students ranging in age from 8 years to 18 years with an average age of 12.6 years were represented by their parents. ADD/ADHD and syndromic conditions were the most frequent medical diagnoses of the students with OHI classification. The mean length of the individual interviews was 49.3 minutes with interview lengths ranging from 28 to 67 minutes.

Description & Inferential Codes

As described in Chapter 3, analysis of the interviews began once transcripts of the interviews were obtained. During the initial analysis of the first interview, several descriptive categories were revealed that became the basis for the categories identified in subsequent interviews. While additional categories were added over time and some categories were not present in all interviews, the categories identified in the initial analysis of the first interview, generally, persisted across the subsequent interviews.

Four of the identified categories resonated with all ten interviewees; first experience, parent feelings, recommended services, and the school's responses to parents. Because these four categories were used across all participants, they were chosen for additional inferential analysis. From this secondary analysis, eight inferential codes were identified as being present across almost all interviews and indicated themes drawn from the interviews. Table 5 lists the codes and an explanation of each.

Inferential Codes

Table 5
Inferential Codes Identified in Interviews

Inferential Code	Explanation
Positive Experiences with Part C Services	Expressions by parents of their positive regard for the Part C services
Loss of Trust	Expressions by parents that their child's school system or school personnel failed to deliver on an assumed responsibility
Negative Emotional Responses	Expression by parents of their adverse emotional responses to interactions and/or engagement with school personnel or school systems
Lack of Systemic Resources	Expressions by parents of resources lacking from their school system or school personnel.
Lack of Interpersonal Integrity	Expression by parents of experiences resulting in the parents feeling the school personnel were not honest, forthright, respectful, or tolerant.
Confusion Regarding OHI Classification	Expressions by parents as to why their child carried the classification Other Health Impairment.
Limited Communication Between Health and Education Professionals.	Expressions by parents of infrequent or non-communication between the health and education professionals involved in their child's care.
Usefulness of School Health Services	A subjective discussion with parents regarding how useful the school health services provided their children was in their child's overall academic experience.

Positive Experiences with Part C Services

Four of the ten participants reported their children were enrolled in Part C services prior to their children's third birthday. Responses from these individuals were universally positive regarding Part C special education services. In their comments regarding Part C services, it was clear that one of the reasons for the families' delight was evidence of the use of family-centered care principles. Specifically, participant #1 reported, "...that's where I started...what they

taught me was really, really helpful...I didn't have one bad experience with anybody who came into my home." Participant #10 reported, "...It made all the difference. It really helped us take a sort of devastating neurology diagnosis and really think from a hopeful lens...It was life changing, I think, to be surrounded by these people who were just hopeful." These statements reflect the use of family-centered care principles such as information sharing, partnership and collaboration, and care in the context of family & community. While not all of the children received Part B-619 (preschool) services, the parents of those that did reported less satisfaction with family interactions when they transitioned into Part B services.

Loss of Trust

At the time of the interviews, all of the participants' children (10) were enrolled in or exiting Part B (3-21 years old) services. Nine of the ten participants discussed either the transition from Part C to Part B preschool services or a specific moment they began to realize the Part B process was not family-friendly. All parents, even those without a Part C experience, entered Part B services trusting that the professionals working with their children would be honest, open, affirming, and cooperative. After matriculating 2-3 years, reports of the parents reversing their positive opinion of both the access and satisfaction with the special education services were repeated in the participant interviews. Participant #1 reported, "my school district is...intolerant of anybody who doesn't fit into the little cookie cutter mold. Further, participant #2 reported her child developed a seizure disorder in the third grade but reported, "...they (school personnel) thought I was just being overprotective and that was a thing that we had a deal with at the end of the school year with an attorney. It got bad!" One student was required to take medication daily while at school. When asked whether the student had a health plan that coordinated the medication administration, the parent participant #1 indicated her decision to

exclude the school from involvement with the medical aspects of the child's treatment, "If my child's going to be on medication, I want to make sure that I do it –to make sure that it's given correctly." These statements seemed to illustrate a lack of respect and honoring of differences and a lack of partnership or collaboration. As a result, these families began to believe the school personnel were untrustworthy, closed to input from the parents, negative and uncooperative.

Negative Emotional Responses

During the interviews the participants were asked to describe their children's school history as it related to special education services. As might be expected, parents were often emotional concerning their advocacy efforts and the challenges they experienced with school personnel. These expressions of emotion became a consistent theme across the ten interviews. Emotions expressed included; fear, frustration, confusion, defensiveness, isolation, and anger. Some examples included participant #3's description of an exchange regarding an assistive technology device, "...I said, we need to try to do something different. I mean the device is not working for her and it's been a year." She went on, "But they still haven't found anything, and I think that's frustrating." The parent had recognized the futility of a particular intervention method and was frustrated that the school personnel had not offered her child another activity or modified the existing activity so the child could experience some success.

Participant #5 reported her personal response to attempts to advocate for her child. "...at that point I was complaining to everybody and anybody and also it led me to have unfortunately a mental health breakdown. Yes, I did. I actually had to be hospitalized. I'm not gonna cry, but it did, because...it was just the lack of help!" The parent indicated that despite considerable advocacy on her part and documentation from outside professionals, the school system was

unwilling to offer any assistance. Because her child had experienced three dismissals from private schools, the parent became fearful that the public schools were failing her as well.

Interestingly, the parents reported that once they came into conflict with the school or district and the conflict was resolved, they often felt empowered and felt they were approached as equals in the planning process during future meetings and interactions. Parents reported that the animus experienced during the conflict did not always persist across their interactions with future school personnel. Parents whose children had matriculated out of the Part B services reported that, in retrospect, while they never again completely trusted that school personnel would make decisions solely based on the needs of their children, they reported that most school personnel made an effort to offer their children appropriate education/intervention services. The conflict appeared to force the parent from a passive role to a more assertive role and in turn allowed the parent to assume equal footing with the school professionals.

Lack of ...

Except for one parent, consistent across nine of the interviews were participant comments regarding services, procedures, attitudes, and school district money woes that became obstacles in parents' and educational teams' efforts to plan and implement special education and school health services for students. In analyzing the data, these obstacles were given the name "Lack of ..." because those words were used by participants in describing these obstacles. Interestingly, the results revealed two codes which described different forms of "Lack of..." One code represented inadequate services, equipment, personnel, money and other types of services and supports – representing systemic shortcomings. The second related code represented the perceived shortcomings of the school personnel as experienced by the interviewees. These short

comings included “lack of...honesty, respect, flexibility, high expectations, information – representing interpersonal shortcomings.

Lack of Systemic Resources

Participant #4 described the complicated access to services this way, “...my most difficult time was related to navigating the systems. Up until the year nine he received every discipline of therapy almost – twice a week.” The parent was describing her experiences accessing multiple interventions across multiple agencies without the guidance of the school personnel. In this case, the students need for multiple service providers across both public and private agencies resulted in the parent’s “navigating” difficulties.

Another parent offered her concerns regarding the school’s access to adequate equipment and materials. Parent participant #3 addressed her concern this way, “They wanted to put that chair on a wooden platform – with wheels and then put a little pommel in between the legs and put a strap. I said, ‘you’re not gonna put my child who already has several special needs in a chair that’s not safe’.” The parent was insecure regarding the safety of the piece of equipment in question. The school personnel were attempting to meet the child’s need by fabricating a solution given readily available resources. The lack of agreement between the school personnel and the parent resulted in the parent questioning the use of her tax dollars while the school personnel may have perceived the parent as obstructive.

Another reported systemic short-coming was a lack of adequately trained personnel. Parent participant #3 reported, “Well, there isn’t a nurse there full-time. When her feeding tube did come out, the protocol for the district is you can’t touch it and they have to call 911.” The lack of school healthcare personnel resulted in a procedural decision by the school district to contact emergency services when any nursing-related care was required for the student. The

parent's dissatisfaction was also amplified regarding related service personnel. The parent expressed, "I mean the child doesn't walk, she doesn't bear weight. She only gets PT once a week – at school for thirty minutes!" Parent participant #7 offered "I didn't feel like, when they first met him, they knew what Fragile X was." Students classified as Other Health Impairment, by their nature, require services (both school health and related services) tangential to most educational environments. The parents interviewed expressed concern that the school districts put their children at risk by not providing adequately trained personnel in the schools their children attended and/or a sufficient amount of therapies/services. Only one of the ten parents interviewed judged the accessible services sufficient to allow her child to achieve his maximum potential

Lack of Interpersonal Integrity

Parents reported a concern about the school personnel's lack of understanding regarding their child's special needs, the need of the parents for information regarding available school services, and the parents' need for mutual respect. Participant #8 - "...especially one or two of the people involved at the school were, I would say, less flexible than some, and more judgmental... Well, sometime it was just lack of understanding on the part of teachers, or the lack of willingness to go far enough in making adjustments." Parents consistently reported that when school personnel were asked for their professional opinions, the school personnel often provided what appeared to be a script originated by the school system rather than a professional opinion. Parent participant #10 remarked "I think parents need to be made aware of what is available. I feel like knowing what accommodations are out there and knowing what interventions are out there is this coveted, held-back list. A parent should not come in with the knowledge because it's not knowledge that parents have." Parents also reported feeling disrespected by attitudes and

verbalizations from school personnel. For example, parent participant #8 explained the time in the school “was punctuated by periods of extreme stress and uncertainty, and kind of veiled threats.” Finally, parent participant #10 also reported feeling blamed for their child’s disability -- “I think that there’s a lot of, ‘what are you doing wrong to make your son have autism?’”

Lack of Communication between Health and Education Professionals

None of the parents interviewed were able to recall any direct interaction or communication between the students’ health professionals outside the school environment and the education personnel within the school environment. All of the parents assumed the responsibility of managing communication between the school and health professionals. For example, parent participant #4 reported “Basically I keep the collaboration with everybody. For the most part, to my knowledge the school hasn’t had to collaborate with the neurologist at all because I pretty much provide them with all the information. So they’ve never really had to communicate with any of the medical personnel. Another parent (participant #9) also reported a lack of coordination between education and medical professionals. She reported, “We see a typical child pediatrician. She doesn’t know. We report to her what’s going on all the time...(my child) has five or six specialists, but nobody talks to each other. So it’s like my child has a series of parts in the hospital and we’re the ones who have to hold all the parts and try to make sense of it, and it’s not our field. It’s not the work that we do or the expertise that we have...They definitely can help parents with that.” Results indicated some parents assumed a relationship between school and health personnel, but most did not.

One reason school and medical personnel may not have communicated is because of the HIPPA (Health Insurance Portability and Accountability Act of 1996). HIPPA privacy requirements disallow health care professionals to discuss patients’ care without the written

permission of the parent. If parents, school personnel, and medical personnel don't take the initiative to ensure communication between the entities or if entities don't see the value in this collaboration, it will not occur.

Confusion Regarding OHI Classification

During the interviews, five of the ten parents shared why they believed their child was given the classification of Other Health Impairment (OHI). Interestingly, the reasons the parents reported often had nothing to do with the qualifications for the classification. Parent participant #10 reported that the classification was related to the classroom to which her child was assigned. She said, "He could not be in an OHI classroom with who he was then. He's been in autism classrooms, and he's been in all kinds of classrooms. It's hard to figure out where to put him sometimes." Parent participant #9 was at a loss as to what the classification meant. In response to a question about how the OHI classification was working for her child the mother responded, "I think it's too vague. I got to learn what OHI meant in regards to the other seven classifications. OHI covers too much." When parent participant #5 was asked what medical condition supported the use of the OHI classification, she responded, "You know, that was such a frustration. They would not use autism which I didn't understand. And I don't even think they ever used ADHD." Parent participant #2 thought the classification was based upon the amount of services the child received, "but we kept with the other health impaired because to get in the extra occupational therapy and stuff like that." And finally, parent participant #1 was under the impression it was a default classification, "they came up with the classification of that she needed services but she didn't fit into any category—so they classified her Other Health Impairment." Clearly, confusion existed within the interviewees as to why their individual children carried the classification Other Health Impairment (OHI).

Usefulness of School Health Services

Parents were asked to provide an opinion regarding the “usefulness” of the school health services provided their child. School health services includes those “health services designed to enable a child with a disability to receive FAPE (free appropriate public education) as described in the child’s IEP... School health services are services that may be provided by either a qualified school nurse or other qualified person.” (Federal Register, 2006). One hundred percent of the parents identified school health services as useful relative to the students’ academic success. Parents seemed to have a clear understanding regarding how management of the child’s health needs assisted in providing the child academic support. Useful school health services allowed the students to participate and benefit more fully from the academic instruction and environment.

Summary

Interview transcripts from ten participants were analyzed for demographic and descriptive information. From this data inferential coding identified six areas of motivation for the parents’ responses during the interview dialogues. These areas of motivation included positive experiences with Part C services, loss of trust, negative emotional responses, lack of systemic resources, lack of interpersonal integrity, confusion regarding the OHI classification and communication between health and education professionals. Parent opinions varied regarding “usefulness” of school health services were reported.

DISCUSSION

This study was designed to explore, using qualitative methods, the perception and satisfaction of parents of students identified as needing special education because of a health impairment. The exploration was motivated by the researcher's desire to confirm or negate assumptions that: (1) OHI classification does not provide sufficient access to special education and school health care services, (2) Parents of students classified as OHI are unsatisfied with special education & school health care services, and that, (3) The use of Family-Centered Care principles enhanced parent satisfaction with OHI classification. Additionally, through the use of a grounded theory design, theories supporting the confirmation and/or negation of the assumptions were generated.

Responses to Research Questions

Research Question: 1. To what extent do parents perceive that the classification of *Other Health Impairment* has provided their child access to appropriate special education and school-health care to achieve their maximum potential?

All children of participants in the study qualified for special education and school health care services by virtue of their classification *Other Health Impairment*. One of the ten interviewed parents reported being universally pleased with the services provided her child, but also reported her child was provided private related services outside the school environment. The child's medical insurance paid for the additional services. Consequently, the report that the services were appropriate and allowed for development of maximal potential were, no doubt, influenced by the inclusion of outside services. Additionally, this parent was employed within a program that advocated for services for children with disabilities. It is reasonable to assume that

the parent may have been more skilled in IEP development and interaction with school personnel than the “typical” parent and, consequently, was able to access more services for her child.

With the exception of the one outlier, the other nine interviewees reported various tales of difficulty acquiring the services, they felt, for which their respective youngster’s qualified. School and school districts reluctance to offer services beyond a minimal level of service, school personnel disrespecting parents, lack of school district material and personnel resources, school system’s reluctance to intervene until problems reached a “crisis” level, lack of knowledge regarding low incidence health impairments, and general lack of flexibility in the provision of services were some of the topics the parent’s discussed that resulted in dissatisfaction with the special education services offered to their children. Some of these topics were repeated across a few interviewees while others were specific to a child’s specific health disorder. Leiter & Krauss (2004) reported in their study that explored the relationship between students offered services and requests for additional related services indicated, “A small, but significant, minority of parents are not satisfied...and their dissatisfaction may be related to their children’s disability characteristics or to problems experienced while advocating on behalf of their children.” When parents seek additional services and experience problems with the request, 90% of these parents were less likely to report being satisfied with services. In this study, 90% of parents were not satisfied.

Parents interviewed were generally unable to detail school health services received by their youngsters. Procedures such as tube feedings, catheterization, medication administration, developing health plans, responding to health emergencies were reported to be assigned to the parents, accessed through emergency medical services, or did not occur per the reports of the families that participated in the interviews. Schools often comply with policies described in the

School-Based Nursing Services bulletin (produced by the state Department of Education) by training non-medical school personnel (e.g. teachers or paraprofessionals) to conduct some nursing procedures like tube feedings and catheterizations, rather than utilizing emergency medical services. Whether or not this is in the best interest of the child remains to be seen, but this practice is consistent with the state Nursing Practice Act. Schools may not have nursing services available every day, or when the child is in need of them. However when school personnel or administrators did not “go out of their way” to insure appropriate health and medical services, students did not receive sufficient assistance. In this study, access to school-based health services allowing the students to achieve their maximum potential were not driven by the classification of OHI. Rather, access to these services were dependent on the availability of these services in the school or by the resourcefulness of the school personnel.

Some parents did not have an awareness that providing school health services was an obligation of the school district in providing FAPE for their youngsters. These families, when faced with the absence of these services, assumed the responsibility of providing the services personally and at their own expense. Others purposely assumed the responsibility (e.g. medication administration) for the school health services because they were unable/unwilling to trust that the school personnel would adequately provide the services. While remedies via the IEP parental due process rights were available to parents, only two of the ten parents reported using these remedies to obtain school health services.

Research Question 2. To what extent are parents satisfied with special education and school-based health care services provided given the classification of *OHI*?

Parent responses in the ten interviews suggested satisfaction varied depending on the point in time the parents were asked to discuss their experiences. As mentioned previously,

families were consistently satisfied with Part C services provided and enjoyed the family-centered approach to intervention planning and implementation. Leiter and Krauss (2004) and Stoner et al (2005) also documented the influence of the child's age on parent satisfaction – parents of older children were less likely to be satisfied.

While parents reported periods of conflict with school personnel regarding access to services they felt were appropriate, when the parents were able to take the “long view” regarding their child's educational history they, in general, did not hold a hostile attitude toward the school personnel. What seems to be working here is perceived control and optimistic bias (Klein & Helweg-Larsen, 2002). Optimistic bias refers to people's tendency to think their risk is less than that of their peers. Research suggests a relationship between optimistic bias and perceived control such that the greater control people perceive over future events, the greater their optimistic bias. By using outside advocates, parents may have perceived a greater level of “control” regarding their child's educational planning and consequently became more optimistic regarding the student's educational course. This finding may explain the ambiguous report regarding parent satisfaction found by Spann et al (2003).

The interviews in this study also suggested trust in the school system is placed in jeopardy when a child moves from Part C (early intervention) to Part B (school-based) services. While enrolled in Part C services, parents described being engaged in “family-centered” planning. All of the participants that experienced Part C services provided positive reports regarding the identification, intervention planning, and implementation processes. These reports are consistent with the results reported by Stoner et al (2005) which indicated that early intervention experiences meet the parental need for external, problem-focused behavior. Also because the early intervention services are often provided in the child's home, the

interventionists interacted frequently with the parents and were better able to establish a positive relationship. Parents came to see the early intervention staff as a “godsend” and “incredible.”

As a result of these positive experiences, the parents moved into Part B services expecting the same level of integrity and honesty from the school-based staff. Parents reported entering the Individual Education Program planning process confident that the “experts” (the school personnel) would advocate for their child. As reported, this confidence was short-lived. Within the first three years after enrolling in Part B services most parents reported recognizing that they (the parents) were the student’s only advocates on the IEP team. The parents perceived the other IEP team members as advocating for the policies of the school system or were non-participatory. Teachers and therapists hired by the school districts often seemed afraid to advocate for services and equipment that the school administration was not willing to support probably due to costs. Perhaps some were fearful of losing their jobs if they stood up to the administration in support of the students’ needs. Thus, some were silent.

The reluctance of school personnel to discuss options other than those routinely offered by the school or school district was often in conflict with what parents had anticipated. The parents expressed that when the “experts” are unwilling to share possible solutions, the parents are reluctant to trust that the school personnel will advocate in their child’s best interest. This “loss of trust” can result in a breakdown of the sense of partnership and collaboration, and on some occasions, can result in an adversarial relationship between the parents and the school representatives. These results also mirrored those of Stoner et al (2005) where trust in educational professionals was reduced when the “experts” were unwilling to provide for their children’s educational needs.

Parents reported they often found the IEP meetings to be school-centric with decisions regarding placement, related services, curriculum, and programming controlled by school or district policy. When parents voiced an objection to the school or district policy, they often found they were subjected to rebuke by school personnel and felt the collaboration between parents and the other team members ceased to exist. At times, the parents sensed that they were the lone advocate for their child resulting in families seeking advocates outside the IEP team to assist them in obtaining team decisions that were in the best interest of their child. These outside advocates were obtained through the state Department of Education, district IEP facilitators, personal attorneys, and other private education/intervention professionals. It is not uncommon for parents who have these feelings to seek outside assistance. Parents who are more educated or have higher incomes are more likely to obtain advocacy help.

Research Question 3. How does the use of Family-Centered Care principles influence parent satisfaction with OHI classification?

As previously discussed within the cohort of ten families, four participants' children were enrolled in Part C services prior to Part B services. These four participants described their experiences receiving Part C services in comparison with their experiences receiving Part B services. Their descriptions clearly indicated the use of Family-Centered Care in the provision of the Part C services. Rarely did parent participants describe Part B experiences that reflected the use of Family-Centered Care. Almost universally (9 of 10 parent participants) related experiences that were in opposition to the Family-Centered Care principles – withholding rather than sharing information, feelings of disrespect rather than respect, policy driven rather than collaborative decision making, and shunning rather than embracing negotiation. The differing response from parents regarding satisfaction with Part C versus Part B services suggested the use

of Family-Centered Care principles were successful in influencing parent satisfaction of service delivery. Unfortunately, the lack of illustrations of the use of Family-Centered Care principles in the parents' descriptions of Part B services prohibited interpretation regarding the effect of the principles on influencing parental satisfaction with Part B services. The strategies recommended by Pruitt et al (1998) for establishing parent and educator decision making relationships, no doubt, would have proven helpful to these families.

As mentioned previously, one parent participant offered only positive comments regarding the delivery of services to her child and consequently was an "outlier" within the data set. This participant's responses included examples of Family-Centered Care principles such as collaboration with education professionals, medical professionals, and the parents; a willingness on the part of the school system to negotiate regarding placement options; honest, open, objective information sharing, and designing education plan in the context of the family. These responses suggest that given Family-Centered Care principles, parent satisfaction could be achieved. This participant's responses also suggest the data gathered across the ten interviews may have oversampled participants who had experienced negativity. Satisfaction was also more positive for younger students than older students

Summary

All parents reported that the classification *OHI* provided access to special education services. However, the vast majority (9 of 10) of the parents questioned the "appropriateness" of the educational services provided by the various school districts. The same thing was not true of school-based health services. On some occasions, some parents reported being unaware that the school systems had an obligation to provide school-based health services while others were unwilling to "trust" the school systems regarding health services. Still others required the

assistance of advocates from outside the school systems to access school health services. Parent satisfaction was greater when elements of Family Centered Care were included in the parents descriptions of the services provided. The use of these elements seemed to be the basis for the parent's preference for Part C versus Part B services.

Limitations of Study

This study used a qualitative methodology and, consequently, conclusions drawn from the study should be viewed as theoretical rather than definitive. Qualitative research, by its nature, is generative and this study generated more questions than it answered. However, certain areas of planning and execution were determined to have a limiting effect on the conclusions. These limitations include sample size, sampling methodology, sample diversity

Sample Size

The sample size selection for this project was an a priori decision. While the sample size provided for adequate saturation regarding negative reporting experiences, the presence of the one outlier suggested that more positive experiences may exist within a larger participant pool and the sample size may have been too small to capture these experiences. However, the sampling methodology may have also contributed to the skewed reported experiences.

Sampling Methodology & Diversity

Convenience and network sampling procedures were incorporated in accessing study participants. While these procedure were successful in obtaining the targeted number of participants within the geographic area focused by the study, these sampling procedures may not have offered the diversity of experiences and diversity of disability conditions that would have resulted in more robust data. For example, the parent advocacy organizations were used as part of the network sampling. The parent advocacy organizations assist families in advocating for

their children enrolled in special education programs. Consequently, families referred for inclusion in the study (n=10) were ones that previously sought out assistance with advocacy. The parents may have sought out advocacy due to frustration in obtaining special education or school health services. This may have resulted in a homogeneous sample without more diverse experiences. Also, as mentioned previously, a single outlier was part of the data for this study. Greater exploration of the positive experiences of the participants during the interviews and the use of extreme case sampling (Creswell, 2002) may have provided greater sample diversity. A follow-up study including confirming and disconfirming sampling (Creswell, 2002) in the data analysis might provide greater authenticity of the sample.

Future Research

This study was successful in responding to the three assumptions initially posed by the researcher. However, the nature of qualitative inquiry often results in more questions than answers and such is the case with this study. Several additional lines of inquiry are suggested.

Data from this study, suggests that determining parent satisfaction with special education services requires consideration of where the parent and student are in their special education history. This study's data supported the findings of other studies [Stoner et al (2005), Lieter & Krauss (2004) & Summers et al (2005)] that parents are most often more satisfied with Part C services as compared to Part B services. Future research designed to determining the critical points in the child's special education history that provide the best indication of overall satisfaction with the program would be recommended.

This study only explored the data obtained from parents. To more clearly understand the relationship between the family and the special education services and to be faithful to the Family-Centered Care model, information from school personnel should also be explored.

Additionally, first-hand observation during IEP meetings, progress reporting meetings, and other parent/teacher interactions, would provide a clearer picture of the dynamics influencing satisfaction. Particular to students with the OHI classification, information from health providers outside the school systems should also be examined to understand the obstacles limiting health providers' active participation in their patients' academic lives and to suggest possible solutions to address these obstacles. The same would be true for school personnel having access/information from health care professionals.

The data from this study suggested that satisfaction was influenced by philosophy (Part C vs Part B), trust, equality, supportive advocacy, material support, availability of qualified personnel and longevity within special education. Almost certainly there are other factors that influence overall parent satisfaction with special education programming. Additional studies to delve into these and other influences could provide insightful in program design.

REFERENCES

- Assistance to states for the education of children with disabilities and preschool grants for children with disabilities; final rule, *Federal Register* (71) 156, (August 14, 2006), 46550-46551.
- American Academy of Child & Adolescent Psychiatry (2012). Lead exposure in children affects brain and behavior. Retrieved July 10, 2013, from [http://www.aacap.org/AACAP/Families and Youth/Facts for Families/Facts for Families Pages/Lead Exposure In Children Affects Brain And Behavior 45.aspx](http://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/Facts_for_Families_Pages/Lead_Exposure_In_Children_Affects_Brain_And_Behavior_45.aspx)
- American Psychological Association. (2001). Publication manual of the American Psychological Association, (5th Ed.). Washington, DC.
- Burgess, R.G. (1984). *In the Field: An Introduction to Field Research*. London: Unwin Hyman.
- Council for Exceptional Children. (2010). CEC special education professional ethical principles. Retrieved from <http://www.cec.sped.org/Standards/Ethical-Principles-and-Practice-Standards> .
- Creswell, John W. (2002). *Educational research; Planning, conducting, and evaluating quantitative and qualitative research*, Merrill Prentice Hall, Upper Saddle River, NJ.
- Cogniglio, S. J. & Blackman, J.A. (1995) Developmental outcome of childhood leukemia. *Topics in Early Childhood Special Education*, 15(1), 19-31.

- DePaepe, P., Garrison-Kane, L., & Doelling, J. (2005). Supporting students with health needs in schools. In Skrtic, T.M., Harris, K.R., & Shriner, J.G. (Eds.), *Special Education Policy and Practice; Accountability, Instruction, and Social Challenges*. Denver: Love Publishing.
- Dempsey, I. & Keen, D. (2008). A review of processes and outcomes in family-centered services for children with a disability. *Topics in Early Childhoods Special Education*, 28(1), 42-52.
- Division of Early Childhood. (2014). *DEC recommended practices in early Intervention / early childhood special education 2014*. Retrieved from <http://www.dec-sped.org/recommendedpractices>.
- DuPaul, G., & Stoner, G. (2003). *ADHD in the schools: Assessment and Practice*. New York: Guilford.
- Education for All Handicapped Children Act. (1975, November). Retrieved July 8, 2013, from The Library of Congress *Thomas*: <http://thomas.loc.gov/cgi-bin/bdquery/z?d094:SN0006:@@L&summ2=m&|TOM:/bss/d094query.html>.
- Encyclopedia of Children's Health (2016). *Forum*. Retrieved November 13, 2016 from <http://www.healthofchildren.com/C/Cri-du-Chat-Syndrome.html>.
- Fidler, D. & Lawson, J. (2003). What do parents want? An analysis of education-related comments made by parents of children with different genetic syndromes. *Journal of Intellectual & Developmental Disability*, (28)2, 196-204.
- Fish, Wade W. (2006). Perceptions of parents of students with autism towards the IEP meeting: a case study of one family support group chapter. *Education*, (127)1, 56-68.

- Fish, W. (2008). The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure*, 53(1), 8-14.
- Garriot, P., Wandry, D., & Snyder, L. (2000). Teachers as parents, parents as children: What's wrong with this picture? *Preventing School Failure*, (45)1, 37-44.
- Glesne, Corrine. (1999). *Becoming qualitative researchers, 2nd Ed.*, Addison Wesley Longman, New York, NY.
- Grice, Kara (2002). Eligibility under IDEA for other health impaired children. *School Law Bulletin*, Summer.
- Heller, K.W., Fredrick, L.D., Dykes, M.K., Best, S., & Cohen, E.T. (1999). A national perspective of competencies for teachers of individuals with physical and health disabilities. *Exceptional Children*, 65(2). 219-234.
- Janz, Janice Rutledge (2003). The perspectives and assumptions of pupil appraisal professionals at key decision points in the identification process for students with behavior problems (Doctoral dissertation, University of New Orleans, 2003) *ProQuest, UMI Dissertations Publishing*, 3093169.
- Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and Advocacy Expectations of Culturally Diverse Families' Participation in Special Education, *International Journal of Disability, Development and Education*, 47(2) 119-136.
- Klein, Cynthia T.F. & Helweg-Larsen, Marie (2002). Perceived Control and the Optimistic Bias: A Meta-Analytic Review, *Psychology and Health*, 17(4). 437-446.
- Kuo, D. Z., Houtrow, A.J., Arango, P., Kuhlthau, K.A., Simmons, J.M., & Neff, J.M. (2012). Family-centered care: Current applications and future directions in pediatric health care, *Maternal Child Health Journal* 16, 297-305.

- LaNear, John & Frattura, Elise (2007). Getting the stories straight: Allowing different voices to tell an 'effective history' of special education law in the United States. *Education and the Law*, 19(2), 87-109.
- Leiter, V. & Krauss, M. (2004). Claims, barriers, and satisfaction: Parents' requests for additional special education services, *Journal of Disability Policy Studies*, (15)3, 135-146.
- Miles, M. & Huberman, A. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd Ed.). Thousand Oaks, CA: Sage Publications, Inc.
- Miles-Bonart, Sharon (2002). A look at variables affecting parent satisfaction with IEP meetings. In *Annual National Conference Proceedings of the American Council on Rural Special Education*, Reno, NV, March 7-9.
- National Cancer Institute. (n.d.). *General information about childhood acute lymphoblastic leukemia (ALL)*. Retrieved July 10, 2013 from <http://www.cancer.gov/cancertopics/pdq/treatment/childALL/HealthProfessional>
- National Dissemination Center for Children with Disabilities (2012). *Other health impairment*. Retrieved July 19, 2013 from <http://nichey.org/disability/specific/ohi>
- National Heart, Lung, and Blood Institute. (n.d.). *What is hemophilia?* Retrieved July 10, 2013, from <http://www.nhlbi.nih.gov/health/health-topics/topics/hemophilia/>.
- National Institute of Health (2016). *Genetics Home Reference*. Retrieved November 13, 2016 From <https://ghr.nlm.nih.gov/condition/fragile-x-syndrome>.
- National Institute of Health (2016). *National Institute of Neurological Disorders and Stroke*. Retrieved November 13, 2016 from http://www.ninds.nih.gov/disorders/asperger/detail_asperger.htm#3080_1.

- National Institute of Mental Health (2016). *Obsessive-Compulsive Disorder*. Retrieved November 13, 2016 from <https://www.nimh.nih.gov/health/topics/obsessive-compulsive-disorder-ocd/index.shtml>
- NVIVO 10 for Windows (Computer Software). QSR International.
- Olivos, Edward M. (2014). Collaboration with latino families; A critical perspective of home-school interactions, *Intervention in School and Clinic*, 42(2), 109-115.
- Pruitt, P., Wandry, D., & Hollums, D. (1998) Listen to us! Parents speak out about their interactions with special educators. *Preventing School Failure*, 42, 161-166.
- Schwartz, David D., Axelrad, Marni E., & Anderson, Barbara J. (2014). Neurocognitive functioning in children and adolescents at the time of type 1 diabetes diagnosis: Association with glycemic control 1 year after diagnosis. *Diabetes Care* 10 (2337/dc14-0103).
- Skrtic, T.M., Harris, K.R. & Shriner, J.G. Eds (2005). *Special education policy and practice; accountability, instruction, and social challenges*. Denver: Love Publishing.
- Smith MA, Seibel NL, Altekruise SF, et al. (2010) Outcomes for children and adolescents with cancer: challenges for the twenty-first century. *Journal of Clinical Oncology* 28 (15): 2625-34.
- Spann, S., Kohler, F., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: an interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities*, (18) 4, 228-237.

- Stoner, J., Bock, S., Thompson, J., Angell, M., Heyl, B., & Crowley, E. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals, *Focus on Autism and Other Developmental Disabilities*. Vol. 2 #1, p39-51.
- Summers, J., Hoffman, L., Margquis, J., Turnbull, A., Poston, D., & Nelson, L. (2005) Measuring the quality of family-professional partnerships in special education services. *Exceptional Children* (72) 1, 65-81.
- Summers, J., Hoffman, L., Marquis, J., Turnbull, A., Poston, D., & Nelson, L. (2005) Relationship between parent satisfaction regarding partnerships with professionals and age of child. *Topics in Early Childhood Special Education* (25) 1, 48-58.
- The Society of Thoracic Surgeons, *What is pediatric heart disease*, Jacobs, Jeffrey P. & Hess, Heidi. (2002) Retrieved July 9, 2013 from <http://www.sts.org/patient-information/what-pediatric-heart-disease>.
- Thies, K.M. (1999). Identifying the Educational Implications of Chronic Illness in School Children. *Journal of School Health*, 69(10), 392-399.
- trust. (n.d.). *Dictionary.com Unabridged*. Retrieved March 20, 2016 from Dictionary.com website <http://www.dictionary.com/browse/trust>
- U.S. Department of Education (2006). *Assistance to States for the Education of Children with Disabilities and Preschool Grants for Children with Disabilities; Final Rule*. Washington, DC: Author.
- U.S. Department of Education (2014). Thirty-fifth annual report to congress on the implementation of the *Individuals with Disabilities Education Act, 2013*. Washington, DC: Author.

U.S. Department of Health and Human Services (2006). *Fact Sheet: Your Rights Under Section 504 of the Rehabilitation Act*. Retrieved November 12, 2012, from

<http://www.hhs.gov/ocr/civilrights/resources/factsheets/504.pdf>

U.S. Department of Justice (n.d.). *Americans with Disabilities Act of 1990 (ADA), including changes made by the ADA Amendments Act of 2008 (P.L. 110-325)*. Retrieved November 12, 2012 from <http://www.ada.gov/pubs/adastatute08.htm#12102>.

Van der Rijken, Rachel E.A; Maassen, Ben A.M.; Walk, Twiggy L. M.; Daniels, Otto; Hulstijn-Dirkmaat, Gerdine M. (2007). Outcome after surgical repair of congenital cardiac malformations at school age, *Cardiology in the Young*. Vol 17 Issue 1 p 64-71.

Vaughn, S., Schumm, J. & Sinagub, J. (1996). *Focus group interviews in education and psychology*, Thousand Oaks, CA: Sage Publications, Inc.

Weber, Mark C., (2011). A new look at section 504 and the ADA in special education cases, *Children's Rights Litigation*, 13 (4).

Whonamed it? A dictionary of medical eponyms (1994-2016). Retrieved November 12, 2016
From <http://www.whonamedit.com/synd.cfm/2982.html>.



UNIVERSITY of
NEW ORLEANS

DEPARTMENT OF SPECIAL EDUCATION
AND HABILITATIVE SERVICES

Appendix A

and

LOUISIANA STATE UNIVERSITY HEALTH SCIENCES CENTER
in
NEW ORLEANS

IRB# 9081

Consent Rev. Date: 07/24/2015

CONSENT FORM

1. Title of Research Study

Parents' Perceptions Regarding the Special Education Classification of Other Health Impairment
(OHI)

2. Project Director

Linda Flynn-Wilson, Ph.D., Professor, Department of Special Education and Habilitative Services, 246 Education Building, 2000 Lakeshore Drive, New Orleans, LA 70148.
Telephone: (504) 280-6609

Co-Investigator: Michael C. Norman, Human Development Center, 411 South Prieur Street, New Orleans, LA 70112. Telephone: (504)452-5766
24-hour number: 504-452-5766

3. Purpose of this Research Study

The purpose of this research study is to understand the perceptions of parents relative to the use of the special education classification *Other Health Impairment*. Specifically, do parents of children so classified find the classification useful for their child related to both education and medical care and has the classification provided satisfactory access to special education and related services. The influence of Family Centered Care principles will also be determined.

4. Procedures for this Research Study

A sixty to ninety minute interview will be conducted at a mutually convenient time and place. The interview will be recorded. You, as the participant, will be free to choose which topics to discuss, may refuse to answer any questions, and may stop the interview at any time.

5. Potential risks or discomforts

Participants may become tired toward the end of the interview. If this occurs, rest breaks can be taken as needed or the interview can be concluded at another time. Please keep in mind that all aspects of your participation in this study are voluntary. If you wish to discuss this or any other discomfort you may anticipate, you may call the Project Director listed in # 2.

6. Potential Benefits to You or Others

The classification of students for special education provides the student entry into a system of education that may allow for successful academic progress. This study is an attempt to better understand the provision of services to students with health impairments. The benefits for you might be the opportunity to voice your opinion on this topic. Your perspective and experience will provide valuable information for this study that will in turn advance knowledge in the field of special education.

7. Alternative Procedures

Your participation is entirely voluntary, and you may withdraw consent and terminate participation at any time without consequence.

If you have any questions about your rights as a subject/participant in this research, or feel you have been placed at risk, please contact Dr. Ann O’Hanlon at the University of New Orleans (504) 280-3990.

8. Protection of Confidentiality

The names of all participants and their associations with schools and/or school districts will be kept confidential at all times. Participants’ names will not be identified on the tape. Professional transcriptionists or the Project Director will transcribe the interview tapes. The signed consent forms, recordings, interview transcripts, and any other materials related to this project will be maintained in a secure and confidential manner by the Project Director. Participants’ and their associations with schools and/or school districts will be protected by pseudonyms or other means in all published reports.

Data will be retained for at least five years at which time all recordings, forms, transcripts, etc. will be disposed by erasing/shredding.

9. Financial Compensation

Participants in this study will also receive a \$100.00 gift card in appreciation for their participation in the study.

10. Release of Information

Organizations that may inspect and/or copy your study-related medical records for quality assurance and data analysis include the UNO Institutional Review Board, the LSUHSC-NO Institutional Review Board, and the investigators listed on page 1 of this consent form and their staff. While every effort will be made to maintain your privacy, absolute confidentiality cannot be guaranteed. Records will be kept private to the extent allowed by law.

11. Signatures and Consent to Participate

The study has been discussed with me and all my questions have been answered. Additional questions regarding the study should be directed to the investigators listed on page 1 of this consent form. If I have questions about subject’s rights, or want to discuss problems, concerns or questions, or obtain information or offer input, I can contact the Chancellor of the LSU Health Sciences Center New Orleans at (504) 568-4801. I agree with the terms above, acknowledge I have been given a copy of the consent form, and agree to participate in this study. I have not waived any of my legal rights by signing this consent form.

Signature of Subject

Printed Name of Participant

Date

Consent Administered by

Printed Name

Date

Appendix B

Interview Protocol

Project: The Influence of Family Centered Care Principles on Parents' Perceptions and Satisfaction Regarding the Special Education Classification Other Health Impairment (OHI)

Time of Interview: _____

Date: _____

Place: _____

Interviewer: _____

Interviewee: _____

Position of Interviewee: _____

Review of Informed Consent Form: to include study purpose, data collected, data analysis, confidentiality

1. Tell me about your child and his/her health condition.
2. Tell me about your first experience with special education services.
3. What specific special education services were recommended for your child?
4. Describe your role in developing the educational program for your child.
5. Describe the way the IEP committee determined the instructional program for your child and the services that would be provided.
6. How were the services determined to be the "best fit" for your child?
7. Tell me about what you envision as an "ideal" program for your child.
8. In your opinion, were the special education services provided useful to your child from a medical perspective? From an educational perspective?
9. How satisfied have you been with the classification of Other Health Impairment in providing access to necessary services for your child?
10. Were there any things that "got in the way" of planning and getting the necessary services for your child?

Appendix C
Invitation to Participate in Study

Subject: Research Study Participation

Dear Parent:

In association with Professor Linda Flynn-Wilson, Ph.D. from the Department of Special Education and Habilitative Services at the University of New Orleans, I am conducting a research study regarding the special education category *Other Health Impairments (OHI)*. The purpose of this study is to gather information from parents' of students classified as *OHI* in an effort to better understand how the classification works for students and families. Also included in the study will be an analysis of Family Centered Care principles used by school and medical personnel when working with families.

Your participation in the study would be greatly appreciated. If you join us in this study, your participation will require you sharing information about your family's experience having a child classified as *OHI* in a 60-90 minute interview. Your participation in the study is entirely voluntary and you may withdraw consent and/or terminate participation at any time without consequence. The names of all participants and their associations with schools and/or school districts will be kept confidential at all times. Furthermore, should the results of this study result in publication, participants and schools and/or school districts will be disguised.

This study will provide you the opportunity to voice your opinion(s) on this topic. Your perspective and experience will provide valuable information for this study that will in turn advance knowledge in the field of special education. Additionally all parents who complete the interview will receive a \$ 25.00 Walmart gift card as a token of our appreciation for your participation.

Please contact me by phone or email if you are interested in participating. I have listed my email address and cellular phone number below. Don't hesitate to contact me should you have questions or concerns regarding the study.

Thank you,

Michael C. Norman
Doctoral Candidate
Department of Special Education and Habilitative Services
University of New Orleans

Phone: 504-452-5766

Email: mcnorman@uno.edu

VITA

The author was born in Thibodaux, Louisiana. He obtained his Bachelor's degree in education from Nicholls State University in 1972 and his Master's degree in Communication Disorders from the L.S.U. Medical Center in 1976. He joined the University of New Orleans special education graduate program to pursue a PhD in Early Intervention and became a student of Professor Linda Flynn in 2003.