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# MANAGEMENT OF THE MEDICALLY FRAGILE CHILD IN THE K-FIFTH GRADE SETTING

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# Management of the Medically Fragile Child In the K- Fifth Grade Classroom Setting

By

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A thesis submitted in partial fulfillment of the Requirements for the Masters of Science in Nursing Degree, In the College of Health, School of Nursing.

Collaboration between Clayton State University and Columbus State University

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#### Abstract

The sim of this focused project was to explore perceptions and identify needs of teachers of medically fragile children (MFC), in the K-5<sup>th</sup> grade setting, with the hope of designing educational modules to be utilized as imprortive measures by the teachers for the classroom setting. The focused project consisted of an extensive literature review of medical fragility in school age children as well as a literature review of teachers' perceptions and needs identified in the past. Note Pender's Health Promotion Model acroed as the conceptual framework in designing the study. Two focus groups were conducted among K-5<sup>th</sup> grade teachers enrolled in Masters level courses, for a total of 27 participants. Focus group results correlated with the literature review findings. Teachers from the focus groups reported inadequate ransing services support and identified a need for better tealning for a fully successful inclusive environment for the KIFC. The project results appoint the need for an educational has recentled to the teachers of MFC.

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The aim of this focused project was to explore perceptions and identify needs of teachers of medically fragile children (MFC), in the K-5<sup>th</sup> grade setting, with the hope of designing educational modules to be utilized as supportive measures by the teachers for the classroom setting. The focused project consisted of an extensive literature review of medical fragility in school age children as well as a literature review of teachers' perceptions and needs identified in the past. Nola Pender's Health Promotion Model served as the conceptual framework in designing the study. Two focus groups were conducted among K-5<sup>th</sup> grade teachers enrolled in Masters level courses, for a total of 27 participants. Focus group results correlated with the literature review findings. Teachers from the focus groups reported inadequate nursing services support and identified a need for better training for a fully successful inclusive environment for the MFC. The project results support the need for an educational intervention for the teachers of MFC.

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Mainstreaming of disabled children into the public school setting initiative began in 1975 with the passage of the Education for All Handicapped Children Act (IDEA, 2012). Now called IDEA, the main goal of deinstitutionalizing disabled or handicapped children has come to fruition. The inclusion of MFC in a normal school setting has benefits for both the MFC and for the non-disabled students (American Youth Policy Forum and Center on Education Policy, 2002). High school graduation, college enrollments, and employment opportunities have steadily increased over the last decade for disabled individuals who have had the opportunity to participate in a normal school setting (American Youth Policy Forum and Center on Education Policy, 2002). For the non-disabled student, benefits include an attitude of acceptance and an understanding and appreciation for differences (American Youth Policy Forum and Center on Education Policy, 2002).

In 2012, the number of children, ages 3 through 21, living in the United States with a disability, was estimated to be 6.558 million (Department of Education, 2012).

According to the Institute of Education Sciences National Center for Education Statistics (2012), this number comprises about 13%-16% of all total public school enrollments, with an average of 131,175 disabled children per state. According to the Department of Education's Special Education Fiscal Year 2013 Budget Request, the amount of money allotted per child will be \$1,762 for a total of \$11.6 billion in awarded state grant money (Department of Education, 2012). The awarded money, according to the Department of Education report, is to assist in "covering the excess costs associated with providing

special education and related services to children with disabilities" (Department of Education, 2012, p. 21). Placing students with disabilities in a regular school setting allows for equal access to a free appropriate public education and encourages them to meet the same standards that have been established for all children to help prepare them for college, career and a productive adulthood. Additionally, the Individuals with Disabilities Education Act (IDEA) has set forth a directive that states disabled children should be in the least restrictive environment possible, having provided for them "appropriate supplementary aids and services" (IDEA, 2012, para.1). Appropriate nursing staff should be available to manage the medically fragile child's (MFC) medical needs in the classroom setting. This, however, is an ideal situation and nursing services are not always available to manage the medical needs of this population.

According to the Department of Education (2012) the average annual per pupil expenditure for non-disabled students is around \$10,785. The disabled child expenditures can be double to triple that of a non-disabled student (Center for Special Education finance, 2004), making the \$1,762 grant money per disabled child not enough to provide the child with all the resources they need to be successful in the classroom setting. Additionally, funding for proper management of medical or nursing services for the MFC may not be in the budget. As expected, teachers are reporting the increase of management responsibility of MFC during classroom time being assigned to them (Barrett, 2000; Mancini, 2003; Nemeth, 1993; Ward, 2009). The difficulty with this reassignment of responsibilities is that teachers are neither prepared nor qualified to manage the special healthcare needs that the MFC often have. The following paper is a discussion of the focused project aimed at assessing the needs of teachers of MFC in the K-5<sup>th</sup> grade setting.

# Background of the Problem

According to the National Association of School Nurses (NASN) (2013), the professional organization representing school nurses, has recommended a staffing ratio of school nurses to general population students at 1:750. The 1:750 ratio is for the general population of students that do not require daily medical care, but may necessitate preventative screenings. For a student population that entails daily professional school nursing services or nursing interventions (i.e. medication administration), the ratio should be one nurse for every 225 students, or 1:225 (NASN, 2013). For students with chronic health conditions, such as that of MFC, that ratio again changes to one nurse for every 125 medically fragile students, or 1:125 (NASN, 2013). Students that need ongoing support, such as that of a ventilator assisted child, the ratio of nurse to student may be 1:1, obliging the school nurse to be present at all times (NASN, 2013).

The recommendations set forth by the NASN regarding nurse to student ratios, often do not match reality when the nurse to student ratio for many states may fall below the recommended guidelines (NASN, 2010). For example, in July 2012, the state of Georgia was mandated by legislation to staff public school nurses based on enrollment, such that for every 750 students there would be one nurse in attendance at all times (Turner, 2012). The mandate is an improvement from the previous requirement of one nurse for every 2,300 students that caused Georgia to be ranked 46<sup>th</sup> among all states for quality of school nursing services (Turner, 2012). The required one nurse to every 750 students is more in line with the NASN's nurse to student recommendations. The new

legislation, still does not address the actual care of MFC in the school setting.

In the past, legislation allowed for schools to interpret and allocate expenditures for the school nursing funds wherever they saw fit (Turner, 2012). As part of the new mandate for Georgia, there exists a requirement to spend the money specifically on school nursing services and/or needs (Turner, 2012). The mandatory allocation of nursing funds is also an improvement for the public school system in the state of Georgia, since spending nursing funds on areas other than nursing was an issue (Turner, 2012). Currently the Georgia Nurses Association (GNA), the state's professional nursing representative, has listed as one of the legislative priorities for 2013, the push for continued funding of nursing care for children enrolled in Georgia public schools (Georgia Nurses Association, 2013). Organizations like GNA will continue to advocate for adequate nursing coverage for the state's most vulnerable population.

A survey was conducted by the NASN in 2012 that supported the school nurse shortage problem. Fifty-five percent of state school nurse consultants reported that some school nurse positions had been dissolved completely or "replaced with unlicensed staff, medical assistants, emergency medical technicians, certified nursing assistants, or volunteers" (NASN, 2013, p. 178). The nurse shortage in the school can then lead to mismanagement of childrens' medical needs during the school day. In the same survey 68% of respondents reported that school nurses had given informal training to an unlicensed staff member regarding medication administration (NASN, 2013). Herein lies one of the problems for teachers of the MFC.

In 2012, legislation was passed in the state of New Jersey addressing the issue of the MFC's care delegation to unprepared personnel. At the time New Jersey did not have

any regulations in place requiring schools in the state to contract with nursing companies that were properly trained to handle the unique healthcare needs of MFC in the school setting (Roderer, 2012). The new legislation now requires for contracting to take place with qualified nursing agencies so that the healthcare needs of MFC can be met by licensed professionals. As well, the nursing agencies will have the power to write the plan of care for the MFC, along with the family and physician, and decide who will be included in the plan of care.

Another concern that teachers have expressed is the lack of knowledge pertaining to MFCs' conditions. Rightfully so, teachers feel the need to learn about the specific disabilities represented in their classrooms to better understand how to manage the childrens' special needs (Reid, 2010). A desire to learn more about the special disabilities in the classroom setting is an admirable quality that all educators should be encouraged to explore, and, it assists in a better blending of medically fragile students into the classroom setting.

Few articles and research studies exist regarding teachers' full inclusion of MFC in the classroom setting. Of those that do exist, a commonly emanating theme is of the teachers' feelings of inadequacy and unpreparedness when it comes to successfully including the MFC in the classrooms setting (Barrett, 2000; Becker, Johnson, & Greek, 1996; Gal, Schreur, & Engel-Yeger, 2010; Krier, 1993; Leatherman, 2007; Leier, Cureton, & Canham, 2003; Mancini and Layton, 2004; Nemeth, 1993; Ward, 2009). The feelings of inadequacy and unpreparedness by teachers of MFC span more than two decades, indicating the need for further research and better support measures.

After gathering the latest information regarding MFC in the classroom setting, the idea was born to create training modules to be available to teachers of MFC in the K-5<sup>th</sup> grade setting as supportive measures for better inclusive practices. A collaboration was created between Columbus State University's School of Nursing and Teacher Education Department to explore ideas in working to assist the teachers of the state. IRB approval was obtained and two focus groups ensued. Nola Pender's Health Promotion Model (HPM) provided the conceptual framework in designing the following research project. Pender's HPM has been found to be of great value to the nursing community with assisting to design studies and guiding research implications.

The teacher's perception of needing more training to promote a better experience for the medically fragile students can be viewed as a health promoting activity for the students. In essence, the teachers are promoting the health and successful inclusion of the MFC in the classroom setting. The HPM is a middle-range theory with high testability and generalizability to nursing practice (Houser, 2012), thereby making it an acceptable nursing theory to frame the study around. Additionally, since the HPM is often used in researching health-promoting interventions (Houser, 2012), suitability for this research topic is high.

bealth cure use (Cohen et al., 2011). The authors explore existing care models for children with complex needs and the failings of those existing models. The care programs that are available may fall short of meeting the MFC's, often complex, set of

# Literature Review

Several major topics will be explored throughout the literature review. The first important subject to define is the phrase "medically fragile". What constitutes a child as medically fragile? How do states define who the medically fragile students are? How is the MFC's plan of care activated during school? What conditions are most prevalent? What is typically involved in the care of a MFC during school? These are the questions to address first in the literature review. CINAHL, Academic complete, Pub MED and a broad Internet search consisted of the methods for gathering information related to the study.

### Examination of Medical Fragility in Children

As reported, research for MFC is scant or inadequate. The studies that are available are often outdated, occurring more than 10 years ago. Underscoring the limited available research finding, one article discusses the MFC as an emerging population in dire need for clinical and research initiatives (Cohen, Kuo, Agrawal, Berry, Bhagat, Simon, & Srivastava, 2011). In this article, the authors provide a definitional framework of children with complex medical problems that consists of substantial family-identified service needs, typical chronic and severe conditions, functional limitations and high health care use (Cohen et al., 2011). The authors explore existing care models for children with complex needs and the failings of those existing models. The care programs that are available may fall short of meeting the MFC's, often complex, set of needs. The authors request for both, creation of "sustainable evidence-based models of

care" and better-trained personnel to manage and resource the needs of the MFC are important issues related to the medically fragile population (Cohen et al., 2011, p. 534). By shifting the focus to finding sustainable evidence-based models of care and working to better train teachers of MFC, a better quality of life as well as a better chance of a successful classroom inclusion can occur for these children.

### Defining medical fragility.

Most definitions that account for being medically fragile consist of criteria about intensity and frequency of needed medical interventions (i.e. involvement of supportive personnel), intensity of symptoms (i.e. propensity to quickly develop into unstable, life-threatening condition), typical duration of symptoms (i.e. one year), and/or the need for any assistive devices (i.e. ventilator or wheel chair, for example) (Muller, 2007). The criteria listed all relate to how the different states within the United States (U.S.) define medically fragile for the students in the school setting. For example, California's definition of medically fragile is "A pupil who has an unstable life threatening physical health disability that requires monitoring and interpretation of signs and symptoms and interventions" (Muller, 2007, p. 5, Appendix A).

For the state of Georgia, medically fragile is defined generally as a "medical condition that can rapidly deteriorate, resulting in permanent injury or death; is a condition that requires medical care and/or technology to maintain health; and/or is a condition that requires extraordinary supervision and observation" (GeorgiaGov, 2013, para. 1).

Georgia's loose definition of MFC can be seen to include the criteria of intensity of interventions, intensity of symptoms, and the need for assistive technology devices.

Georgia provides examples of commonly seen conditions such as fetal alcohol syndrome, symptomatic HIV positive status, and congenital defects (i.e. spina bifida, sickle cell and cystic fibrosis) (GeorgiaGov, 2013). The list of conditions is not limited to only these conditions and Georgia makes the acknowledgment that other conditions as seen on a case-by-case basis may fall under the medically fragile umbrella. Finally, Georgia lists some examples of medical care that are included, but not limited to: "intravenous therapy, catheterization, dialysis, oxygen, medication administration and feeding tubes" (GeorgiaGov, 2013, para. 1).

Dream House for MFC is a 501(c)3 not-for-profit organization in Georgia that assists to represent MFC in a supportive environment, allowing for them to be cared for in their home setting rather than an institution setting. Their definition of medically fragile is a "child who, because of an accident, illness, congenital disorder, abuse or neglect, has been left in a stable condition, but is dependant on life sustaining medications, treatments, equipment, and has need for assistance with activities of daily living" (Dream House, 2013, para. 1). This definition seems to be in line with that of various state's definitions of MFC as well. Dream House's definition of medical fragility involves similar criteria such as intensity and frequency of medical interventions, symptom intensity and duration, and the need for assistive devices.

In 1997 The American Federation of Teachers (AFT) created a guide for teachers who had MFC in their classroom setting. It was entitled The Medically Fragile Child in the School Setting and was established to serve as a resource to educate teachers, paraprofessionals, and any other school employees on their roles and responsibilities and their rights as school employees (American Federation of Teachers, 1997). In 2009 the

AFT created the third edition of the Medically Fragile Child guide with additional attention paid to outlining possible solutions and protections for teacher groups to pursue on behalf of their schools. In the third edition, it is important to note, that the descriptor phrase "medically fragile children" was replaced by "children with special healthcare needs" (American Federation of Teachers, 2009), signifying a possible change in the view of MFC. Instead of viewing MFC as medically fragile, and perhaps difficult to manage in the classroom, the view may be seen as shifting more towards a child with prominent, but manageable healthcare needs.

In fact, the AFT points out that each child is individually unique, and should be managed on a case-by-case basis (AFT, 2009). This includes deciding who is eligible for both IDEA and Section 504 of the Rehabilitation Act of 1973. IDEA is a public law that has changed the landscape of education for special needs students in America (AFT, 2009). Children who were once considered uneducable are now entitled to the same education with the least restrictions possible and should have special needs provided by licensed healthcare professionals (Individuals with Disabilities Education Act, 2012).

For IDEA eligibility, a student must have one of the following disabilities: autism, deafness, emotional disturbance, hearing impairment, mental retardation, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury or visual impairment, including blindness (AFT, 2009). Governing states may also add to this list when determining eligibility.

Section 504 of the Rehabilitation Act of 1973 is a federal law that protects the civil rights of persons with disabilities (United Sates Department of Education

[U.S.D.E.], 2011). In other words, no one may be denied access to programs or activities that receive federal funding. A student with a disability may be eligible for Section 504 protection if they have a mental or physical impairment that substantially limits major life activities (U.S.D.E., 2011). Section 504 describes "impairments" to be: attention problems, severe allergies, cerebral palsy, diabetes or epilepsy, and describes "substantially limits" to include: walking, seeing, hearing, speaking, breathing and learning as compared with peers in general education (U.S.D.E., 2011).

# Defining the nurse's role in management of the medically fragile child.

When defining medical fragility, it is important to know how the IDEA and Section 504 describe their own defining terms to decide who will be eligible for services within their protective parameters. Additionally, there is a need to understand what the role of the school nurse is in the eligibility and plan-of-care processes for the MFC. According to the NASN (2005), the school nurse is often the one to recognize and identify students who may need accommodations or other services and leads the process of creating individualized healthcare plans (IHP) for the MFC. An example of this would be a diabetic student who required accommodations for testing blood glucose levels, administering insulin or glucagon when needed, and making up missed work when insulin levels were low.

The AFT recognizes the school nurse's pivotal role in recognizing and initiating the IDEA and section 504 processes (AFT, 2009). However, this is the first step of a sometimes lengthy process. Once the needs are established, licensed personnel have to be available to initiate and complete suggested or required healthcare procedures. In some instance nonlicensed personnel may be trained to perform certain tasks, but only at

the discretion of the licensed nurse (AFT, 2009). Laws vary from state-to-state regarding who the nurse may delegate to and what tasks the nurse may delegate (AFT, 2009). Active school nurses should be aware of the nurse practice acts for their state and understand the delegation process.

For the state of Georgia, the Registered Nurse Practice Acts (2013) reads, "It shall be a misdemeanor for any person, including any corporation, association, or individual to: knowingly employ any person to practice nursing as a registered professional nurse who is not a registered professional nurse or knowingly aid or abet any person to violate this article" (p. 125). In other words, no person or association may encourage or condone unlicensed individuals to perform healthcare procedures that they are not licensed to perform. The American Federation of Teachers (2009) describes that often times it may be the principal or other supervisor that asks the teachers to perform healthcare tasks that are considered nursing procedures. Clearly, this would be a violation of the state practice acts of Georgia. Teachers however may not be aware of the legal framework and, perhaps out of fear of losing their job, will agree to perform the necessary nursing procedures.

In 1993 in Knoxville, Tennessee, five teacher aides were fired from their positions at the Knox County School system for refusal to perform catheterizations on students.

Six years later, in 1999, the court system decided that they had been wrongfully fired and were due back-wages from 1993-1994 (Cantrell v. Knox County Board of Education, 1999). This case is an example of unlicensed personnel refusing to perform tasks that, by law, they are not allowed to perform. The plaintiffs, in fact, quoted the state nurse

practice acts for use in their defense and successfully won their case. This case helps to delineate the role of the school nurse from the role of nonlicensed personnel.

Had the school nurse and administration been familiar with the nurse practice acts for the state, administrators would have never asked the teachers aides to perform the catheterizations. For the state of Georgia a decision tree was created to assist in delegation of tasks to unlicensed personnel. When a decision has to be made about what tasks can be delegated and to whom, the school nurse can refer to the decision tree resource to help him or her decide if the tasks are able to be delegated and to whom they may be delegated (Georgia Secretary of State, 2012). With the nursing practice acts and decision tree in place for use in the school setting, healthcare procedures for MFC can be more clearly delegated and performed by the proper school personnel.

### Teachers' Attitudes and Perceptions Regarding Inclusion

In many states funding is not available to fully support the needed number of school nurses to manage the medically fragile population. Subsequently, teachers have reported varying degrees of involvement with the management of care for MFC in the classroom setting (Barrett, 2000; Becker, Johnson, & Greek, 1996; Gal, Schreur, & Engel-Yeger, 2010; Johnson & Asay, 1993; Krier, 1993; Leatherman, 2007; Leier, Cureton, & Canham, 2003; Mancini and Layton, 2004; Nemeth, 1993; Ward, 2009). Authors Gal, Schreur, and Engel-Yeger (2010), examined teachers' attitudes and requirements for accommodations and inclusion of MFC. The focus of this study was to discover what barriers existed to successfully achieve inclusion of MFC in the classroom setting (Gal, Schreur, and Engel- Yeger, 2010). The study conclusively showed that barriers to inclusion include a lack of direct support for the student (i.e. continued nursing

services) and lack of indirect support for the teachers by the school and the general education system (Gal, et al., 2010). The teachers reported that professional training regarding MFCs' conditions could improve their ability to better include the MFC in the classroom environment (Gal, et al., 2010). Successful inclusion begins with creative solutions for eliminating barriers to success. Gal et al. explored the teachers' perceived barriers and reported on the teachers' insightful solutions. Researchers may use the reported information when creating new studies for successful inclusion for the medically fragile population.

A narrative study conducted by Leatherman (2007), examined teachers' perceptions of their inclusive classroom environment. The themes that emerged were: the inclusive classroom is a great place for all children, the teacher needs additional training and education, the teacher needs administrative support including taking part in the decisions regarding the inclusive classroom, and positive experiences become the foundation for successful inclusion (Leatherman, 2007). Again, the themes that are emerging are that teachers need more training, better administrative support, including consistent nursing services, and that inclusion is a positive experience if managed properly. What is emerging, through the identified themes, is a better understanding for successful classroom inclusion for the MFC.

In a recent study by Schieve et al. (2012), children included in the National Health Interview Surveys from 2006- 2010 were analyzed for the presence of development disabilities (DD) and other concurrent medical conditions. They were then compared to children without DD. This study found that children with DD had a markedly higher incidence of concurrent medical conditions (i.e. asthma, skin allergy, food allergy,

recurring ear infection, frequent headaches, migraine, colitis, and diarrhea) when compared to their non-developmentally disabled counterparts (Schieve et al., 2012). This supports the findings that MFC in the classroom setting have special and sometimes complex needs that require ongoing support and services for successful inclusion.

There exists other studies and research related articles pertaining to teachers' perceptions of inclusion, however, many are more than 10 years old and may no longer be entirely relevant for discussion in the literature review. Often the studies surrounded either the teachers' perceptions of inclusion or their perception of the role of the school nurse or other classroom assistants (Barett, 2000; Becker, Johnson, & Greek, 1996; Johnson & Asay, 2003; Krier, 1993; Leier, Young Cureton, & Canham, 2003). Not surprisingly, the themes that were prevalent regarding inclusion, such as lack of special needs training, and lack of supportive staff, are very similar to what they remain today. Studies often questioned who was to provide the care for the MFC and what procedures were performed most often. Since then legislature has been written in most states that cover the question of who should provide the care, including having access to the nurse practice acts to be used as a reference point by the schools.

### Commonly Performed Healthcare Procedures for the MFC

Some of the procedures reported for MFC in the literature are as follows: catheterizations, tube feeding with tube care, suctioning with tracheostomy care, diapering, other toileting needs, colostomy/ileostomy care, medication administration, injections, diabetes management, CPR emergency management, seizure monitoring, diet monitoring for allergies, prevention/treatment of skin breakdown, oxygen related procedures, prosthesis care, mechanical ventilation, and patency of shunt monitoring

(Barrett, 2000; Becker, Johnson, & Greek, 1996; Krier, 1993; Leatherman, 2007; Mancini and Layton, 2004; Nemeth, 1993). The list of possible health-related procedures performed in the classroom is lengthy and is expected to continue to grow, especially with the continued advancements in medical technology that allow for the MFC to live longer and perform in school settings. Since the children are functioning on a higher level and living longer, there is an increase of MFC in the classroom setting. As a result, disease advocacy groups like the American Diabetes Association are providing guidelines for classroom management related to their disease process.

In 2011, The American Diabetes Association (ADA) published a position statement on management of the child with diabetes in the school setting. The position statement discusses the need for all personnel who might be involved with the child in the school setting, including teachers, to be appropriately trained in diabetes management and diabetes emergency management (American Diabetes Association, 2011). The general guidelines for the care of the diabetic child includes, creating a diabetes medical management plan, developing a list of responsibilities of the various care providers, and description of age-related expectations of students requiring care related to diabetes (ADA, 2011). The position statement concludes that with safe handling, proper training, and guideline adherence, the school setting can be a safe environment, full of learning experiences for the diabetic child. The ADA's conclusion of classroom safety and fulfilling experiences for the MFC is in agreement with the findings discussed before, indicating that with proper training and support, inclusion can be successful.

The research articles combined collectively point in the same directions. First,

MFC and nondisabled students can have wonderful experiences in an inclusive classroom

setting. Second, through the inclusive experience, MFC can thrive and are more likely to go on to lead more successful lives than their non-inclusive counterparts. Third, teachers support inclusion but feel that more support from nursing staff is needed. Lastly, teachers report needing more training to have a better understanding of best management practices for the MFC in the classroom.

#### Nola Pender's Health Promotion Model

Medical professionals have long since known the benefits of early detection and illness treatment, however, more recently, attention has been paid to preventive health and wellness promotion for improving quality of life. One nurse theorist that recognizes the preventive health movement and has her own part in helping to create the health-promotion movement, is Nola Pender. She is known for creating the Health Promotion Model (HPM), a prominent and widely research-applicable, nursing theory (Pender, 2011; Peterson & Bredow, 2004). Pender's HPM has been used in numerous studies since its creation in 1982 (McEwen & Wills, 2011). In fact, nurses can use the HPM to develop and execute health-promoting interventions to individuals, groups, and families in a wide variety of settings, including the community at large (McEwen, 2011).

The HPM will be described in detail to better understand its applicability to this project, with an examination of background factors that have the ability to influence health behaviors (Pender, 2011). The central focus of the model is on eight beliefs, assessed by the nurse, which are the critical points for targeted nursing interventions (Pender, 2011). By working with the individual and using the HPM as a guide, healthy lifestyle behaviors can be the outcome (Pender, 2011). With the use of the HPM in this study and the teachers' beliefs about the medically fragile students and their

perceived needs for success, a nursing intervention can be created and tested for successful promotion of healthy behaviors among the teacher population.

The HPM has five key concepts that should be defined first. Person, is defined as a "biopsychosocial organism that is partially shaped by the environment that also seeks to create and environment in which inherent and acquired human potential can be fully expressed" (Pender, 2011, p. 3). For this study there are two "persons" that are being examined; there is the medically fragile student and the teacher who is managing the students' education and immediate needs. Both "persons" are important for this study because it is the teacher that is targeted for the health promotion activity, not personally, but for the medically fragile student. The MFC will be the person that benefits most from the healthy behavior outcome.

The second concept important to define is that of the environment. Pender defines environment as "the social, cultural, and physical context in which the life course unfolds" and continues to say that "the environment can be manipulated by the individual to create a positive context of cues and facilitators for health-enhancing behaviors" (Pender, 2011, p. 3). The environment is an integral component of the healthy behavior outcome dynamics and if the environment is one of non-support then the health promoting behavior may not occur. From the defining aspects of the concept of environment, it can be inferred that the classroom setting, wherein the inclusion takes place for the MFC, can be viewed as positive or negative, thereby encouraging or hindering the health promoting activity.

The third concept in the HPM is nursing. Nursing is defined as, "the collaboration with individuals, families and communities to create the most favorable

conditions for the expression of optimal health-enhancing behaviors" (Pender, 2011, p.

3). The nursing aspect for this study is the Nursing and Education Departments at Columbus State University, collaborating to examine what the needs are for this specific population and offering possible solutions to the perceived issues. Without paying attention to the environmental aspect of this study, key pieces of information can be missed and may result in a missed opportunity of health promoting activities.

The fourth concept in the HPM is health. Health in reference to the individual is defined as the "actualization of inherent acquired human potential through goal-directed behavior, competent self-care, and satisfying relationship with others, while adjustments are made as needed to maintain structural integrity and harmony with relevant environments" (Pender, 2011, p 3). Health is a major concept in this study and is one of the big driving forces behind the interest in this topic. In order for medically fragile children to have the best chances of success in the educational environment, the focus has to be on attention to their health needs. From the literature a recurring theme for optimal success for the MFC's inclusion was when teachers thoroughly understood the MFC's condition and knew how to mange the child's needs during the classroom setting.

A major strength of Pender's definition of health is that it takes a positive, humanistic and unifying approach to health (Peterson & Bredow, 2004). The nursing profession is no stranger to the holistic approach to patient care. It is a known fact that patients experience better outcomes when the nurse shows sincere concern for their health and not just the status of their disease state. For Pender, health is not only the absence of disease, or minimizing limitations of functioning, it is also an increased opportunity to strengthen resources, potentials, and capabilities (Peterson & Bredow,

2004), such as the possibilities that exist with this study. With this study, the possibilities of strengthening resources (i.e. the teachers ability to improve the inclusive experience for the MFC), strengthening potentials (i.e. the MFC's potential as both a student, and a developing individual), and strengthening capabilities (i.e. the capability of the teacher to enhance the inclusive opportunity and the child's capability of functioning in the classroom setting) all exist to enhance functionality and improve quality of life for MFC.

The last concept of the HPM is illness. Illnesses are described as "discrete events throughout the life span of either short or long duration that can hinder or facilitate one's continuing quest for health" (Pender, 2011, p. 3). For the children in this study, their medical conditions are not the defining illnesses; rather, the proper management of the children, working to create successful and meaningful inclusion, is the freedom from illness. In other words, the teachers' desire for successful inclusion can facilitate their quest for a continued state of health for the MFC, allowing for a better chance for learning to occur. The five concepts can have an interactional affect with each other and, in fact, serve as the foundation for the eight critical points where nursing interventions are targeted.

The eight points, also known as behavior-specific cognitions and affect, can be influenced by individuals' personal characteristics and experiences, which include prior related behavior and personal factors (McEwen & Wills, 2011; Pender, 2011). The behavior-specific cognitions and affect include: perceived benefits of action, perceived barriers to action, perceived self-efficacy, activity-related affect, interpersonal influences, situational influences, immediate competing demands, and a commitment to a plan-of-action (McEwen & Wills, 2011; Pender, 2011). The behavior specific cognitions and

affect of individuals, or groups, can be analyzed by the nurse for readiness to commit to a plan-of-action. Readiness to commit directly influences the outcome of the HPM, which is performing the health promoting behavior (McEwen & Wills, 2011; Pender, 2011).

The literature review revealed that most teachers were ready to commit to a planof-action. Teachers' perceptions to inclusion were positive, for the most part, indicating
the benefits for the MFC and non-disabled students (i.e. perceived benefits to action)
(Barrett, 2000; Gal, Schreur, & Engel-Yeger, 2012; Leatherman, 2007; Mancini &
Layton, 2004). The teachers who were not as positive about inclusion shared experiences
that indicated a need for better classroom support (i.e. perceived barriers to action)
(Barrett, 2000; Gal, Schreur, & Engel-Yeger, 2012; Leatherman, 2007; Mancini &
Layton, 2004). Additionally most teachers' attitudes about personal ability to
successfully achieve inclusion were positive (i.e. self-efficacy, activity-related affect) but
often cited needing more support to perform their role in a greater capacity (i.e.
situational influences and barriers to action) (Barrett, 2000; Gal, Schreur, & Engel-Yeger,
2012; Leatherman, 2007; Mancini & Layton, 2004).

Many teachers offered suggestions for better support in the classroom such as special training related to conditions of the MFC and better nursing support, showing readiness to commit to a plan-of-action. As readiness to commit to a plan-of-action occurs, the intended health promoting behavior can become a reality. For MFC, the health promoting behavior, performed by teachers, has potential to make a profound difference in the MFC's life. The outcome is successful inclusion and a fully supported population of MFC that lead productive lives both during school and after school as promising adults.

To have a target for a successfully inclusive reality for the MFC it is important to examine how other researchers have applied the HPM to their studies. McEwen and Wills (2011), reported in 2008 that a search in CINAHL found 235 English language articles that reported using Pender's HPM for the previous decade. A recent search in CINAHL using "health promotion model" as a search phrase, from 1990-2013, turned up 496 results. The HPM has been used for decades in explaining and predicting behaviors by numerous nursing researchers and scholars (Ripollone, 2011). The HPM's applicability to multiple situations and environments makes it an ideal conceptual model in which to frame studies.

Multiple studies have been conducting using the HPM to relate behavior-specific cognitions of construction workers, farmers, and factory workers use of hearing protection. One study in particular analyzed the HPM's ability to predict hearing-protective behavior among construction workers. The study found that three behavior-specific cognitions (perceived benefits, perceived barriers, and self-efficacy) accurately predicted construction worker's use of proper hearing protective equipment (Lusk, Ronis, Hogan, 1997). The study was later examined for continued accuracy in light of the revised structure to Pender's HPM. The validity of the study was proven in 2006 that the HPM was still an accurate predictor of use of hearing aid protection among construction workers (Ronis, Hong, & Lusk, 2006).

The applicability of the HPM to the adolescent population has been shown as well. Multiple studies exist linking connection between behavior-specific cognitions to desired healthy behaviors. In an older study, Garcia et al. (1995) demonstrated that background characteristics such as gender could play significant roles in determining

exercise behaviors. The study also found that the HPM was an accurate predictor of physical activity health-promoting behaviors among teens (Garcia et al., 1995). Utilizing the HPM to create strategies for teens and adolescents is of great value to solidify a healthy foundation for life.

In 2006, Srof and Velsor-Friedrich, conducted an integrative review of Pender's HPM in regard to adolescent health. They noted that teens could be especially at risk for negative behaviors. At the same time, they noted that teens are equally impacted by positive influences as well, creating a stronger sense of self-efficacy (Srof & Velsor-Friedrich, 2006). This shows that the interpersonal influences for teenagers can have influential effects on self-confidence and belief in their abilities to perform health-behavior activities. Use of the HPM with teenagers can be of value when determining ways to promote exercise and healthy lifestyles.

In 2007, Mendias and Paar used the HPM to examine perceptions of health and self-care strategies of persons living with HIV/IDS. In addition to perceptions of health and self-care learning needs, perceived barriers and preferred learning modalities were examined. Health promotion is known to increase healthy behaviors, enhance health status, and decrease health care costs of chronically ill patients. With HIV/AIDS patients, making meaningful connections between behavior-specific cognitions and health promoting behaviors is essential for identifying strategies for continued health maintenance. The findings from this study were conclusive that the HPM can be applied with success to this population of individuals.

Pender's HPM was applied again to a different population in 2013. Authors

Anderson and Pullen conducted a randomized study among four Christian faith

communities from which 27 African American women 60 years of age and older were recruited (2013). The purpose of the study was to determine whether African American women receiving a physical activity intervention, with spiritual strategies, compared to a control group, would demonstrate differences in physical activity behaviors, self-efficacy for physical activity, and in barriers to physical activity (Anderson & Pullen, 2013). The intervention group was favored on all counts indicating that the HPM can be used to develop physical activity interventions with spiritual strategies to increase physical activity behavior for older African American women in faith communities.

Pender's HPM is a holistic approach to the needs of the patient, assessing the patient's background and self-perceptions to understand how better to plan appropriate nursing interventions (Ripollone, 2011). As well the health promotion theory can easily be applied to all populations to fit the needs of the population. The HPM was chosen as a conceptual framework for its range and ease of applicability to the educational setting.

Since this study is focused on the teachers of MFC, and not directly on the MFC themselves, the range of HPM interpretations suited the needs for the study well.

#### Project Plan and Implementation

The goal of this project was to discover the perceptions of inclusion of MFC and perceived needs of local K-5<sup>th</sup> grade teachers and to create a resource tailored to the needs identified. The first step was to gain the opinions of local teachers. Dr. Cheryl Smith, Associate Director of the School of Nursing Graduate Program, and Associate Professor, Mrs. Pamela Wetherington, Assistant Professor in the College of Education, and I worked together, creating a project team, to decide who to utilize for a discussion group. Since the project team consisted of collaboration with the education department at Columbus State University, the team looked at forming a focus group of teachers who were currently enrolled at CSU. In the summer of 2012, a class of students who were seasoned teachers with experience in teaching MFC were invited to take part in the focus group. They were excited to provide opinions and insight related to the topic.

During the summer of 2012, IRB approval was obtained from Columbus State

University. The approval gave permission to conduct a focus group with the possibility
of conducting a second focus group, in the event that the first focus group did not yield
sufficient results (See Appendix A for the completed IRB application). The first focus
group was conducted on July 19, 2012, with the second focus group to be determined at a
later date. The first focus group consisted of six participants. Five participants were K5<sup>th</sup> grade teachers; one of the five was a special education teacher. The sixth participant
had yet to begin teaching in a classroom setting. All six participants were enrolled in
Masters level courses. Before the focus group began, a script was read detailing the
purpose for the focus group and the intended use of their responses (See Appendix B for

Focus Group Script). All six education students verbally consented to participate in the focus group discussion.

It was determined that the first focus group yielded inconclusive results due to the limited amount of participants. The project team was able to determine some areas of interest with the first focus group, however, it was decided that the group of six participants was too small to conclusively design a pilot survey to administer to K-5<sup>th</sup> grade teachers in the Harris County school system. It was then determined that a second focus group was needed to better guide the pilot survey direction. The team decided to wait and do the second focus group during the fall semester, with hopes of having more educational students enrolled in courses. September 4, 2012, was the date set for the next focus group and the focus group would have 21 participants.

Of the 21 participants in the second focus group, all but three had experience teaching K-5<sup>th</sup> grades. The remaining three had yet to begin teaching in a classroom setting. All participants in the second focus group were enrolled in Masters level courses, just as the first focus group. The focus group script was read again at the beginning of the discussion and all 21 teachers verbally consented to participate.

The following questions were asked to both focus groups. Do you teach K-5<sup>th</sup> grade students? Do you teach special education classes? Do you have access to a school nurse the entire school day, part of the day, or on an on-call basis? Do you have medically fragile children in your classroom? Have you ever been asked to administer any kind of treatment or medication to a medically fragile child? How do you feel about being asked to administer treatment to medically fragile children? Have you received any education about care for medically fragile children? If a resource existed to educate you about medically fragile conditions, would you utilize it?

#### Project Results

The following is a summary from the first focus group and their responses. The first question pertained to their experiences with MFC in the classroom setting. The project team wanted to know what the teachers' experiences comprised of and what specific medical conditions they had encountered. Three participants reported currently having MFC in the classroom setting. One reported a student as having tumor growths on her legs and on her brain. Another reported having diabetic and asthmatic students. Other participants reported varying degrees of integration of autistic, asthmatic, diabetic, and allergy prone students into the classroom setting on previous occasions.

The next question surrounded the availability of nursing services throughout the school day. Differing levels of availability were reported. Some reported having a nurse available and others reported paraprofessionals as the available nursing staff. It was reported by one participant that the paraprofessional referred to herself as "the nurse" for the school. One reported that a nurse was available at anytime during the day. Others reported that their school nurse was available only for half of the day; it was mentioned that this nurse was shared with another school. One participant reported that his school nurse was on call, via a pager system, if a nursing need arose. The last participant reported that his school nurse was only at school during certain days of the week.

Next, the project team asked if any of the teachers had been asked in the past to administer medications or treatments to any medically fragile students. All but one participant answered no. This participant went on to say that she had not received any

specialized training and that she had sought training and additional information on her own. She reported doing this so that she would be better prepared to handle the student in her classroom. Since only one participant positively identified involvement with performing healthcare procedures, the team asked all participants about how they would feel if asked to perform specialized treatments or to administer medication. The answers listed were, being uncomfortable, unprepared, and fearful of legal actions if done improperly.

All participants agreed that they would not, however, feel comfortable "sitting and waiting" for help to arrive in the event of an emergency. They reported that they would want to know ahead of time what the MFCs' needs might be so if an emergency arose, they would be more prepared to meet those emergent needs. When asked if they had received any specialized training for managing the MFCs' needs, all answered no. The question then was posed, if special instructional modules were easily available and accessible for teachers with MFC, would they utilize the available resources. All reported they would use the resources when it pertained to a MFC in their class. The last question was in regard to what they felt the priority conditions were that would most benefit from educational modules. The following key areas were identified as priorities: allergies, diabetes, asthma, autism and seizure disorder. This concluded the first focus group.

Ultimately, the first focus group was too small to conclusively draw upon. The project team expected the group to have dealt more with administering care in the classroom setting, so when only one in the initial focus group reported having administered medical interventions, the team felt that the need existed to conduct a

second focus group with the aim of having more participants. The project team was pleased to note that almost all participants had at some point experienced MFC in their classroom settings. The team knew that the teachers' experiences with inclusion would give rise to emotions and perceptions regarding the inclusive environment. Accordingly, the reported concerns of feeling uncomfortable, feeling unprepared, and fearfulness of legal actions surrounding the MFC in the classroom, were not unexpected. Still, insight gained from the focus group was limit due to the small number of participants.

The following is the account of the second focus group discussion. There were many participants that identified having MFC in the classroom setting. The medical conditions that were reported to be prevalent in the MFC were: spina bifida, food allergies, severe seasonal allergies, seizures, diabetes, sickle cell anemia, irritable bowel syndrome, asthma, self-mutilation disorder, behavior disorders, kidney failure, frequent nosebleeds, clotting disorders, and other lung disease that led to frequent hospitalizations. Medical interventions that were reported to be needed for their MFC were: catheterization and foley catheter care, wheel chair transfers, shunt care, cochlear ear implant care and maintenance, administration of medications, bandage changes, and diabetes care.

When asked if anyone had to administer care for their MFC, many different answers surfaced. Medication administration was reported by many participants as having occurred throughout their time with various MFC. One teacher reported that her diabetic student had passed out in class and she had to administer a "sugar pill" and call the office for help. Another teacher reported a severe environmental "grass" allergy reaction occurred during class with her MFC. She shared with the group that she had to

quickly call the child's mother and wait for her to arrive. There was not a nurse present that day. One teacher reported having to change bandages for a student; the nurse was not always available to do it. Several reported having to manage cochlear ear implants. Some reported experiences of seizures in the classroom. Numerous teachers reported having been given an epinephrine pen to use in case of an emergency. One reported that she was told she had to do wheelchair transfers for her student; as well she had to be responsible for adherence to a catheterization schedule for her student (she never did the catheterizations herself).

The next question for the participants was the level of nursing services involvement in the day-to-day setting of school. Ten responded that they had a full time nurse every day for the care of MFC. Eleven responded that they did not have access to a full time nurse every day. Some reported that a "clinic" worker was available some parts of the day; no one knew the credentials of the clinic worker. Also mentioned was sharing of a single nurse among multiple schools. If the nurse was needed they could alert her through a pager/beeper system. Some reported that the secretary or administrative staff had been known to administer medicines and/or care to students if the nurse was unavailable.

Next participants discussed how they felt about being asked to administer care for their medically fragile students or how they would feel if they were asked to do so. Some said they felt comfortable and others said they felt very uncomfortable. One participant reported that she felt comfortable because she had once been a medical assistant in a hospital setting. She felt that her experiences from her previous position helped her in better understanding the medical needs of the medically fragile students. Another

participant reported being comfortable with having diabetic students in her class. She said that a friend of hers had diabetes and she had some experience helping him with blood sugar regulation. This experience helped her to have a positive outlook with diabetic students.

Another participant had been asked to provide the student's physician with detailed records of the medically fragile student's progress. She reported having had little guidance on how to document and on what to focus her notes. She reported feeling very uncomfortable having been assigned this task. Many participants voiced that they did not have sufficient knowledge to provide special assistance needed by the MFC without the direct supervision of the nurse or clinical support person. All participants regarding this issue reported feelings of apprehension and alarm. Additionally, discomfort was voiced over special assistive device management, such as the cochlear ear implant. Most reported not wanting the responsibility since the device is very expensive and can be broken easily.

The last question posed to the group concerned whether they had received specialized training and if not, would they have wanted it. Some reported they had been given a "talk" by the nurse regarding the MFC, but nothing formal had occurred. A few reported that the parents of the child had come to them discussing the child's specialized needs. One teacher shared a story of how the guidance counselor had shown him how to use an insulin pump for his diabetic student. Another reported that special food-allergy guidance had come from the lunchroom manager. All participants reported that zero formal training had occurred. All reported that they would have benefited from formal training for the MFC's condition, had it been offered. When asked if specialized modules

were made available to them regarding the medical conditions, would they use them, all answered yes.

Many themes emerged from the combined focus groups that appeared to align with themes found in the literature review. The first theme that emerged from the focus group was an increase in the presence of MFC in the classroom setting. The next theme that appeared in the focus group was that a wide range of medically fragile conditions existed among the students. The next theme that materialized was that the teachers felt inadequately prepared to manage the MFC in the classroom setting. Additionally noted from focus group teachers was that there were not enough supportive measures for the teachers to include the MFC; they needed better nursing services coverage and they needed formal training for management of the medically fragile conditions. The last two themes to emerge were feelings of discomfort when managing the MFC and a desire to have training interventions available for use when needed.

Positively identifying an increase in MFC in the school setting needed to occur first. Teachers from the focus groups reported that they had noticed an increase with inclusion of MFC in the classroom setting over the last several years. Now that this finding had been correlated with the literature review finding, the project team could move on to more discussion of inclusive practices.

Next the project team explored with the teachers which conditions they found to be prevalent among the medically fragile students. There were a wide variety of conditions reported among the MFC. This too coincides with the literature review findings. While conducting the literature review the project team was able to establish that because of increases in medical technology and medical advancements, children who

previously were considered too fragile to go to school and to be productive, are going on to live longer lives with more chances for productivity. The gains in medical technology and medical advancements are allowing for more MFC to be included in the classroom environment with hopes of having a brighter future. The problem that arises from this, as found in the literature review, is that teachers are not getting the support or training that they need to successfully and completely include the MFC in the classroom setting.

Teachers in the focus group positively connected the literature review findings with their inclusion perceptions. With the increase of MFC in the classroom setting, the teachers in the focus groups discussed the many concerns they had with the inclusive process. Teachers found that the MFC had specialized needs that they, the teachers, had not been trained to meet. Therefore the MFC must rely on nursing services to meet their specialized needs. However, nursing services, as reported by the focus group teachers, were available for the care of MFC in varying degrees.

The finding that nursing services are not available on an on-going basis was found in abundance throughout the literature review. So much so, that the National Association of School Nurses (NASN) made general recommendations for minimum requirements for nursing services in schools. The NASN's recommended ratio of school nurses to students is posted for use by schools as a guideline in deciding how many nurses should be available during the school day. What was found in the literature review is that many schools fall below these recommendations on a continual basis. The reports from teachers in our focus group seem to support the finding that the NASN's minimum requirement for nurses is not being followed. The State of Georgia, in July 2012, had legislation passed to demand that monies set aside for nursing services actually be spent

on those services. If laws have to be passed in Georgia to assure nursing monies be spent on nursing services, might this represent a trend prevalent among other states?

The reports from the focus group teachers that they, or other administrative staff, have had to perform some special care for the MFC, is not an unexpected finding. From the literature review it was found that the reporting teachers had to perform special care because either the qualified personnel were not present, or because they had been told they would perform the procedures as part of the plan-of-care for the MFC. From the focus group, it was determined that nursing services were available on an inconsistent basis. Nurses were reported to be available on a part time basis, via a pager system, or sometimes not available at all. These reported findings correlate with the literature review findings that nursing services may not always be present during school hours.

Next, focus group participants discussed their varying degrees of involvement with the MFC healthcare needs. The focus group participants shared experiences with administering medications, assisting diabetic students, making bandage changes, observing for allergic reactions, being aware of seizure activity, and assisting with wheel chair transfers. Their shared stories correlate with the literature review finding that teachers are more frequently having to assist the MFC with their special needs during class. Now that it has been established that the teachers are reporting their involvement with MFC healthcare needs, the need for an intervention for the teachers to better support them in the classroom is paramount.

The focus group reported that the teachers had feelings of discomfort regarding the new responsibilities. When asked for further extrapolation of their discomfort, it was discovered that their fears were directly related to their inexperience and lack of training

in regard to the MFC's condition. This finding is important because it shows that with training and support for the teachers, their fears can be diminished and the teachers may be better suited to provide a more inclusive, learning environment for the MFC. Other teachers in the focus group reported that they felt comfortable teaching MFC because of prior experiences with certain medical conditions. Their prior experiences contributed to their body of knowledge and understanding of certain conditions and therefore helped them to feel more comfortable working with MFC in the classroom setting. This finding further supports the need for training, as it will encourage the teachers' growth in knowledge and experiences with related conditions.

As part of the literature review, teachers' perceived needs and barriers to success in the classroom were explored. It was discovered, as it was with the focus group, that teachers feel a need for not only nursing services support but a need for teacher support as well. Support was recommended by the teachers in the form of educational training regarding medically fragile conditions and a more collaborative relationship with nursing services. The teachers, from the literature review, provided feedback on what they felt they needed for successful inclusion, i.e. more training and better collaborative relationship between teachers and nurses. This correlates with the findings among our focus group teachers.

Teachers from the focus group responded that they would like to have specialized training in regard to the MFC's condition. They reported that they would feel more comfortable managing the child in the classroom setting if they had a better idea of what the child's problems were. If the event rose that the teacher needed to intervene or direct the child's focus back to learning exercises, the teacher felt that he or she would know

better how to meet the MFC's needs. These findings further support the need for an educational training intervention to occur for the teachers of MFC.

This project has described that teachers of MFC need established extensive uniting protocols to propose down for the inclusive environment. The next step is to determine what specific information the teachers would like to have and design an education intervention that they have need. The next phase of this research project will include creating a puter servey to be administered to Harris County schoolteschers K-5<sup>th</sup> grade. Once results from the pilot study are asserted and analyzed, a more detailed survey can be administered. Perhaps more than one acheol system can be surveyed, for a broader scope of teacher feedback regarding needs with MFC. The ultimate goal of the study will be to design and implement educational training modules for teachers to access on an as needed basis for continued educational support in their clustroom settings.

Ultimately the desire exists for teachers K-5<sup>th</sup> grade to be better prepared to manage and

## Possibility for Continued Research

This project has determined that teachers of MFC need established extensive training protocols to prepare them for the inclusive environment. The next step is to determine what specific information the teachers would like to have and design an education intervention that fits their needs. The next phase of this research project will include creating a pilot survey to be administered to Harris County schoolteachers K-5<sup>th</sup> grade. Once results from the pilot study are examined and analyzed, a more detailed survey can be administered. Perhaps more than one school system can be surveyed, for a broader scope of teacher feedback regarding needs with MFC. The ultimate goal of the study will be to design and implement educational training modules for teachers to access on an as needed basis for continued educational support in their classroom settings.

Ultimately the desire exists for teachers K-5<sup>th</sup> grade to be better prepared to manage and successfully include MFC in the classroom setting.

### Conclusion

The inclusion of MFC in the classroom setting is no longer a novelty, however there has not been an establishment of standardization for proper training of teachers of MFC. The twenty-year-old article entitled "Who meets the special healthcare needs of North Carolina schoolchildren?" called for the establishment of a standard of care for this vulnerable population (1993). Two decades later, no standard operating procedure has been established. The Americans with Disabilities Act and the Individuals with Disabilities Education Act were passed in order to allow MFC access to an equal education opportunity. Unfortunately resources are limited in allowing for the full realization of inclusion. The change that is needed is to provide the best supportive environment possible for learning to occur for the MFC. It is known that with proper support and encouragement this special population can thrive and go on to be productive members of society. Educators and nurses must communicate and collaborate to create the protocols necessary to propel the MFC forward to a bright future. The collaborative relationship established during this research project is an example of a partnership that has potential to create invaluable benefits for individuals and society.

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## Appendix A

# Columbus State University Institutional Review Board Application for Institutional Review Board Review

Part I – To be completed by researcher:

General Instructions for Completion of Protocol: Unless otherwise instructed, type all information in the area below each question, using as much space as necessary.

I. Principal Investigator(s):
-Name: Dr. Cheryl Smith CSU ID: 909094255
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Faculty Supervisor (if applicable): Dr. Cheryl Smith Department: Nursing Education
Faculty Supervisor E-Mail: smith_cheryl6@columbusstate.edu Phone: 706-507-8578

- **II. Title of Project:** A Focus Group of Teachers of K5-5<sup>th</sup> grades about the care of medically fragile children in the classroom
- III. Dates of Proposed Research: Start: July 15th, 2012 End: December 31st, 2012

IV. Source of Funding for the Protocol: no funding needed

**V. Purpose of the Study:** In a brief statement, clearly describe your research reason for performing this study, including: 1) all of the objectives of the study (including hypothesis when applicable), and 2) the anticipated outcomes.

A focus group will be conducted among education students taking a summer course at CSU. The objective of the focus group is to discuss the topic of having medically fragile students in the elementary school setting and to determine what needs, if any, the teachers feel are not being met regarding their care of students who are medically fragile. It is hypothesized by the researchers that medically fragile students in the elementary school setting can cause distress among teachers who may have to perform medical procedures with little to no training. The anticipated outcome is to have a better understanding of the teachers' needs while managing medically fragile students.

VI. Description of Participants and Recruitment:

Number of Participants: 10-25, depends on the number of students taking the summer course

Age of Participants: \_X\_ 18 and older \_ n/a\_ under 18 (specify age(s):

How are participants to be selected and recruited?

Participants have been chosen because they meet the requirements needed for the focus group in that they are elementary (K5-5<sup>th</sup> grades) school teachers and are easily accessed through their CSU summer class.

What is your relationship to the participants?

No relationship currently. The participants are taking an education class through CSU.

Compensation: If compensation is to be awarded for participation in the study describe below. Be specific. If no compensation will be given, state "none".

NONE

VII. Methodology: Explain exactly what the participants will be asked to do. Include the amount of time that each participant will need to devote to the study. Insert copies of any questions or surveys that will be given to the participants. Researchers should take care not to collect any data, especially demographics, unless doing so is necessary and they have specific plans to analyze or otherwise make use of the data. Explain how each

variable measured supports the purpose of your study. If this is part of a thesis or dissertation, insert the Methodology section of the thesis or dissertation proposal below. Use as much space as necessary.

Participants will be encouraged to take place in an open classroom discussion regarding their experiences with medically fragile students in the elementary classroom setting. Students will have the option not to participate in the discussion. The time is limited to one hour. No written survey will be conducted. No identifying demographic information will be gathered.

Here are the questions that will be asked of the participants.

Do you teach K5-5<sup>th</sup> grade students?

Do you teach Special Education classes?

Do you access to a school nurses for the entire school day?

Do you have medically fragile children in your classroom?

Have you ever been asked to administer any kind of treatment for the medically fragile child?

What types of treatments have you been asked to administer?

Have you received any type of training to administer treatments to medically fragile children?

How do you feel about been asked to administer treatment to medically fragile children? General responses will be noted with no identifying data for the participants. All information gathered will be used in developing a pilot survey to be administered to K5-5<sup>th</sup> grade teachers in a local school system. Once the survey has been piloted then another survey will be administered to a larger population of teachers of K5-5<sup>th</sup> grades.

VIII. Risks of Participation: List all physical, economic, social, and/or psychological risks. If the risks of harm to a participant are not greater than those ordinarily encountered in daily life or during the performance of routine physical or psychological examinations, then state no more than minimal risk. If, however, the protocol involves more than minimal risk, specify procedures for protecting participants.

Risk is minimal. The students who are teachers will be asked to share their experiences with researchers regarding medically fragile students in the classroom setting. Some participants may not feel comfortable discussing scenarios in which they did not know how to operate. They may feel uneasy discussing such a topic. If this happens than they will not be required to participate. At any time the students will be allowed to withdraw from the discussion. No identifying data will be collected and no rewards or punishments will take place due to their participating or not participating. As the teacher of record for this class, Dr. Hipps will not be involved in the discussion and will not be privy to who participates and who does not. So no student will be harmed by participating or not participating.

**IX. Benefits:** Describe the potential benefits to the participants and/or others as a direct result of this research project.

The potential benefit is that the teachers will have the opportunity to discuss the important topic of managing medically fragile students in the school setting and feel as though researchers are listening to their needs in hope of offering solutions to the dilemma. Once all survey results have been gathered and analyzed and the research process has been concluded, then education for the educators regarding this topic will be developed based on the needs ascertained by this study. The researchers hope to develop online modules for teachers to use as resources when called upon to administer care and treatment of medically fragile children.

**X. Informed Consent Process:** Explain the process through which you will provide the potential participant all the information they need to decide whether or not to participate. Append a copy of any written forms, cover letters, verbal scripts, and/or assent scripts that you will use. Waiver of the informed consent process is limited to research involving the collection or study of existing data, publicly available information, and observation of unmanipulated public behavior where data is recorded in such a manner that identifiers cannot be linked to individuals.

The reason for the focus group has already been discussed with the head of the education department as well as with the students taking the summer class. All participants are willing to help with the focus group. No consent form will be used for the focus group. Participants will be told that they are not required to participate in the discussion and will not suffer or benefit from the participation or non participation.

a. What types of information will be collected? Attach a copy of all survey instruments, interview questions, word or activity tests, etc.

In the focus group researchers will encourage participants to discuss the topic of medically fragile students in the teaching setting. For example, what types of "medically fragile students" scenarios they have encountered while teaching and what difficulties they had.

b. Will demographic information be collected? \_\_\_ Yes \_X\_ No *List all demographic information that will be collected if applicable:* 

No demographic information will be collected.

c. Will participants be identifiable to anyone? *If so, explain how their identity will be safeguarded:* 

Participants will not be identifiable to anyone. We will not be collecting names or any identifying information from participants.

d. For what purpose is the information being collected (e.g., publication, thesis)?

The information is being collected so that a pilot study can be produced and administered in Fall of 2012, to a selected group of elementary school teachers. Furthermore, based on study results, learning modules will be developed to better address the growing need of teacher assistance in the classroom with medically fragile students. Publication will follow. One of the principle researchers will also be writing her thesis based on results from the study.

**XI. Electronic Signatures:** This page may be submitted in hard copy if necessary. It may be faxed.

## Principal Investigator(s):

I understand and will abide by federal policy concerning human subjects research. In addition, I agree to:

- •Obtain approval from the IRB prior to instituting any change in project protocol.
- •Inform the IRB immediately of any unforeseen risks or adverse effects.
- •Keep signed consent forms, if required, from each participant for the duration of the project, including publications.
- •Submit a Continuation/Conclusion report at 12- month or shorter time intervals (as indicated on the approval letter).

I accept the responsibilities indicated above. I have attached a copy of my training certificate.

Signed: Cheryl M. Smith, EdD\_\_\_\_\_\_ Date: July 6, 2012\_\_\_\_\_ Principal Investigator 1 Signed: Mandy Cranney Date: July 5<sup>th</sup>, 2012

Principal Investigator 2

Faculty Advisor (if student-only project)

I have collaborated in the development of the research proposal described in the attached and have reviewed all of the information enclosed and will oversee the work described. I will endeavor to ensure that all of the PI responsibilities are fulfilled. I have read the protocol submitted for this project for content, clarity, and methodology.

Faculty Advisor (Please Print) Faculty Advisor's Signature Date

## Appendix B

## Script to be read before meeting with potential focus group

We realize that the economic downturn has affected many education budgets with many school nurse positions being eliminated. Also, more medically fragile children are enrolled in our elementary schools as a part of our inclusive enrollment policies. In our study we are interested in the needs of teachers (K5-5<sup>th</sup> grade) pertaining to the care of medically fragile children in their classrooms.

Our purpose today with you as a focus group is to discuss some issues you may encounter in your role as a teacher and the care you take of students who are medically challenged. The results of our focus groups will be used to develop a survey that will be administered to groups of teachers about this subject.

The anticipated outcome is to have a better understanding of the teachers' needs while managing medically fragile students. In the future we will develop education modules that will assist teachers in becoming more comfortable with various treatments and procedures they may have to administer to children in their classrooms.

If you volunteer to participate in our discussion today, we assure you that no identification of your participation will be made.....no demographic data will be obtained. There will be no repercussions should you decline to participate. If you do not wish to participate for any reason, you may leave before the discussion begins.

We appreciate your willingness to help us with our study.

### Ouestions:

- 1. Do you teach K 5 -5<sup>th</sup> grade students?
- 2. Do you teach Special Education classes?
- 3. Do you have access to a school nurse the entire school day? Part of a day? On call school nurse that covers several schools?
- 4. Do you have medically fragile children in your classroom?
- 5. Have you ever been asked to administer any kind of treatment or medication to a medically fragile child?
- 6. How do you feel about being asked to administer treatment to medically fragile children?
- 7. Have you received any education about care for medically fragile children?
- 8. If you had the opportunity to receive special training or additional instruction for medically fragile children, what would you say the most important topic would be?
- 9. Do you have any questions for us?

