A CONTENT ANALYSIS OF POLICIES AND PROCEDURES FOR SERVING CHILDREN WITH SPECIAL SCHOOL HEALTH NEEDS IN EARLY EDUCATION ENVIRONMENTS

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Children with special school healthcare needs (CSSHN) are entering early education environments with increasing frequency. Advances in medical technology and interest in providing early education in least restrictive environments are cited as the reasons for the phenomenon. Most often, full-time nurses are not available in such settings to care for the needs of children with medical complexities. And yet, case law dictates that the delivery of nursing services is indeed the responsibility of the local education agency and, furthermore, that such nursing services do not need to be related to a special education program in order to be provided (Diaz, 2000). This case law, coupled with a current overall shortage of school nurses, results in a certain conundrum for early educators (Barrett, 2000).

Literature is reviewed about the attitudes of teachers and other personnel, the delegation of nursing duties to unlicensed assistive personnel (UAP), and the needs of school entities and staff members in serving this population of children. Taken together, the studies indicate that the body of knowledge is growing about how to best serve children with such needs and that further study is needed to keep pace with medical advances that enable increasing numbers of children to access least restrictive environments.

Via this research, policies and procedures were gathered from early intervention service providers across the Commonwealth of Pennsylvania revealing the extent to which agencies have formalized planning for supports and services to CSSHN. The text from the policies and procedures was coded and analyzed to reveal the elements of service delivery to Children with Special School Health Needs (CSSHN) receiving early childhood special education (ECSE). The study concludes with a suggested framework for practice in serving CSSHN.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

PREFACE

Completion of this work leads me to reflect upon those who have helped me along the way. I am very appreciative of the support of my Pennsylvania MAWA colleagues, who supplied the data for this research. They are a group of extremely hard-working professionals, dedicated to the welfare of the young children they serve…a very special group indeed!

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I. INTRODUCTION

To participate in the stream of society is the norm for most, a dream for some, and the right of all. And yet, faced with the juxtaposition of finite levels of resources coupled with infinite levels of demand, educational leaders are confronted with difficult decisions. In an effort to make this point salient, four stories about children with special school health needs (CSSHN) are offered.

A. Stories of Children with Special School Health Needs: Habeeth, Krista, Tamoyya, and Charlie

1. Habeeth

Habeeth is a 39 month old boy whose family recently moved to Pennsylvania from Chandigarh, India. His father is a representative of the Ministry of Tourism for the Government of India. Though he is based in Pittsburgh, the father's assignment demands that he travel widely throughout the United States and Canada. Habeeth is cared for by his mother and maternal grandmother in their new home in a suburb of Pittsburgh. The sole language spoken by the mother and grandmother is Punjabi, their native language.

Habeeth is a gorgeous child with large brown eyes that avoid contact with others including his teachers and preschool friends. In addition to his language and communication barrier, he displays social issues that are of concern to his teacher. While his peers in his preschool setting enjoy pretend play, taking on personas of a variety of action figures in imaginary play scenarios, Habeeth prefers lining up his action figures in a corner of the classroom separate from the rest of the children. When his same-age peers congregate for the daily Circle Time, sitting on their designated mats, Habeeth ignores the cajoling of his teacher to join the group. He elects to spin on his right knee in his own isolative tight circle.

One morning, Habeeth's mother delivers him to preschool pointing to a new cast on his arm. Wordlessly, she gives the teacher a doctor's prescription with the words "Broken arm. Casted. Limit physical activity." The teacher wonders whether Habeeth should indeed be in attendance at preschool, and how she will limit his physical activity given his reluctance to engage in appropriate preschool activities.

2. Krista

Krista is a 4 year old with the distinction of being 1 in 30,000 children who experiences anaphylaxis. Krista experienced her first anaphylactic reaction when romping in her neighbor's backyard swimming pool area. She inadvertently stepped on an underground hornets' nest resulting in swarming and stinging of multiple locations on her stomach, arms and legs. Her skin immediately developed bright red blotchy patches, her mouth and throat area swelled resulting in gasping for breath. Krista was rushed to the emergency room of the local hospital, treated for a moderate anaphylactic reaction, and released.

When Krista's mom later had allergy testing conducted, it was learned that Krista is allergic to a variety of foods, and bee stings. Krista's food allergies include shellfish, peanuts, tree nuts, and eggs. The allergic reaction Kristen experiences is multi-systemic involving her skin and swelling in her respiratory tract. For Krista, symptoms occur within minutes after contact with the allergy-causing substance; the anaphylactic reaction is diagnosed as moderate and short-term.

When presented with this information, Krista's child care teacher has many questions. She wonders what allergens may be present within the child care setting and how she can purge the setting in order to assure that Krista will not have exposure to them. She also worries that, in the event Krista does experience an anaphylactic reaction in the child care setting, the response needs to be immediate and appropriate. Who will respond and how? What are the potential risks during trips into the local community and field trips? Also, what will happen for the rest of the children while care is being conducted for Krista in the event of an allergic reaction?

3. Tamoyya

Tamoyya lives with her mom in a public housing community on the outskirts of a major metropolitan area. The identity of Tamoyya's father is unknown. Her mom is a caring mother who wishes to improve upon her living condition so that her daughter "grows up better" than she did. Consequently, Tamoyya's mom is working hard in a training program for single impoverished mothers; she also has a part-time job at a local fast food restaurant. Needing care for Tamoyya, she co-enrolled her in a full day, full year Head Start Program located within her community center and in a local child care setting for care before and after the Head Start program.

Upon enrollment into the Head Start Program, Tamoyya's Mom informed the social worker that Tamoyya was born with a genetic skin disease called Congenital Ichthyosiform Erythroderma (CIE). The disease causes Tamoyya's skin to have a reddened, scaly appearance; she has neither eye lashes nor eyebrows. CIE also results in an associated increased susceptibility to infection due to skin fragility. Environments in which Tamoyya lives and plays must be cleansed frequently; Tamoyya's skin must be lubricated with an emollient every 2 hours. Tamoyya must be protected from skin abrasions or tears. Another issue is that Tamoyya is unable to tolerate heat. In the Head Start setting, the environments include the classroom, library, outdoor play area, the mini-bus, and environments traveled to during field trips. There is no cure for this ichthyosis, only prescribed treatments to help manage Tamoyya's symptoms.

For Tamoyya, CIE is a life-long, disfiguring disease. CIE has already resulted in numerous social and psychological implications for Tamoyya during her pre-kindergarten years. Children in her neighborhood and her Sunday School class have teased her because of her appearance. She has not had playmates in her 3 years, other than her mother.

Upon entry to her Head Start setting, staff members notice that Tamoyya attempts to gain entry into play situations by hitting her preschool counter-parts or robbing them of the toys with which they are playing. The staff has ideas about how to encourage inclusion for Tamoyya into her peer group of preschool friends. But the staff finds themselves in a quandary about how to create a safe, healthy environment for her in view of her ichthyosis.

4. Charlie

Charlie is a vibrant 5 year old excitedly preparing to transition from his early intervention setting to his neighborhood kindergarten. His next door neighbor, Jack, and his cousin, Theresa, will be 2 of his 18 classmates. Charlie has a diagnosis of Duchenne Muscular Dystrophy (DMD), a genetic, degenerative disease primarily affecting voluntary muscles. Recently, Charlie has experienced a surprisingly aggressive and progressive decline of motoric function. Though Charlie has had surgery for hip tendon release to prevent disabling contractures, he remains a wheelchair user. His physical therapist has prescribed a regiment of daily stretching exercises to keep his range of motion as flexible as possible; however, he is not able to complete these exercises without the support of an adult. He is experiencing a generalized weakness and muscle wasting affecting his hips, pelvic area, thighs and shoulders. Though Charlie was potty trained at 2 years 6 months, he is now incontinent due to degeneration of muscle tissue. He therefore needs to be cleaned and changed on a regular basis.

Charlie's lungs are also adversely affected by DMD resulting in severe respiratory insufficiency from weakened diaphragm muscles. He now has a tracheotomy, and a portable ventilator. His preschool staff members needed to learn how to use an oximeter to measure Charlie's blood oxygen levels.

Aerosol therapy has recently been prescribed for Charlie so that bronchodilators can be administered. This medication is administered to open and clear his airways. Charlie's nebulizer turns this liquid medication into a fine mist that can be inhaled. A small air compressor is attached to the nebulizer to generate a flow of air. Charlie must breathe slowly and deeply through the nebulizer for 15 to 20 minutes three to four times a day. Charlie needs a manual cough assist maneuver to be administered so that his airways remain clear.

A swallow study indicates that Charlie had an impaired gag reflex allowing liquid to enter his lungs. As the risk of aspiration and infection of the lungs is deemed to be ever-present, Charlie receives his nourishment through a Percutaneous Endoscopic Gastrostomy (PEG) feeding tube. This tube is inserted into the stomach through a surgically implanted "button" at the incision site. Care must be taken by school staff in cleanliness, food handling, cleaning of the site and tube, leakage around the insertion site, and purulent drainage (pus) around the tube. The insertion site must be cleaned several times a day.

Charlie's health status changes from day-to-day. Needless to say, poorly functioning muscle, gastrointestinal, and respiratory systems can be life-threatening. Though he loves preschool, his absenteeism is high due to frequent surgeries, time needed for recovery, and infection. He talks about going to the “big school” all the time, and wanting to play with Jack and Theresa in kindergarten. But Charlie’s mom and his Early Intervention teacher fret about the school’s ability to respond to Charlie’s extensive health needs.

B. *Considerations*

For Habeeth, Krista, Tamoyya, Charlie and many children with special school health needs (CSSHN) and their families, accessing regular environments in local communities and schools continues to remain a tenuous or even an unattainable dream despite the clearly allocated responsibility of provision of nursing services by educational entities subsequent to the Cedar Rapids Community School District v. Garrett F. (526 U.S. 66, 1999) case. For young CSSHN, the dream becomes even more elusive because the supports and services available in public school settings may not be as readily attainable in early care and education environments. In recent years, educators have been faced with the challenge of determining how to serve CSSHN in least restrictive educational environments. This is a population of children that teachers may know how to educate while feeling uncertain about how to maintain healthy and medically safe environments.

This dissertation considers the current status of service for CSSHN by investigating what educators know about this topic to date, what educators may learn from research findings in related fields (e.g. medicine and law), and what is yet to be determined about serving CSSHN in educational environments. The study addresses the current status of service to preschool-age CSSHN in one state through a content analysis of written policies and procedures guiding the practice of service for these children subsequent to the 1999 Cedar Rapids case.

C. Definitions

This paper investigates service to young children with special school health needs (CSSHN) educated in least restrictive educational environments. The population of CSSHN is a subset of a larger population, Children with Special Health Care Needs (CSHCN). This larger group is defined using a broad definition which results in identification of a great number of children in this category. This definition, developed by McPherson, Arango, and Fox (1998) is:

> CSHCN are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (p. 137).

This definition is currently utilized by the Maternal Child Health research study currently being conducted nationwide (U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, 2008). This study will be discussed later in this paper. However, the reader must note the broad overarching aspects of the definition of CSHCN results in approximately 16-17% of the total school population falling into this category (van Dyck, McPherson, Strickland, Nesseler, Blumberg, & Cynamon, 2002). This encompassing definition includes children who are “at increased risk for” medical conditions. It also includes children with developmental, behavioral, or emotional conditions.

As the definition of CSHCN is a broad one, it is notable that not all of the children who fall into this category have needs that have implications for school. A portion of the total population of CSHCN are children that educators may know how to teach, but may not be trained to serve from the perspective of health maintenance and care. These are the children who require health supports and services in order to access their educational program and attend school in a safe, healthy manner. These are the children who are the focus of this paper. As there is no universally accepted definition of the population, and in order to assure clarity for the reader, this author proposes a new term to define the subset of CSHCN whose conditions have implication for school environments. The term is children with special school health needs (CSSHN). The population includes both children served under IDEA and those protected by Section 504 of the Rehabilitation Act. For the purposes of this paper, and benefiting from the contributions of other authors, the population of CSSHN can be defined as

> those children who, due to temporary, or chronic medical condition or illness, require ongoing monitoring, assistance, equipment, devices, or technology to sustain life or health within school settings.

CSSHN is the term that will be used for the purpose of this study. Other authors have used related terminology to describe children who may be part of this group. For example, the terms “children with medical fragility” and “children who are technologically dependent” may refer to similar populations. Another term found in the literature is “children with complex health care needs.” In some literature, those terms are used interchangeably.

Several authors have offered definitions using varying terminology and specificity. In an address to the International Early Childhood Conference on Children with Special Needs, Bruder (1990) proposed that “children with special health care needs are those…who have a chronic illness and/or who require technology or ongoing support for survival." CSSHN also have been defined as having a wide range of disabilities and illnesses with health conditions ranging from mild to severe and whose need could be of a short term, intermittent, or chronic nature (Koop, 1987).   Chronic illnesses have been defined by the American Academy of Pediatrics (1990) as "conditions that last at least three months, (and) require extensive hospitalization or in-home health services” (p. 636).

Other terminology has been used in reference to the same or closely related populations of children. Definitions of terms such as “medically fragile” and “technology dependent” are also descriptive in considering this population of children. “Medically fragile children are those children who require specialized technological health care procedures for life support and/or health support during the school day...they may or may not require special education” (Council for Exceptional Children, 1988, p.5). In its 1987 report to Congress, the Office of Technology Assessment defines a child who is technology dependent as "one who needs both a medical device to compensate for the loss of a vital body function and substantial and ongoing nursing care to avert death or further disability" (p. 6). Some authors have defined students supported by medical technology as those children receiving procedures such as tube feedings, clean intermittent catheterization, dialysis, as well as use of equipment such as tracheotomy tubes, oxygen tanks and ventilators (Heintz-Caldwell, 1997). Another definition of a technology dependent child has been put forth as a child who has a chronic disability and requires routine use of a specific medical device to compensate for the loss or use of a life sustaining body function and requires daily, ongoing care and monitoring by trained personnel (Task Force on Technology Dependent Children, 1988).

In some cases, a child’s medical complexity results in eligibility for special education as defined in the Individuals with Disabilities Education Act (IDEA). This would occur if the child meets the definition of a child with Other Health Impairment, thus, demonstrating a need for the delivery of specially designed instruction in educational settings (IDEA, 1997). The IDEA defines a child with Other Health Impairment as

> having limited strength, vitality or alertness, due to chronic or acute health problems such as a heart condition, tuberculosis, rheumatic fever, nephritis, asthma, sickle cell anemia, hemophilia, epilepsy, lead poisoning, leukemia, or diabetes that adversely affects a child’s educational performance (34 C.F.R.§300.7 (b)(8)).

In other cases, a child may possess medical fragility or a special health care need and demonstrate no need for specially designed instruction. Instruction for these children can occur in a fashion commensurate with same-age peers in spite of the fact that a special health care need exists. In those cases, a child may be declared a ‘protected handicapped student’ and, in Pennsylvania, receive Chapter 15 services as specified under PA State School Code (Bard, 1991), Section 504 of the Vocational Rehabilitation Act (1973), and the Americans with Disabilities Act (ADA,1990). Therefore, CSSHN may or may not require special education (Sirvis, 1988).

The term “early education environment” also requires definition. Public and private community settings that serve children from ages 3 to 5 are included in this definition. This would encompass environments such as preschool, childcare, Head Start programs, and early intervention classrooms, services, and programs.

D. Prevalence of the Population

Determining the prevalence of any population is highly predicated upon use of a universally agreed upon definition; this is a definition that the fields of medicine and education have yet to determine. Thus, the true prevalence of CSSHN is unknown (Lehr, 1990). It is known that chronic illness has been estimated to affect from 10 to 15% of the population of school children (American Federation of Teachers, 1997). In 1987, it was estimated that there could be as many as 17,000 to 30,000 children who are technology dependent (Office of Technology and Assessment, 1987). The frequency of children assisted by medical technology in the general population has been estimated at 1 or 2 per 1,000 (Heintz-Caldwell et al., 1997; Palfrey et al., 1991). The most recently published Section 619 Profile notes that 2.2% of all preschool age children receiving early intervention services are eligible under the eligibility category of “other health impairment" (Danaher, Kraus, Armijo, & Hipps, 2003). Thus, it is reasonable to assume that the population of CSSHN is a low incidence one, with an undetermined number of children affected.

In the Twenty-seventh Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act (2005), the U.S Department of Education notes that the number of students ages 6 to 21 with disabilities served under IDEA has continued to grow at a steady rate, rising from 8.1% of the total school population in 1993 to 9.1% in 2005. This represents a difference of 1.2 million children served in IDEA across the nation.

The other health impairment category experienced substantial growth in both the number of children served, and as a percentage of all children with disabilities (p. 33). At first examination, the reader might conclude that these numbers indicate that the prevalence of CSSHN is rising. However, it is notable that the OHI special education category is being used by some local education agencies to qualify and serve children diagnosed with Attention Deficit Hyperactivity Disorder (ADHD), which is also a rapidly rising population. Thus these US DOE statistics cannot assist the reader in ferreting out the characteristics of the children being served through the OHI category and which portion truly have health conditions that result in a special need in school.

It should be noted that the U.S. Department of Health and Human Services has commissioned an effort entitled Healthy People 2010. As part of that effort, the Maternal Child Health Bureau, Division of Services for CSHCN has set forth goals for the development of services for this population. One associated activity is the National Survey of CSHCN that will be conducted annually. This survey has provided information on prevalence, services, and barriers both by state and nationally (U.S. Department of Health and Human Services, 2001).

Using the broad definition of MCH, this survey estimates that 16-17% of the total population of school-age children fall within the category of CSHCN. The children who are the concern of this study are a subset of this population. They are those children who need special consideration due to their health concerns within school settings.

E. Location of Service Delivery

Traditionally, CSSHN and medical fragility have been routinely assigned to special education centers or, if thought to be medically necessary, to hospital programs, which may or may not have had an educational component (Sirvis, 1988). In either setting, full-time medical personnel are typically on staff. In the case of the special education center, at least one full-time registered school nurse is on-site at all times. This enables medical procedures to be administered, medical conditions to be monitored and educational staff to receive advisement on medical conditions from the school nurse who is in attendance daily and familiar with each child and his or her medical condition. However children with disabilities, including those with special health care needs, are no longer being routinely assigned to special education centers.

During the 2003-2004 school year, preschoolers with developmental delays or disabilities served under the IDEA were served in a variety of placements, namely: 34 % in typical early childhood settings; 32.4% in early childhood special education settings; and 16.4% in shared programs in which children were supported part-time in early childhood settings and part-time in early childhood special education settings. An additional 2.9% were served at home; 10.4% were supported with itinerant services outside of the home; 2.7% attended a separate school; 1.1% children were served in a reverse mainstreaming setting; and 0.1% lived in a residential facility. Taken together, these data indicate that 60.8% of preschoolers with developmental delays and disabilities were served in typical early childhood settings for at least all or part of their program day (U.S. Department of Education, 2005). This means that schools and neighborhood settings such as private child care centers and preschools, Head Start, and inclusive early intervention programs administered by public schools are the places in which early intervention services are being delivered to children with disabilities, including those with special health care needs and medical fragility (National Association of State School Nurses, Inc., 1995).

F. The Challenge

The challenge of provision of service for CSSHN in safe, healthy ways within least restrictive environments is the consideration of this study. The challenge relates to issues as far-ranging as agency policies and procedures, teacher preparation and attitudes, environmental concerns and constraints, and changing health status of the population of children served.

The reasons we face this challenge are as diverse as the persons, educational entities, and situations involved, but include 3 prevalent themes: 1) advanced medical technology; 2) federal and state mandates to serve children within least restrictive educational environments; and 3) the Healthy People 2010 initiative.

1. Advanced Medical Technology

Advanced medical technology is responsible for increasing the survival rate of children who heretofore may not have survived congenital anomalies, challenging medical conditions, or fatal illness (American Federation of Teachers, 1997). Consequent to these advances, children who have undergone life-threatening birth experiences or surgeries are surviving, coping with health-related anomalies in their young lives, and coming to school ready to learn. Equipment and systems such as ostomies, ventilators, and tracheotomies enable children to enter and participate in community settings and engage in developmentally appropriate child-centered activities.

Technology such as portable suction machines and ventilators are now light-weight and compact enough for small children to transport from place to place at home, play, and in community settings (Office of Technology and Assessment, 1987).

2. Federal and State Educational Mandates

The reasons for this challenge to the educational system cannot be fully understood without an overview of the legal dictates surrounding service to CSSHN. An understanding of federal and state statutes, as well as the case law resultant from judicial rulings concerning children with medical fragility provides educators with knowledge of their obligation and responsibility in service provision.

On a federal level, the IDEA defines students with disabilities by disability category (34 C.F.R. § 300.7 (a)(1)). One disability category is Other Health Impairment; CSSHN may fit into this or another of the 12 disability categories identified by IDEA. The IDEA ensure(s) that all children with disabilities have available to them a "free and appropriate public education (FAPE) that includes special education and related services to meet their unique needs" (34 C.F.R.§300.1 (a)). IDEA gives children with medical issues the right to come to school; consequently, districts have the obligation to serve these children in public school settings.

Public Law 99-457, which was passed in 1986, extended PL 94-142, the Education for all Handicapped Children Act to include preschoolers with developmental delays and disabilities. Thus, many young CSSHN are becoming the responsibility of school systems at three years of age (Lehr & Noonan, 1989). The federal law contains a least restrictive environment (LRE) clause which dictates that children with disabilities be educated with non-disabled peers to the maximum extent appropriate (C.F.R.§300.550(b)(1)). It further stipulates that

> special classes, separate schooling, or other removal of children with disabilities from the regular educational environment occurs only when the nature or severity of the disability of a child is such that education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily" (20 U.S.C. § 1401 Section 612[a][5][A]).

For CSSHN, fulfilling the LRE requirement often means providing special educational services in community schools with the supports from school health services (Sobsey & Cox, 1991). "Least restrictive environments" for children under 5 years include community preschools, child care centers, and neighborhood Head Start classrooms. As a result, children who are eligible for early intervention who have special health care needs are entering these settings with increasing frequency (Lehr, 1990; National Association of State School Nurse Consultants, Inc., 1995). However, these settings do not typically have staff available and trained to provide the types of health care services often needed by CSSHN.

Both the National Association of School Nurses and the American Federation of Teachers support the inclusion of CSSHN in the least restrictive environment given appropriate supports (American Federation of Teachers, 1997; National Association of School Nurses, Inc., 1994). They make the point that the school nurse must be a vital member of the interdisciplinary team when formulating plans for students with health care needs to be integrated into regular education environments.

The IDEA defines the term "related services" as "transportation and such developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education…" (C.F.R.§300.16(a)). Related services may include such supports as school health services, social work services in schools, and parent counseling and training. Among the related services included in the IDEA are "medical services for diagnostic or evaluation purposes," which are particularly pertinent when considering CSSHN (C.F.R.§300.16). The IDEA states that

> such medical services shall be provided by a licensed physician for diagnostic and evaluation purposes only as may be required to assist a child with a disability to benefit from special education, and include the early identification and assessment of disabling conditions in children (C.F.R.§300.16 (b)(4)).

The IDEA makes a distinction between medical services and school health services. Some medical services may be acceptable as related services if they are provided by a licensed physician to diagnose and/or evaluate a child's condition related to eligibility determination or programming for special education and related services. However, IDEA does not require schools to provide medical services that may be needed by a child on an ongoing basis to treat a medical condition. On the other hand, school health services are provided by a school nurse or other qualified person and may include services such as health screening and assessment, clean intermittent catheterization, administration of medication, lifting, handling, and positioning of children, and so on (C.F.R.§300.7(b)(11)).

Another federal law, Section 504 of the Vocational Rehabilitation Act of 1973 (P.L.93-112) prohibits discrimination of individuals with disabilities by institutions receiving federal aid. This civil rights law applies to individuals with disabilities, whether eligible for special education or not. Children who have health care issues and do not qualify for services under the IDEA, will qualify for services and supports under Section 504, as much as those services are necessary for the child to attend and benefit from school (29 U.S.C.§706(8)(b)).

The Americans with Disabilities Act of 1990 (P.L. 101-336) extends and strengthens Section 504 of the Vocational Rehabilitation Act by prohibiting discrimination against individuals with disabilities in participation of all activities of public entities, whether federally funded or not. Thus, rights are extended to arenas such as preschools, children's entertainment venues, child care centers, restaurants and shops.

State law must mirror or exceed federal law in protections. The Commonwealth of Pennsylvania establishes its school law in the Pennsylvania School Code. Special education services and programs are delineated in Chapter 14 of the PA State Code. The responsibilities to students with exceptionalities with regard to free and appropriate education, least restrictive environment, and related services, are the same as federal law or more stringent, as defined in Chapter 14.

Chapter 15 of the PA State Code is the Commonwealth's parallel to the federal Section 504 of the Vocational Rehabilitation Act. Chapter 15 relates to protected handicapped students, those students who are of school age and "have a mental or physical disability which substantially limits or prohibits participation in or access to an aspect of the student's school program; and (are) not…eligible as defined in Chapter 14" (Bard, 1991). These students have a right to:

> related aids, services, or accommodations which are needed to afford the student equal opportunity to participate in and obtain the benefits of the school program and extracurricular activities without discrimination and to the maximum extent appropriate to the student's abilities (Bard, 1991).

It is thus possible for CSSHN to fall within the protection of the Individuals with Disabilities Education Act, Section 504 of the Vocational Rehabilitation Act of 1973, the Americans with Disabilities Act of 1990, or the PA State School Code Chapters 14 or 15.

Each state also has a Nurse Practice Act. Although the Nurse Practice Act of each state is unique, generally these laws require that nursing functions be performed only by those persons licensed to practice nursing. The nurse may train and delegate nursing duties to other people. These persons are sometimes referred to as Unlicensed Assistive Personnel (UAP). Unlicensed Assistive Personnel (UAP) may perform nursing duties only after training and delegation of a licensed nurse. The term delegation has been defined as "transferring to a competent individual the authority to perform a selected nursing task in a selected situation" (National Council of State Boards of Nursing, 1995, p. 38). However, the nurse continues to be responsible for those activities and is liable should a mishap occur (American Federation of Teachers, 1997). The Nurse Practices Act of Pennsylvania does allude to and permit "health teaching" but there is no mention of delegation or supervision of nursing duties in the PA Act at this time.

3. Case Law

An examination of the plethora of case law that exists on serving CSSHN in educational settings is in order. This is a body of information that is not easily summarized, nor is it cohesive. A degree of variability exists across the outcomes of the cases; simple deductions are difficult to make about the predisposition of the courts (Thomas, 1999). A review of related cases reveals that at times, the justice system has found for the families of children with medical fragility; for the districts serving those children; and some cases have had mixed outcomes.

One milestone case that had great implication for those served by IDEA was Timothy W. v. Rochester, N.H. School District (875F.2d 954 (1989)). In this case, the school district contended that, due to the severity of his disabilities, Timothy could not benefit from an educational program and denied the child access to a public education. The court sided with the family and wrote " the Act adopted a 'zero reject' principle which brings within its protective ambit a wide range of handicapped children who require special education and related service" (Wiseman, 1994). This germane point to this case is the right for all to be educated, regardless of the level of severity of the disability.

Another landmark case was that of Irving Independent School District v. Tatro (Id at 892 & n. 10, 104 S. Ct. at 3377 & n. 10., 1984). In this case, the court ruled that the clean intermittent catheterization required by a child in order to attend school represented a related service. The court further declared that "excludable medical services" are only those that must be provided by a physician. Services provided by a school nurse or other qualified personnel are considered to be "school health services" and thus are the responsibility of the district.

A more recent case that echoes the Tatro decision was that of Cedar Rapids Community School District v. Garrett F. (526 U.S. 66, 1999). In this case, a child who was paralyzed from the neck down due to a motorcycle accident at age 4 needed extensive full-time nursing assistance to progress through the school day. Services such as clean intermittent catheterization, suctioning of a tracheotomy, monitoring a ventilator, assistance in positioning, handling, mobility, eating, drinking, and so on, were required by this child. Garret was a wheelchair user and tracheotomy dependent. A bright child, Garret was found not to require any modification in his educational program. The school district contended that assumption of the cost of Garret's medical needs would place an undue burden upon the district. The Supreme Court upheld the decision of a lower court that held that these services were appropriate for the district to provide (Bartlett, 2000). It was also determined that as these services were necessary for this child to access general education and thus did not necessarily need to be related to a special education program (Diaz, 2000). In the event that a special education program did not exist it was nevertheless the obligation of the district to provide nursing services on a "stand alone" basis. It is interesting to note that the Tatro case was decided 15 years prior to the Cedar Rapids case and had a similar ruling: a clear and consistent message that nursing services are the responsibility of educational entities.

4. Healthy People 2010

A clear reason for this challenge is the federal call to action entitled Healthy People 2010. A part of the President's New Freedom Initiative, Healthy People 2010 is a 10-year action plan to achieve community-based service systems of care for CSHCN and their families. The Maternal Child Health Bureau (MCHB), Family Voices, the American Academy of Pediatrics, the March of Dimes and many other partners are participating in this initiative. Healthy People 2010 encompasses 6 goals including:

i. All CSHCN will receive coordinated ongoing comprehensive care within a medical home.

ii. All families of CSHCN will have adequate private and/or public insurance to pay for the services they need.

iii. All children will be screened early and continuously for special health care needs.

iv. Families of CSHCN will partner in decision-making at all levels and will be satisfied with the services they receive.

v. Community-based service systems will be organized so that families can use them easily.

vi. All youth with special health care needs will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and

> independence. (Division of Services for Children with Special Health Care Needs, 2001) (p.2)

Measurement of the outcomes for these 6 objectives is occurring within 6 states that are conducting pilot projects. Those states are: Arizona, Ohio, Oregon, South Carolina, Vermont, and Utah. This national initiative presents a reason to meet the challenge of serving CSHCN within inclusive environments.

The Healthy People 2010 initiative has a clear impact upon the education of CSHCN. As families are seeking, demanding, and procuring community-based, coordinated, comprehensive systems of care, they are better able to care for their CSHCN in their homes. Thus, local community schools become the obvious choice for educational service delivery. These local educational settings need to join together with medical providers to ensure that programming is not only educationally sound, but medically safe and healthy for this population of children. The target population addressed in this dissertation is a subset of the total population of CSHCN; it is the population of children for which their medical condition presents the need for accommodation within school environments, the population of CSSHN.

G. Nursing Services in Educational Settings

1. Lack of Nursing Personnel

The identification of appropriate personnel to plan for, train, and deliver medical services to CSSHN proves not to be a simple matter. Whereas nurses working in hospital settings are practicing in a medical environment among doctors and nursing colleagues who are medically trained and oriented, school nurses practice in an educational environment isolated from other trained medical personnel. Children served in neighborhood community early educational settings, nevertheless, may have needs equally as special as those children residing or served in health facilities. Some of the special health care needs that children within educational settings may have include insulin-dependent diabetes, tachycardia, life-threatening asthma, tracheotomy maintenance and care, clean intermittent catheterization, and detailed routines for skin care associated with ichtheosis, to name a few (Hootman, 1994).

As discussed above, there may be one school nurse assigned to a special education center. In neighborhood schools, however, the assignment of a school nurse is variable. Recommended practices have been established by national nursing organizations about the ratio of school nurses to students served. In school settings, one full-time registered nurse is recommended for every 750 students in typical school-age populations by the National Association of School Nurses (NASN, 1995). For students with disabilities, the recommended ratio is one full-time registered nurse for every 225 students, or in the case of students with severe and profound disabilities, the NASN recommends one full-time nurse for every 125 students (Bauer & Wolmut, 1992; Luckenbill, 1996). Despite these recommended ratios, however, a national membership survey conducted by the NASN indicated that the typical school nurse is responsible for 1,280 students (National Association of School Nurses, 1993). The shortage of school nurses increases caseloads and exacerbates problems related to safe, effective nursing services (Heller, Fredrick, Best, Dykes, & Cohen, 2000).

Statistics from one state reflect the low prevalence of nursing personnel in public schools. In Pennsylvania, in the 1997-98 academic year, there were approximately 8,000 school buildings. To meet the needs of the students within those buildings, there were 1,900 school nurses (Reynolds, 1997). It can be deduced, therefore, that most school buildings in Pennsylvania receive the services of a school nurse little more than one day per week. Nationally, there is one school nurse per 1,500 children (Barrett, 2000). This low prevalence of nursing supports in schools coupled with the proliferation of children entering school systems with special health care needs and medical fragility, are two trends that are counterpoised and challenging to school systems.

The dynamic tension created between the low presence of school nurses and the increasing presence of CSSHN in schools makes it difficult for school administrators to plan and deliver services for this population of children. Yet at least one professional organization asserts that school nurses must be involved in the development of policies, protocols, and procedures for the administration of health services and medical interventions to students with special health care needs (National Council of State Boards of Nursing, Inc., 1991).

This dismal situation worsens when focusing upon community childcare centers located outside of school settings. Though childcare centers are carefully regulated by the Department of Welfare and must abide by stringent health and safety regulations, those regulations are universally applicable and focus upon provision of general health, well-being, and safety for all children. Such regulations are not specific to maintenance of health care for medically special students. There are no health regulations for preschools. There are no requirements nor is there capacity for childcare centers or preschools to provide nursing services to children who need such care.

Head Start programs do have a health component as defined in the Head Start Program Regulations and Program Guidance Part 1304.20, Administration on Children Youth and Families (ACYF, 1999). That service area may or may not be overseen by a registered nurse within the grantee’s or delegate’s program. Such a staffing assignment is not mandated by the federal Head Start Performance Standards. Also, the Head Start regulations are pointed toward ensuring the general health and well-being of all enrollees, and do not make specific provisions for individuals with special health care needs.

2. Delegation of Nursing Duties to Unlicensed Assistive Personnel (UAP)

As school nurses are largely scarce or absent from school staff configurations, and almost never present on the staffs of childcare, preschool, or Head Start sites, the issue of who will plan, coordinate, and deliver health care services to children with special school health needs in early education settings is paramount. One solution to the dilemma involves the procedure of delegation of nursing duties to unlicensed assistive personnel (UAP). On a national level, nurses receive guidance on matters about delegation of nursing duties from documents published by the American Nurses' Association (1992) and the National Association of State Boards of Nursing (1995). In addition, two organizations addressing the specific needs of school nurses, the National Association of State School Nurse Consultants (1995) and the National Association of School Nurses (1995 & 2005), have published documents on supporting the medical conditions of children with health care needs in school settings. In fact, the National Association of School Nurses published a clarification of the appropriate procedure for delegation of nursing duties to UAP in school settings in a consensus statement (2005). Furthermore, various states have adopted differing postures around the issue of delegation of nursing duties to UAP within their Nurse Practice Acts. The Commonwealth of Pennsylvania allows health teaching by licensed nurses. No mention, however, of delegation or supervision is included in the Pennsylvania Nurse Practice Act (Krajicek, 1995).

The American Nursing Association (1992) defines a UAP as “an unlicensed individual who is trained to function in an assistive role to the licensed nurse in the provision of patient/client activities as delegated by the nurse. The activities may generally be categorized as either direct or indirect care” (p. 51). UAP are “any unlicensed personnel, regardless of title, to whom nursing tasks are delegated" (National Council of State Boards of Nursing, Inc., 1995, p. 39). Delegation is "the transfer of responsibility for the performance of an activity from one person to another while retaining accountability for the outcome" (American Nurses Association, 1992, p. 51). Said another way, delegation is the "transferring to a competent individual the authority to perform a selected nursing task in a selected situation" (Hansten &Washburn, 1998, p. 9). Delegation can be conceptualized as a managerial tool that nurses may use in order to organize tasks to meet the needs of patients in their care. One advantage of delegation may be that it improves the quality of care because it increases the number of individuals available to provide care while also freeing nurses to spend increased time on specialized nursing tasks that require more professional knowledge and judgment (Hansten &Washburn, 1992).

In early education settings, UAP may include a plethora of individuals such as health aides, certified nursing assistants, teachers, classroom paraprofessionals, or the school secretary. Nursing supervision of UAP consists of “the active process of directing, guiding, and influencing the outcome of an individual's performance of an activity" (American Nurses’ Foundation, 1994, p. 53). Supervision can be on-site (with the RN physically present or immediately available) or off-site (the nursing supervisor provides guidance through written or verbal communication). The professional nursing judgments of assessment, evaluation, and care planning may not be delegated (National Association of School Nurses, Inc. 1995).

In their book *Clinical Delegation Skills: A Handbook for Professional Practice*, Hansten and Washburn (1998) advise that nurses must know the parameters of the Nurse Practice Act in the state in which they are practicing and know the rules and restrictions of the agency in which they are employed. Nurses also must know themselves and their personal strengths and challenges when considering delegation of nursing duties, and understand the tasks that need to be accomplished. The nurse must give thought to the delegate and his or her capacity to perform selected tasks. Feedback to the delegate and evaluation of the delegated tasks and activities must occur. Ongoing monitoring and adjusting of the delegated nursing duties must also be in place in order to ensure maintenance of skills by the delegate, as well as responsiveness to changing patient needs. Thus, the Hansten and Washburn model of delegation of nursing duties to UAP views delegation of nursing duties as a dynamic process as opposed to a singular event.

Barriers to delegation of nursing duties to unlicensed personnel include: attitudes such as a nurse's belief that (s)he can perform all nursing tasks more proficiently than other personnel; the belief that teaching takes too much time; the feeling that the nurse will no longer be a "real" nurse if nursing duties are delegated; lack of trust in the skills and abilities of others; and a preference for working alone as opposed to part of a nursing team (National Association of State School Nurse Consultants, Inc., 1995). The delegation of nursing duties to UAP is undeniably a cost saving measure. Nevertheless, it must be decided when quality and integrity of the health procedure suffers due to the delegation. Managers and supervisors of nursing services must be responsible for the health and safety of the patients served (Tri-Council for Nursing, 1995). However, measuring the efficacy of use of UAP in delivery of health services in schools is difficult due to the low incidence of the population of CSSHN in schools (Schwab & Haas, 1995).

3. Use of Paraprofessionals and Other School Personnel

Similar to the nursing regulations, the American Academy of Pediatrics recommends "when paraprofessionals are part of the school health team, their performance of nursing services should be directly supervised by a professionally prepared and licensed school nurse." The Academy further asserts that "if paraprofessionals are used to perform specialized caretaking procedures, the school physician or school nurse should determine competence, conduct inservice training, and then provide regular supervision and documentation of the paraprofessionals' competence" (Committee on School Health, 1987, p. 78).

The question of how best to serve CSSHN in schools is a closely related issue to the delegation of nursing duties to unlicensed assistive personnel. One group to address that question was the Council for Exceptional Children (CEC). Specifically, a subcommittee of the Division of Physical and Health Disabilities (DPHD) of the CEC was convened to identify the critical issues related to service to CSSHN in school environments. The DPHD developed a two-part position statement on specialized health care procedures in schools. The first part addresses school personnel and their obligation to maintain a safe, healthy environment for students in collaboration with other personnel in the school. Educators must know the major problems and emergencies that could arise; they must have a plan in place to address emergencies, and assure that universal health care precautions will be followed, and that first aid and CPR will be delivered when necessary. The second part of the position statement asserts that specialized health care procedures should be viewed as self-help, or independent living skills, to the greatest degree possible. This assures that educators will provide appropriate instruction in these areas to insure maximal independence for students (Division for Physical and Health Disabilities, 1999).

Another group to tackle the issue of service to persons with special health care needs in community settings is The Association for Persons with Severe Handicaps (TASH). This group revised the position statement "TASH Resolution on Individuals with Special Health Care Needs Including Individuals with HIV" in March, 2000. Similar to the DPHD statement described above, this declaration calls for a full-range of community-based medical and human services supports for persons with special health care needs including those with HIV. It also calls for supports that will enable maximal independence for this population (TASH, 2000).

H. Summary

The term children with special school health needs (CSSHN) was coined to refer specifically to children whose medical conditions result in school health needs. This term was offered in an attempt to plan for and address the subset of CSHCN whose medical conditions result in the need to make accommodations within school settings. About 1 to 2% of the total school-age population has special school health needs.

This population of young children must be educated in least restrictive environments including community daycare, family daycare, Head Start, and preschools. This location of service delivery is grounded in federal, state, and case law, as well as research-based recommended practice. This fact, coupled with the medical concerns of this population and the virtual absence of nurses in such settings, poses a challenge to early educators.

Nursing shortages are occurring. This makes it extremely difficult to place nurses in every school setting. The difficulty is exacerbated when attempts are made to locate nursing personnel in early care settings. The process of delegating nursing duties to unlicensed assistive personnel affords one method of supporting CSSHN in least restrictive environments.

A review of the literature establishes what is known and unknown about the topic of service to CSSHN. Studies are examined that address the prevalence of CSSHN, the delegation of nursing duties to UAP, the needs of families of CSSHN, and issues related to serving CSSHN in educational settings. This knowledge will assist in shaping research questions and defining methods to discover the answers.

II. REVIEW OF THE LITERATURE

In order to gain an overview of and familiarization with the research efforts that have occurred focusing upon serving CSSHN in least restrictive educational settings a review of the literature was conducted. Informational databases including ERIC, Medline, and Dissertation Abstracts were investigated. Searches included the Boolean method using keywords and phrases such as special health care, medical fragility, complex health care, medically fragile, inclusion, severe disability, early education, nursing, delegation, and unlicensed assistive personnel (UAP). The results of these search efforts yielded a total of 30 research studies. This body of empirical research fell into four broad categories. Those categories are: 1) the prevalence of CSSHN (4 studies); 2) the delegation of nursing duties to UAP (3 studies); 3) the needs of families of CSSHN (7 studies); and 4) serving CSSHN in educational settings (18 studies). A review of the literature in each of these categories follows. Two of the studies were found to be relevant to two categories and thus are included twice in the narrative, due to their dual relevance.

Though this paper is primarily focused upon service delivery for CSSHN in early educational settings, this literature review includes research on school-age populations and families. Such works are helpful in learning about service delivery to the population of CSSHN and applicable to younger populations. Also, few studies exist focusing exclusively on CSSHN in early education settings.

A. Prevalence of the Population

The review of the literature revealed that, although many authors have estimated the number of children with medical fragility and special healthcare needs (e.g. American Academy of Pediatrics, 1990; American Federation of Teachers, 1997; Office of Technology & Assessment, 1987), only 4 research efforts have empirically identified the prevalence of CSSHN within the general population (Chappell, 1997; Johnson & Asay, 1993; Palfrey et al., 1991; van Dyke, 2002).

Palfrey et al. (1991) conducted a census of children, ages 3 months to 18 years of age, who were dependent upon medical technology. This study represented a statewide effort to collect data in Massachusetts. All pediatric and educational providers in the state were polled as to the number of children who required daily medical support. Respondents indicated that 1,244 children in the state required such support. These data represented a one-month point prevalence of the population. This number comprised approximately .08% of the total population of children. Of this population of children, 57% had neurologic involvement; 13% had multi-system involvement; 7% had gastrointestinal involvement. In the cases of 5% of the children, etiology related to an injury or accident. Seven percent of the children had conditions that were inherited. Two or more devices were used by at least 21% of the children who required daily medical support. There were no significant gender differences in the children. The racial distribution of the children who were medically special mirrored the overall racial distribution of children in the state. For most medical conditions (i.e. tracheotomy, oxygen, gastrostomy, intravenous device, respirator, and ostomy), the majority of children requiring daily support were from birth through 5 years of age with the highest prevalence peaking at one year of age. However, the occurrence of special medical conditions was not limited to early childhood, but spanned the entire age group of 3 months though 18 years of age. Of the total population of CSSHN, 80% were determined to be living at home while the remaining 20% live in residential settings with medical care. Recommendations were made for universal access and cost efficient care, family participation in care and case management, public and private third party cooperation, assurance of high quality care, expansion of service capacity on a local level (Palfrey et al., 1991).

Another research effort involved a statewide survey in North Carolina. In this study, a survey was developed by the North Carolina Office of Public Health Nursing and Division of Maternal and Child Health (Johnson & Asay, 1993). It requested that respondents report the number and types of support and specialized health care procedures required by children in schools. There were 25 procedures included in the survey ranging from activities such as toileting, dressing, and feeding, to urinary catheterization, chest physiotherapy, use of feeding tubes, administration of inhalation medication, suctioning, and tracheotomy care. The survey was distributed to 141 school nurses, special education directors, and principals in the state. Seventy-five percent of the survey recipients responded. The resultant data were manipulated to glean descriptive statistics. It was determined that almost 10,000 school-age children in the state required support for functional activities or health-related procedures during the school day. This number represented approximately 1% of the state’s children.

The North Carolina researchers defined CSSHN as those children who, during school hours required at least one of the twenty-five predetermined specialized health care procedures identified in the survey. This is significant in that prevalence of any population is highly predicated on how that population is defined.

Another research effort conducted to determine the prevalence of CSSHN in schools was conducted by Chappell (1997). The purpose of the Chappell study was to determine the nature and scope of specialized health care procedures delivered to students in public schools in the State of California. The researcher divided California's 1,046 school districts into 3 categories designated by their size. Each participant was asked to complete and return the survey via US mail. One area of the Chappell study was related to the prevalence of children with chronic and severe illness. The data revealed that CSSHN were attending all 3 types of school districts in the state of California. The largest districts reported having proportionately more children with physical disabilities. Chappell determined that less than one percent of the children enrolled in California's public schools had chronic and/or severe illness.

The most extensive survey to determine the prevalence of CSHCN was conducted via funding from the Maternal and Child Health Bureau (MCHB) in 2002 (van Dyck et al., 2002). The scope of this research, the National Survey of CSHCN, encompassed all 50 states and the District of Columbia. The data collection period extended from October, 2000 to March, 2002 and was conducted to provide national and state data on the prevalence and impact of special health care needs among children. The purpose of the study was to estimate the prevalence of CSSHN on a state-by state basis, to determine the health and functional status of this population of children, to determine the types of care and services this population requires, and to determine the shortcomings of the system of care. The data collected by the National Survey of Children with Special Health Care Needs will also be used to assess progress made toward accomplishment of the goals set forth in Healthy People 2010. As mentioned above, prevalence data are highly predicated on the definition used for the population of children with special heath care needs (CSHCN). In this survey, the MCHB definition as quoted earlier in this paper was used.

The methodology employed in this research included initial use of the Children with Special Health Care Needs Screener. The Children with Special Health Care Needs Screener is comprised of 5 questions including: 1) Does your child need or use more medical care, mental health, or educational services than is usual for most children of the same age? 1a) Is your child's need for medical care, mental health, or educational services because of ANY medical, behavioral, or other health condition? 1b.) Is this a condition that has lasted or is expected to last 12 months or longer? 2) Does your child need or use medicine prescribed by a doctor, other than vitamins? (2 a. and 2b. same as 1 a. and 1 b. above, but relevant to medicine); and 3) Is your child limited or prevented in any way in his or her ability to do the things most children of the same age do? (3a. and 3b. same as 1 a. and 1 b. above, but relevant to ability to do things children of same age do); 4) Does your child need or get special therapy, such as physical, occupational, or speech therapy? (4a. and 4b. same as 1 a. and 1 b. above, but relevant to therapy); 5) Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs treatment or counseling? (5a. asks if condition expected to last 12 months or longer.)

Families were contacted to complete the Screener using the State and Local Area Integrated Telephone Survey (SLAITS). This is a list-assisted random-digit-dial system used to access randomly generated telephone numbers. First, the mechanism dialed randomly generated telephone numbers; if a household with children under the age of 18 was contacted, a parent or guardian was identified and consent to proceed was obtained. Next demographic information was obtained and the CSHCN Screener applied for each child in the household.

Participants for a more extensive National CSHCN Survey were randomly selected from those families that included a child with special health care needs as identified by the Screener. This National CSHCN Survey had a total of 10 major domains including: 1) demographics; 2) health and functional status; 3) health insurance coverage; 4) adequacy of health insurance coverage; 5) public program participation; 6) access to health care; 7) health care utilization; 8) care coordination; 9) satisfaction with services; and 10) impact on the family.

In the first 6 months of utilizing the SLAITS system, the response rate for completion of the screener was 75.2%. The analysis of the data indicates that 16 to 18% of the population of children from birth to 21 fall within the parameters of the definition of CSHCN. Given the total sample size of those screened nationally, the prevalence data for each state are predicted to be accurate within 1.0 to 1.5 percentage points, using a 95% confidence interval. Since the definition used in this study was much broader than most of the others cited in the research above, the prevalence is considerably greater than that identified in the earlier studies.

The response rate for those selected as eligible for completion of the National Survey for CSHCN was 98.9%. Through use of the above process, 750 CSHCN were identified in each state and the District of Columbia, yielding a national sample size of 39,000 families with CSHCN. Data from the recent National Survey of CSHCN has revealed that approximately 52% of the nation’s CSHCN receive comprehensive, coordinated care within the context of a medical home (van Dyke et al., 2002). A medical home ensures that CSHCN have access to health care environments that are accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent (American Academy of Pediatrics, 2004).

1. Summary

Determination of the prevalence of CSSHN is critical in determining the importance of the problem. Four studies were found that focused attention on this issue of prevalence. These studies define and discuss this population in different ways. The researchers use diverse terminology such as “children having specialized physical health care procedural needs” (Chappell, 1997, p. 6), “children dependent on technology support” (Palfrey et al., 1991, p. 612) and “children with special health care needs” (Johnson & Asay, 1993, p. 417; van Dyke et al., 2002) to discuss the population they studied. Furthermore, each research effort used differing methodologies for determining the set of children in the population. For example, one study utilized a list of 25 health care procedures to define children who were considered members of the group (Johnson & Asay, 1993). Another study used children with conditions contained in The International Classification of Disease volume 9 to define the population (Palfrey, 1991). The most recent study utilized the broader MCHB definition in assessing prevalence (van Dyke et al., 2002). The studies on prevalence also targeted different areas of the country in identification of the prevalence of CSSHN. These diverse geographic areas include Massachusetts (Palfrey et al, 1991), North Carolina (Johnson & Asay, 1993), California (Chappell, 1997), and all 50 states including the District of Columbia (van Dyke et al., 2002).

Given these fundamental differences, the findings of the first three studies point to strikingly similar results. It was determined by each researcher that about 1% of the school-age population of children that they studied has special health care needs.

This paper focuses upon the population of children who, due to temporary, or chronic medical condition or illness, require ongoing monitoring, assistance, equipment, devices, or technology to sustain life or health within school environments. This is certainly a low prevalence population. Researchers point out that this is a population of children who, two decades ago may not have survived and if they survived, would certainly not have been unable to attend their neighborhood school. Each of the three researchers asserted that this is a population of children that is increasing, thriving, and ready to be served in local educational environs.

A dissimilar finding is the projection of the National Survey of Children with special Health Care Needs. This study determined that approximately 16% to 18% of the total population of children will be identified as having special health care needs. This is a significantly larger percentage than other researchers have obtained. This is due to the use of a much broader definition encompassing more children including those “at increased risk” for chronic conditions and extending beyond medical conditions to emotional or behavioral issues. The definition, reviewed below, also is broadened by the inclusion of children who receive related services. In review, the MCHB definition, developed by McPherson et al. (1998) is:

> CSHCN are those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally. (p. 137)

This paper focuses upon a subset of the children defined by the MCHB as CSHCN. The population of focus is CSSHN.

B. *Delegation of Nursing Duties to UAP*

The delegation of nursing duties to UAP is a topic of relevance when considering methods of support for CSSHN in educational settings. As discussed previously in this paper, full-time nurses cannot be present in every educational setting in which CSSHN are served. Thus, the nurse must assess which nursing duties may appropriately be delegated to other personnel working in the educational setting. A health care plan must be developed, and training must occur. A search of the literature in the medical and nursing fields contained many position papers on the subject of delegation of nursing duties to UAP (American Nurses Foundation, 1994; Committee on School Health, 1987; Hansten & Washburn, 1998; Luckenbill, 1996; Manuel & Alster, 1994; National Association of School Nurses, Inc., 1995; National Association of State School Nurses, Inc., 1995; National Council of State Boards of Nursing, Inc., 1995; Panettieri, 1996; Parette, Bartlett & Holder-Brown, 1994).   Taken as a whole, this body of literature makes salient points reflecting upon the delegation of nursing duties to unlicensed personnel. Specifically, the literature emphasized that no one but nurses may delegate nursing duties and nurses must ultimately decide to whom and how delegation occurs.

In spite of the wealth of position papers on this topic, only three empirical research efforts were found on the subject of delegation of nursing duties to UAP (Conger, 1994; Josten, Smoot, & Beckley, 1995; Jung, Pearcey, & Phillips, 1994). Two of these efforts involved evaluation of training interventions for personnel working in health care facilities, whereas one study addressed delegation of nursing duties in school settings via a survey methodology.

One research effort evaluating a training intervention delivered in medical settings was entitled the Work Load Redistribution Program (Jung et al., 1994). This system was designed to increase the productivity of registered nurses working in hospitals by instructing them in delegation of nursing duties to UAP. Registered nurses working in a North Carolina hospital setting participated in a 4 hour inservice training program (N=167). Topical areas included in the training were roles and responsibilities of both nurses and UAP, the art of delegation, communication of expectations, and ongoing supervision. Role playing scenarios were also part of the training.

The efficacy of the Work Load Distribution Program was evaluated using a pre and post intervention and implementation questionnaire administered to the nurses who participated in the training. Items included in the questionnaire assessed the nurses' perceived workload, job satisfaction, quality of nursing care, capacity to supervise UAP, and ability to coordinate care. In addition, hospital departmental data were collected and analyzed quarterly. This process queried patients on their level of satisfaction with the nursing care received during their hospital stay.

Results of the study indicated that there was a statistically significant ($p < .001$) improved nursing workload. Following the training, nurses had a significantly increased ability to delegate nursing duties to and supervise UAP. The nurses also reported a perceived improvement in quality of nursing care following the training as a result of participation in the program. Results of the pre and post implementation surveys demonstrated that job satisfaction for nurses, coordination of care, and patient satisfaction remained stable.

Although the number of nurses who reported improvements in their ability to delegate nursing duties was significantly increased, Jung et al. (1994) found that a large percentage of nurses continued to be uncomfortable with delegation procedures. The authors deduced that this is an area for follow-up training and ongoing research.

The impact of the Work Load Redistribution Program upon the job satisfaction of UAP was another area of interest that was analyzed in the Jung study. Reports of the Human Resources Department of the health care facility where the study occurred indicated that turnover rates for unlicensed personnel remained stable or decreased following the training and implementation of the Work Load Redistribution Program (Jung et al., 1994). This could be indicative of increased job satisfaction for nursing assistants involved in the study.

The authors did find that there was an increase in the retention rates indicating job satisfaction. Although cost analysis was not directly examined in this study, the authors projected that increased retention rates would lead to a commensurate reduction of recruitment and training costs that may result in significant cost savings for hospitals. The authors acknowledged that cost saving is an area of related interest and must be addressed in future research.

The second study of a training effort for nursing personnel in the delegation of duties to UAP was conducted by Conger (1994) in 2 acute care hospitals in Southern California. Conger measured the ability of registered nurses to effectively delegate nursing duties to UAP before and after a short training experience and introduction to the Nursing Assessment Decision Grid. This grid was developed in an effort to support nurses in making effective delegation decisions. The tool guides the registered nurse through a series of steps in which analysis of a patient's health status occurs, and decisions can be made in assignment of nursing duties. Specifically, skills targeted for development were patient problem analysis and assignment-making to UAP.

The research design included an intervention in which nurses were exposed to the Nursing Assessment Decision Grid during a 2 hour training in order to increase their capacity in making delegation decisions. Analysis of pre and post implementation skill measures occurred with the null hypothesis being that there would be no statistically significant difference between the pre and post-intervention scores. The study involved a convenience sample of 93 subjects who were registered nurses employed by the hospitals in which the training occurred.

The results of the study demonstrated that, given 2 patient vignettes before and after the training, the nurses experienced statistically significant improvement in their ability to analyze patient problems and make assignments to UAP, as measured by a paired sample t test. These findings suggested that training in use of management tools such as the Nursing Assessment Decision Grid assist nurses in increasing their capacity to effectively delegate nursing duties (Conger, 1994).

School nurses in Minnesota were surveyed about their experiences delegating nursing duties to UAP in another study. Blengen, Gardner, and McClosley (cited in Josten, Smoot & Beckley, 1995) developed a research survey addressing the issue of delegation of nursing duties in school settings. The survey was developed to examine the characteristics of personnel who served as nursing delegates. Factors examined were level of training and experience, the nurse’s preparation for delegation of nursing duties, the considerations of the nurse when contemplating delegation, and challenges, barriers, and problems encountered during the delegation process. A total of 15 semi-structured questions were included in the questionnaire. A final open-ended question asked for any further issues or concerns associated with the delegation of nursing duties

Descriptive statistics indicated that 40% of the 400 nurses who received the survey responded. This was a veteran population of school nurses who had been working an average of 19.37 years (sd = 9.57 years). The median number of children assigned to one school nurse was 1,298 students. Results of the survey determined that 58% of the nurses had received some training in the delegation of nursing duties within the context of continuing education opportunities, 48% received training within their formal nursing curricula, and 34% received on-the-job training. Twenty-five percent of the nurses received no training related to delegation of nursing duties. Less than one third (28%) of the schools were reported to have policies that addressed delegation of nursing duties to UAP whereas only 19% of the districts had any type of procedures outlined to delegate such duties.

In the open-ended question, the nurses were asked to list crucial factors that they considered when delegating duties to unlicensed personnel. Ninety-four percent of the respondents mentioned level of competence of the delegate. Over 50% of the nurses mentioned the medical condition of the child and procedure required whereas 34% of the respondents indicated nurse availability. In analyzing the results of the Blengen survey, Josten et al. (1995) reported that school nurses said they were grossly overworked, and that educational settings generally lacked policies on the delegation of nursing duties. Regarding legal issues, most nurses (61%) reported that they refused to delegate nursing duties at some point in their careers; similarly 36% reported delegating against their better judgment (Josten et al., 1995).

1. Summary

Two of the three studies on delegation of nursing duties to UAP were similar in that they offered inservice training programs for participants who were staff members in hospital settings. The success of both the Work Load Redistribution Program and the Nursing Assessment Decision Grid training was determined by comparison of the results of pre and post-test measures. Both studies offered successful interventions in the sense that nurses increased in their ability to complete tests about successful delegation of nursing duties. Both interventions resulted in nurses reporting increasing levels of confidence and comfort when delegating nursing duties. However, one limitation of both studies is that no effort was made to assess demonstration of delegation skills in the actual work place. Thus, it is unknown whether skills taught were applied in vivo.

Though these 2 studies occurred in health care facilities and not within school settings, it is promising for educators to review these studies and learn that appropriate delegation of nursing duties can be successfully taught. Via these studies, training methods were established so that delegation of nursing duties to UAP could occur.

Although the third study focused more specifically on the delegation of nursing duties within educational settings, it is less than encouraging. Josten et al. (1995) reported that school nurses felt they were overworked, and educational settings lacked policies on the delegation of nursing duties. Furthermore, the school nurses surveyed indicated that they have delegated nursing duties in school settings against their better judgment.

There is a critical lack of knowledge about delegation of nursing duties within school settings. This calls for increased efforts to replicate the validated training of healthcare institutions for nursing delegation to UAP within schools. The fields of education and nursing would benefit greatly from further study of delegation of nursing duties to UAP in educational settings. Perhaps the short supply of school nurses can hope to meet the rising support needs of CSSHN in school settings if such methods as those developed by Jung (1994) and Conger (1994) were used.

C. Families of Children with Special School Health Needs

Clearly, children are inextricably woven into a family structure. The dynamics within that structure impact upon the status of the child; conversely, the status of the child impacts upon each family member and the family unit as a whole. Given a child with special school health needs, emotional, health, and financial complications certainly impact upon the family dynamic. In this review of the literature, consideration must therefore be given to CSSHN and their family structures. Seven research studies were found that addressed the needs of CSSHN within their families (Bruns, 1996; Chesler & Barbarin, 1986; Diehl, Moffitt & Wade, 1991; Lynch, Lewis & Murphy, 1993; Myers, 1997; Taras & Martino, 1996; and Tommet, 1997).

The earliest study focused on the feedback of 59 parents of children who had cancer (Chesler and Barbarin,1986). Most children who have cancer attend school both during and following treatment. This study focused upon the parents’ perspectives about the school experiences of their children with cancer. All interviews were conducted in the homes of families and interviewers were trained graduate and undergraduate students. The sample of families was stratified on the basis of type of cancer and health status of children so that it would represent the broad perspective of diverse families. The families were also evenly distributed across income and educational levels.

The interview method utilized both open and close-ended questions. Following establishment of the child’s type of cancer and health status, the interview focused upon the parent’s view of 2 key areas: 1) schooling problems upon the child’s return to school; and 2) degree of helpfulness of assistance received from school staff. The interviewees were asked to rate the degree of helpfulness on a 5 point Likert-type scale. Following the face-to-face interview, the parents were also asked to complete a 6 page questionnaire covering the same topics, returning it to the researchers by mail. This questionnaire was administered in an effort to validate the verbal responses given during the face-to-face interviews. There was a high rate of return on these questionnaires, with 90% sent back to the researchers.

The results of the study revealed that 51% of the parents interviewed reported that their children experienced problems upon returning to school following treatment for their disease. The most frequent problems mentioned included teasing by peers (37%) and missing too much school (31%). A smaller percentage of families interviewed (12%) cited relationships with teachers as problematic upon the return of their children to the school setting. Some teachers were perceived as not understanding the limitations, fatigue, or medical conditions of the children and thus not accommodating to the needs of the child. A small number of participants mentioned complications with siblings as a problem related to the re-entry to the school setting of the child with cancer. Siblings, in a few cases, were acting out, seeking undue attention, or defending the ill brother or sister from teasing or bullying. Teachers and other staff members were not perceiving such inappropriate sibling behaviors as part of a larger family dynamic, but rather looking upon them as simply noncompliance with rules and expectations.

The helpfulness of school personnel in dealing with the above-mentioned problems was rated by the families. The majority (55%) of the families described school staff members as very or quite helpful. Conversely, about 45% of the families interviewed described the staff members on the lower end of the helpfulness scale. Interestingly, parents who were more highly educated reported that school staff members were very or quite helpful significantly more often than less educated parents. There was no difference in the reports of families from various socioeconomic levels about helpfulness. It was, however, determined that the perceived level of helpfulness of staff was related to how well the parents perceived the child was doing in school. Thus, if parents felt that school staff had been helpful in the re-entry process, the parents likewise felt that the child was doing well in school. Some of the actions of teachers that were cited as helpful by families included: caring attitude, treating the child as normal, providing special academic help, and keeping parents informed of school progress.

Analysis of the results from the Chesler study yields some fascinating conclusions. While educators strive to provide typical school experiences for all children, special considerations must also be made for those in need in order to avoid school problems and to foster success. Teachers must find the balance between offering a normal school experience for CSSHN and providing necessary or helpful specialized services and supports.

Another of those research efforts was related to the needs of parents of CSSHN (Deihl et al., 1991). This group conducted a series of structured focus groups in order to determine the perceived needs of parents of this group of children. Participants in the study were 80 caretakers of children, birth through 21 years of age; all children had special health care needs. The caretaker group was composed of 71 females and 9 males. Focus groups consisted of 6 to 10 participants in a 2 to 2 1/2 hour audio-taped session. The design of this research study was developed following a review of the literature and the approval of an advisory council.

In order to analyze the data, audio-tapes from the focus groups were transcribed. The transcripts were evaluated to identify trends and patterns. As themes began to emerge from the text, comments within the transcripts were coded accordingly. Twelve categories of issues were identified. In descending order, from greatest to least concern, the concerns identified were: 1) family issues; 2) illness specific information; 3) equipment; 4) case management; 5) financial assistance; 6) educational needs; 7) medication and pain management; 8) hospitalization; 9) daily physical needs; 10) child's emotional communication needs; 11) growth and development; and 12) death and dying.

The largest area of concern was the deterioration of the family structure. The stress on internal family relationships was clearly expressed. Husbands and wives reported rarely spending time together. When elective time did become available, it was spent with a sibling of the medically special child. Furthermore, care-taking typically fell to one primary caregiver. Seemingly simple daily family activities, such as grocery shopping or going to the park, assumed a new complexity when considering the needs of a medically fragile child. Sibling jealousy of the attention that the medically complex child received was noted as problematic. Also, sibling embarrassment of the child with complex needs was also sited as an additional exacerbation for the family structure.

Each of the 12 trend areas was analyzed for thematic patterns. The two most frequently held opinions in each of the 12 trend areas were noted. For example, in the area of equipment, families mentioned that they were either frustrated by incorrect equipment being prescribed, or by the lack of awareness that certain equipment was available. In the area of medication, families reported that medication interfered with daily life and, secondly, that scheduling the administration of medication was too demanding. A huge barrier to successful family functioning was found in that 25 percent of the caregivers reported having no respite care (Diehl et al., 1991).

In another study (Taras & Martino, 1996), a questionnaire was used to gather information from parents of children enrolled in early intervention programs. This study focused upon the medical status as well as the childcare needs and care status of their children (N=678). Questionnaires also were issued to the early childhood special education teachers of the children in order to establish reliability. The response rate was 57% of the families surveyed.

The San Diego researchers determined parents who have children with medical complexity were likely to report that they had difficulty in finding child care for their children. Of the population of parents whose children were receiving early intervention, 34% reported looking for and identifying satisfactory child care services. However, 35% of the respondents reported that the lack of day care prevented them from being employed. Another 24% said that they would not accept day care even if it were available to their child and family. The analysis of the families using daycare indicates that 45% of the families hired a baby sitter to work within their homes, 36% used a friend or relative's home, 34% used family day cares, and 7% used center-based care.

The study concluded with recommendations for the field. The researchers advised that a child’s special health care needs should not preclude a family from receiving child care. They further purport that early childhood special educators and early intervention programs must work together to offer the necessary supports for CSSHN to be successful in child care environments. Finally, they recommend that the medical profession needs to enter the conversation about how to best support this population of children in day care settings (Taras & Martino, 1996).

Another study focusing on parents of children with special health care addressed family need and existing educational services in California schools (Lynch et al., 1993). California's school districts were stratified by size of enrolled population. A total sample of 80 small, medium, and large school districts were selected for participation in the study. Within those participating districts, the researchers identified 72 families of children with chronic illness using a nomination technique for sample identification. District representatives and parents of children with chronic health conditions enrolled in those districts were queried using similar probes. The probes consisted of two parallel interview protocols. One protocol was designed for representatives of school districts; the other protocol was designed for parents of CSSHN.

When asked to identify the barriers to serving CSSHN, district personnel identified lack of public and staff awareness of health information, and funding difficulties associated with serving this population of children. Similarly, parents also listed lack of awareness of health information as a barrier to effective support in educational environments for their children.

When asked to identify the problems of children with chronic illness, the responses of the district representatives and the families were variable. District representatives focused upon difficulty of providing accommodations for the children in order to allow access to typical classroom and programming. Conversely, families of children with chronic illness listed more personal and life issues such as restricted activity, limited acceptance by a peer group, and the inability to keep current in schoolwork due to illness, trips to the doctor, and absence from school due to hospital stays (Lynch et al., 1993).

Similar to the research conducted by Lynch et al. (1993), another study focusing on family needs and educational services children with chronic illness was the Bruns study (1997). This research was a poignant case study of a two-year effort for a young child to gain access into a public school setting from his residence in a specialized care facility. The study was substantiated by anecdotal records, educational documents, and professional correspondence. Throughout this account, a child with Marshall-Smith Syndrome was largely rejected by neighboring school systems near to his residence. A variety of reasons for the multiple rejections were offered by the school systems, ranging from legal rationale, to cost, to lack of capacity to serve.   The over-riding factor at work in this case study, however, seemed to be the phenomenon of fear. Teachers and administrators alike felt afraid to have the child in the neighborhood setting and did not know how to access medical resources to allay their fears. This case study punctuated the need for interdisciplinary systems to be developed and available for schools in the advent of a child with medical fragility.

In contrast to the Bruns case study describing the experiences of one child and family, another case study involved the process of the transfer of information from pediatric hospitals to schools (Myers, 1997).   Through the reputational methodology of networking and snowballing, Myers identified 10 chronically ill children whose families agreed to participate in the study, and whose chronic illness severely impacted upon their abilities to learn through traditional school methodologies. Five of the children were oncology patients and 5 of the children were patients involved with the Genetics Department of Canadian pediatric hospitals. Children who received their medical diagnosis before entering school were considered “early diagnosis cases;” children whose diagnosis was obtained after entering school were considered to have “sudden onset.”

Using a qualitative approach, the researcher collected data using three key procedures: semi-structured interviewing, document analysis, and personal observation. Boundary spanners were considered to be those persons who were most frequently responsible for moving information between the hospital and the school. The researcher sought to identify who were the boundary spanners in support of children with chronic illness transitioning from hospitals to schools. Initially, the researcher interviewed the parents of each of the children. School and hospital files were then examined. All data were coded in separate files for each subject.

The data were analyzed using a triangulation approach. The results indicated that, in all cases, it was the mother who was responsible for transferring information between hospital and school. Various special education personnel, utilizing special education policies and procedures, made accommodations for the children who had “early onset” of a chronic illness. For children with “sudden onset” of chronic illness, accommodations were made through informal organizations within the school with leadership provided by the principals. It was not necessary for those people who were identified as boundary spanners to understand the concept of boundary spanning in order to effectively assume this role.

The nurse-family interaction for families of CSSHN who were in the process of choosing a school for their children was examined in another case study (Tommet, 1997). The sample included parents of children with medical fragility enrolled in preschool, kindergarten, or first grade. All families resided in urban areas having school districts that offered comprehensive services. All of the families were in the process of choosing an elementary school program for their children. A total of five families were selected as participants. The activities of the study included a series of 45 to 90 minute interviews for each family during which they were invited to tell their story. During a second interview, each family was presented with a diagram analyzing the stages of their family story, as associated with family events they had reported. Feedback to and from the families occurred.

An analysis of the family stories revealed that each family progressed through a series of similar stages: 1) Disruption and disorganization-loss of control, uncertainty, extended crises and hospital stays, passive acquiescence to physician recommendations, conflict, financial pressures, and isolation from friends and family; 2) Reorganization-'order in chaos,' reinterpretation or reframing of uncertainty, procuring information, active participation in medical decision-making, increased confidence in advocacy, reaching out to support other families with similar needs; 3) Stability-coping with situation; knowledge of what might happen and how to respond; families able to live in an expanded time-frame (i.e. rather than from day-to-day, week-to week or even month-to-month).

In the second interview, a diagram was presented to the family. The graphic represented events the family reported associated with stages the family was experiencing at that time. Families saw that separate events of their lives fit into a whole-life trajectory. This pattern recognition was essential to the process of expanding consciousness for families, giving them insight into their own development.

For these families, choosing a school-age program represented returning to the stage of Disruption and Disorganization. The families had adjusted to a period of relative stability, living from week-to-week, or, at best, month-to-month, with their children involved in the preschool special education program with which they were comfortable. Upon transition to school-age programming, they were being asked to plan something 6 to 9 months in advance. Factors such as health condition of the child at that future time, characteristics of the next school environment, and competency and acceptance of school personnel loomed as unknown factors.   This study points to the need for support for CSSHN and their families in the transition process.

1. Summary

The review of the research involving families of CSSHN highlights several issues germane to families of this population of children. Taken together, these studies demonstrated that families of CSSHN are faced with significant levels of stress emanating from difficulty in procuring illness specific information, financial stress related to the child's illness, medication and pain management, and inability to procure child care (Diehl et al.,1991; Taras & Martino, 1996).   In fact, family members (most often mothers) need to assume the increased role and responsibility of spanning or straddling the boundaries between school and hospital, brokering information from one entity to the other (Myers, 1997). Added to these stressors, families are also faced with a lack of awareness on the part of school personnel about how to respond to health conditions (Bruns, 1996; Lynch et al., 1993). Tommett (1997) addressed the stress caused to families by this lack of awareness on the part of school personnel, identifying the disconcerting stages that families experience as children transition from one educational setting to another. It is thus imperative that educators become familiar with and sensitive to the plethora of issues for CSSHN and their families. These children and families must be responded to and supported by school officials in ways that enable them to remain functional, intact, physically and mentally healthy, and financially viable.

Future research on the efficacy of educational models for serving CSSHN in school settings can only serve to support children and their families as they strive to meet the needs of their children in each of life's arenas. Such research could include effective methods for involving families in the design of instructional programs, and use of interdisciplinary approaches involving physicians, nurses, teachers, and administrators in design and implementation of individual health care plans in schools.

D. Serving CSSHN in Educational Settings

The final and perhaps most relevant category of research in this review is that of special services to CSSHN in educational settings. The literature review gleaned 18 such studies. The studies were eclectic, widely ranging in topic, research question, methodology, and results. Thirteen of these studies offered some sort of assessment of the 'current status' of health practices for serving children with medical fragility and special healthcare needs. These 13 "current status/needs" studies may be parsed into 3 categories: 1) information about the current status and needs of schools and school systems (7 studies); 2) information about the current status and needs of school staff members (5 studies); and 3) information about the current status of the law and litigation (1 study). In addition, a few research efforts (4 studies) offered evaluation of an intervention or model program designed to serve CSSHN in educational settings. One research study utilized a consensus building technique to produce predictions of future trends for CSSHN in schools.

1. Current Status and Needs of School Systems

Some of the research conducted on serving CSSHN in schools was focused on identification of the current status and needs of school systems. Neither interventions nor solutions were the focus of this group of studies.

The earliest study was conducted by Palfrey (1986). This research investigated the experience of 5 urban school systems in implementing IDEA for children with disabilities. These school systems were distributed across the United States. A researcher-developed survey was used to determine the current status of serving CSSHN in the 5 urban districts. The interaction of physicians with school systems was an area of focus in this study. Descriptive statistics were derived from the gathered data.

The results of the study indicated that school systems were challenged by early identification of childhood disabilities, classification of functional disorders in children, and inadequate participation of practicing physicians in school programs, especially in the areas of behavioral and developmental issues. The researchers concluded that improved collaboration is needed between the health and education systems.

The impact of the least restrictive environment (LRE) requirement of Public Law 94-142 was another concern of school system personnel revealed by analysis of the data. It was anticipated by the school representatives that the LRE requirement might result in decreased numbers of children being enrolled in hospitals and institutional settings with a commensurate increase in enrollment in traditional school environments. The researchers asserted that should this trend be realized, a need for procurement of health services in school settings will emerge (Palfrey et al., 1986).

A state level study asked whether nursing guidelines existed for practice in school settings. Wood, Walker, and Gardner (1986) focused on state level health and educational agencies. Their research was conducted to determine whether guidelines existed for the administration of selected nursing procedures in schools. Although the researchers solicited information from each of the 50 states, a total of only 32 states were represented in the respondents’ group. Descriptive statistics were generated using the data collected from the 32 states. Thirteen states, or 26% reported having no written guidelines for nursing procedures. Another 13 states, or 26%, had guidelines that addressed administration of medication only. Finally, only 6 states, or 12%, had guidelines for the 8 selected nursing duties. The researchers concluded with comments advising that increased attention must be paid on a state level toward construction of policies and guidelines to assist school districts to serve this population of children.

Another study ventured to determine the current status of serving CSSHN in educational environments within the state of Michigan (Hook, 1992). The purpose of this study was: 1) to review the way in which health care procedures are administratively handled for children with medical fragility in that state; and 2) to determine whether there is a correlation between administrative practices and qualities of size, location of district, and board policies. A theoretical ideal of administrative practices was also examined.

A survey was disseminated to 72 special education administrators who were reported to serve children with medical fragility; 49 of the surveys were returned. Respondents indicated that 29% had a policy in delivery of health care procedures to CSSHN although only 18% kept that policy on hand for staff to review. It was also determined that 65% of the administrators reported that emergency procedures were posted in a location accessible to the staff. Results reported on record keeping indicated that: 86% of the involved personnel kept a written log of administration of health procedures, and that 27% of the respondents required that a witness sign the log for verification that a procedure has taken place. Ninety-two percent of the administrators surveyed reported that a written physician prescription was required in order to provide a medical procedure in school. Similarly, in 90% of the cases, parents were required to submit written authorization in order for health care procedures to take place, as per state law.

The data indicated that there was a correlation between the level of experience of the administrator and the quality of health care practices. Administrators having fewer years of experience provided the higher level of precaution. Also, those education agencies that had been involved in hearings or litigation surrounding delivery of health procedures tended to report that they have more rigorous procedures in place.

Another research effort investigated the current status of service to CSSHN in educational settings in North Carolina (Johnson & Asay, 1993). A survey about nursing care in school settings was conducted by the Board of Nursing of that state. The purpose of the survey was threefold: 1) to create a data base of information which would reveal the number and type of health procedures being conducted within North Carolina school settings, including personnel responsible for accomplishment of, training for, and supervision of such procedures; 2) to collect information about the extent to which registered nurses were coordinating health care services within school settings; and 3) to develop position statements for public policy development on the accomplishment of nursing duties in school settings. Surveys were sent to school nurses, directors of programs for students with exceptionalities, and school principals. Seventy-five percent or 105 surveys were completed and returned. The data were tabulated and statistically analyzed.

It was found that, on average, 142 hours were spent per month providing nursing services to children per school district. Given a 40 hour work week, this was less than one full-time nursing position per school district. It was also reported that thirteen school districts had no school nursing services.

The survey contained probes about who conducted initial health evaluations, developed the individualized health care plan, delivered health care services, and monitored the ongoing health status of the student. Respondents indicated that a variety of stakeholders including parents, both licensed and unlicensed school personnel and the students themselves, were providing combinations of health services and supports to students. The persons involved in providing the initial health assessment was most frequently a registered nurse (39%), followed by a medical doctor (23%), physical or occupational therapists (9%), a teacher (7%), and a parent (4%). A miscellaneous category of "other persons" provided initial health assessments in 12% of the cases.

The development of an individualized health care plan for a student while attending school was, in 36% of the cases provided by a registered nurse, and in 16% of the cases by the medical doctor. In 15% of the cases the physical or occupational therapist developed the health care plan. Parents developed the health care plan in 7% of the reported cases, whereas "other persons" developed such a plan 13% of the time.

The person(s) conducting the evaluation of the ongoing health status for students was another area of concern. The personnel most often cited as responsible for ongoing monitoring of student health status was a registered nurse (40%), followed by the medical doctor (12%). Physical and occupational therapists were involved on ongoing monitoring of health status of students in another 14% of the cases. Parents monitored ongoing health status 4% of the time, whereas "other persons” monitored and evaluated the student 11% of the time.

The persons providing health care procedures in school settings were determined to be a diverse group including personnel ranging from the building principal to the secretary, volunteers, and even maintenance workers. Combined data collected on the 16 health care procedures surveyed indicated that, in 44% of the cases, teacher and teachers' assistants were responsible for providing health care procedures. Registered nurses were most frequently cited as the persons conducting training for delivery of health related procedures (44%), and supervising the ongoing medical status of the student (41%). Nevertheless, training and supervision of most health care procedures were conducted by persons other than registered nurses including teachers, teachers' assistants, parents, licensed practical nurses, principals, secretaries, and other persons.

The conclusion of the researchers was that a Standard of Care must be established for children who need health care procedures while attending school. The Standard of Care proposed by Johnson and Asay (1993) is:

> A registered nurse shall be available for assessment, care planning, and ongoing evaluation of CSSHN in the school setting. Special health care needs include procedures that are invasive, carry "reasonable" risk for harm if not performed correctly, may not have a predicable outcome, or may require additional action based on results of testing or monitoring. Care planning should include: 1) Identification of appropriate person(s) to perform the procedure, 2) Teaching those persons to perform the procedure, and 3) Identification of a mechanism for registered nurses to provide ongoing supervision to ensure the procedure is performed appropriately and monitoring the child's response to care provided in the school setting (p. 419).

The final statewide study reviewed concerning the current status of CSSHN was conducted to determine the nature and scope of specialized physical health care procedures (SPHCPs) for students enrolled in public schools in the state of California (Chappell, 1997). This state has a mandated plan for the provision of specialized physical health procedures.

Specialized physical health care procedures included, but were not limited to: tracheotomy care, suctioning, catheterization, gastrostomy tube feeding, and mechanical ventilation.

The first research question in this study dealt with determination of the extent to which specialized physical health care procedures existed in California's public school districts. The next research question sought to identify personnel who were providing specialized physical health care procedures (SPHCP) to technology dependent and medically fragile public school students and to determine their level of preparedness, education, and training to deliver such procedures. Such procedures included: tube feeding, oral suctioning, tracheostomy suctioning glucose monitoring, oxygen therapy, injections, catheterization, and an “other” category. The third research question asked who supervised the providers of SPHCPs in the state of California, and whether differences existed in the level, form, and frequency, of such supervision. Lastly, the researcher sought to determine the trends that occurred over the past 5 years in specialized physical health care issues as observed and reported by school district personnel involved in such service delivery.

California school districts were conceptually divided into three types predicated upon the number of enrolled students. Type 1 counties had 15,000 or fewer students. Type II counties had between 15,000 and 100,000 students. Type III counties had more than 100,000 students. Counties were equally divided and randomly selected to participate; each of the county types was equally represented. A sample of directors of special education, California special education local plan directors, and school nurses was randomly selected from the participating school entities as respondents. The total sample size of 867 educational personnel was derived from this method of sample selection.

The survey instrument was developed by the researcher specifically to gain data necessary to answer the research questions. The survey included probes to obtain pertinent demographic information, multiple choice questions, short essay, and statements requiring a Likert-type scale rating as a response. There were a total of 33 questions. The survey was distributed to the participants via U.S. mail. Participants were asked to return the survey within 10 days of receipt.

The findings of the study directly addressed the research questions. It was determined that, overall, in the three county types, less than one percent of the students enrolled in public schools received specialized physical health care procedures. All counties employed registered nurses. Type 1 counties (those with up to 15,000 students) employed one registered nurse for 1,400 students, while Type 2 counties (15,000 to 100,000 students) employed one licensed vocational nurse for slightly over 500 students and 1 registered nurse for every 2,800 students. Type III counties (those serving over 100,000 students) reported employment of an average of one nurse for every 4,600 students. A range of 60 to 70% of the SPHCPs were found to be coordinated by a nurse. Other persons who assumed the role of coordinator for SPHCPs were full or part time health coordinators, principals, superintendents, and paraprofessionals. Between 42 to 58% of the counties reported that they conducted annual training for personnel related to delivery of SPHCPs. Approximately 81% of counties within the Type I and III ranges reported listing the SPHCP on the student's IEP as a related service, whereas Type II counties reported listing SPHCPs on the IEP in 72% of the cases. In response to an item probing whether the districts allowed students with special medical needs to enroll in neighborhood schools, 81% of Type I and Type III counties responded affirmatively. Type II counties reported that students and their families had this choice in 74% of the districts. Other school choices for the students included hospital, home, residential center, private school, or an alternate school. When asked if they thought that an “environment of harm” was created by allowing individuals without specialized health care training to provide treatment to medically special students, 96% of the respondents from Type I counties and approximately 82% of the participants from Type II and Type III counties responded affirmatively. The educational level of providers of SPHCPs was high school education with on-the-job training reported by 65% of the respondents. Nurses were the primary providers of supervision of the providers of SPHCPs, with the primary modality of supervision occurring by telephone or pager and seldom “on-site.” All respondents reported an increase in the number of students having special medical needs. The respondents reported that changes were warranted in the areas of law, funding, and training relative to this population of children. Annual training and monthly reviews, required by California state, were not occurring at the rate required by law, according to the respondents.

Another study of this group focused on determination of the current status and needs of school systems in serving CSSHN by gaining the perspective of the children themselves. This study involved conducting semi-structured interviews with 33 mainstreamed secondary age students who attended schools and had special health care needs (Lightfoot, Wright & Sloper, 1999). The interviews addressed the students’ perceptions of: 1) the impact their illness, disability, or medical condition had on various aspects of their school life including socialization, curricular, and extracurricular activities; 2) the strategies they used to cope with their condition in school; and 3) the formal and informal supports they received from a variety of persons within the school community. In addition to a traditional interviewing technique, information was gleaned using several unique methods. For example, the students were asked to draw a diagram or map of where they were in the school structure, along with a representation of their proximity to other systems of support. A sentence completion strategy was also employed at the end of the interview that allowed for verification of student’s earlier responses and expansion on themes mentioned at other times in the interview. The resultant qualitative data were analyzed using a 4 stage “framework” process involving: 1) thorough familiarization with the transcripts of the interviews; 2) identification of thematic frameworks; 3) indexing the framework against the actual transcripts, systematically charting data; and 4) identification of over-arching themes.

Several over-arching themes were identified from the interviews. Those included: concerns with school absences; exclusion from school activities; relationships with teachers and peers; and the role of school health staff. Regarding the impact their condition had upon attendance, the students clearly viewed absences from school related to their illness as very problematic. Some reported feeling isolated from peers, unfamiliarity with the curriculum, and lack of support, understanding, or accommodations from school staff due to their high level of absenteeism. The interviewees used strategies to cope with frequent school absences including studying whenever possible during lunch or free periods during the school day; prioritizing subjects, assignments, and tasks; and having other students or classroom assistants take class notes or explain curricular content.

The interviewees reported feeling excluded from various aspects of school activity while attending school, especially from curriculum and social activities. Completion of schoolwork was reported as difficult with many students reporting pain and tiredness as major barriers. Also, accommodations were often not made by the teachers or available through other means. Some students mentioned that equipment needed to enable them to read, understand or complete the work was not available or at least not in a timely manner. Other students mentioned a lack of understanding on the part of teachers as indicated by making requirements that were unreasonable or physically impossible. One area mentioned frequently was Physical Education—students reported being forced to participate in activities that were unsafe or unhealthy for them.

Another area of exclusion from school activity was that of school social life. Of the 33 interviewees, 32 reported that their social lives were restricted by their medical condition. After-school activities were virtually impossible for this population to participate in due to pre-arranged transportation scheduling, medical procedures taking place during lunch or free times, or the unwillingness or inability for accommodations to be made to enable participation in social activities.

The data from the interviews also contained a theme about relationships with teachers and peers. Virtually all of the respondents reported having a special relationship with a teacher or professional at school. Often this was the special education teacher; sometimes it was a pastoral care staff member. The role these special professionals played ranged from motivating the student to return to school, nominating the student for a special role or award, and helping the student to explain their condition to the larger school community. The converse was also true, however, with interviewees reporting that some teachers lacking knowledge, understanding, or patience with a student's condition. Students reported that their parents were very helpful in rectifying this lack of knowledge on the part of school staff, and that parental knowledge was best utilized in school when accompanied by a physician's verification.

Interestingly, the interviewees had mixed reactions when speaking about their relationships with peers. Approximately one third of the respondents (10 of 33) reported that their medical condition had no effect upon their relationships with peers; 5 of the respondents reported that their condition had a positive effect on their peer relationships, and the remaining respondents reported having difficulty with peer relationships. Some of the difficulties respondents reported having with peers included bullying, curiosity and lack of understanding about their medical condition. One strategy that students mentioned that helped to rectify this bullying and inordinate curiosity was the intervention and explanation by health professionals.

The last theme that emerged from the interviews was related to school nurses. The students reported that school nurses were not viewed as a source of support. Many school nurses were perceived as not understanding their special condition. The role of the school nurse was perceived as dealing only with collecting and maintaining records of height, weight, and immunization. The school nurse was reported as not available during times when students needed supports.

This study was unique and valuable in that it addressed the needs of school systems by soliciting information directly from the recipients of school services, the CSSHN. Often information is gathered from the perspective of the family, educator, or health professional and surmises the needs of students. This research sought out and analyzed data gathered directly from young students who are actually consumers of school services.

The final study in this group was different from the others in that it focused on the current status and needs of educational systems serving CSSHN on a local level (Crawford, 1994). Crawford disseminated a 2 page survey consisting of 4 statements assessing the principals' self-perceptions of preparedness for supervising delivery of care to CSSHN. The instrument required respondents to rate statements using a 7 point Likert scale. The principals’ perceptions about district readiness, building readiness, ability to supervise, and willingness to become better trained were assessed. Factors hypothesized to have influenced these perceptions included adopted Board of Education policy, attendance at inservice training programs, completion of coursework beyond Masters Degree level, previous experience with the population, and so on.

The survey was completed by 84 randomly selected Illinois elementary school principals. The majority of respondents (61%) had no formal training in special education. Of the principals who responded, 56% reported that there was an adopted Board of Education policy and dissemination of practices. It was determined that the existence of an adopted Board of Education policy on the provision of health services for CSSHN and participation in an inservice training program on this topic were significantly correlated with the principal's perception of preparedness in the 4 variables (district readiness, building readiness, self-perceived readiness, and willingness to receive additional training). It was clear that the participation of principals in training programs offering practical information and suggestions increased their perceived ability to serve this population of children.

a. Summary. Cumulatively, 7 research efforts were reviewed about the current status and needs of school systems serving CSSHN. Each of these 7 studies involved dissemination of a researcher developed survey to state or local level administrators. Results were analyzed, most often yielding descriptive statistics.

The national study conducted by Wood et al. (1986) evidenced a wide diversity across the 50 states in serving CSSHN. States had a variety of levels of laws, procedures, and policies in place dictating service to CSSHN. The results of the study also pointed to the dearth of guidance on a state level to support local school districts in this area.

Although the survey conducted by Palfrey et al. (1986) was not national in scope, as was the Wood study, the focus upon 5 urban school systems was also significant and revealing. The results of this early survey indicated that school systems need medical professionals to join as partners in designing safe, healthy ways for CSSHN to enter into least restrictive educational environments.

Three of these studies involved statewide probes of current practices, the most ambitious and most recent of those in the state of California (Chappell, 1997). The research that occurred in Michigan (Hook, 1992) and California were similar in that the results in both states indicated that laws, policies, or guidelines existed for serving CSSHN in schools, but were not necessarily followed. The North Carolina study was unique as a statewide survey in that it asked the key question, “Who is meeting the needs of North Carolina school children?” Unfortunately, the researchers reported that the answer was not always one that would meet a minimum standard of care (Johnson & Asay, 1993).

The Lightfoot study took a different approach in identifying the needs of school systems in serving CSSHN by soliciting information from the students themselves (1999). This provided an authentic view from the perspective of the consumers of services.

The Crawford study was also unique in this group (1994). Although it did focus upon the current status and needs on a systems level, the specific area of focus was on the preparedness of local school buildings. Rather than attend to systemic status and need on a statewide or school systems level, this study concentrated on the building level. The principals surveyed reported that perceived preparedness increased with Board of Education policies and procedures in place, and availability of training supports for staff.

As a whole, this group of research findings alerts the reader to the need for increased preparedness and supports on a national, state, and building level. Policies and procedures must be in place, and followed on each of these levels. Systems must support the development of training plans to increase the capacity of staff members serving CSSHN. Finally, relationships must be strengthened between the medical and educational communities so that this population of children can safely be served in local school settings.

2. Current Status and Needs of Staff Members

The prior group of studies addressed the current status and needs of school systems in serving CSSHN. It reviewed findings of studies that focused upon the status and needs of school systems. The group of studies in this section of the literature review examines a related but distinct group of studies. This research addressed current status of needs, not of systems, but of people working within those systems. In this group of studies, persons working on the "front lines" such as regular education and special education teachers, school nurses, and other school staff members were the subjects.

There were 5 studies reviewed in the literature about the current status and needs of staff members serving CSSHN in educational settings. The first was a national study (Izen & Brown, 1991). This study involved a survey of 500 special education teachers who taught students with profound, multiple handicapping and medically fragile conditions and focused upon their perceptions of: 1) the important variables in delivering quality educational programs; 2) current classroom practices; and 3) strengths and weaknesses of their university teaching preparation programs. The instrumentation utilized was the Education and Treatment Needs Survey (ETNS), a tool developed by The Association for Persons with Severe Handicaps (TASH) Critical Subcommittee for Serving Persons with Multiple and Profound Handicaps. For the most part, the ETNS is a 4 point Likert scale format, with the exception of one open-ended survey question. Of the randomly selected 500 teacher-TASH member population who were surveyed, 123 persons responded. The analysis of the data involved computation of descriptive statistics, mainly percentages. Responses to the open-ended question were analyzed via content analysis.

The analysis of the data revealed a variety of interesting findings. A little over half of the teachers who responded taught in segregated center-based settings. Most teachers (59%) had a master's degree or better. Respondents indicated that there was a general inadequacy of teacher preparation programs in preparing them to meet the needs of their students with significant needs. Academic instruction was not considered important by the teachers for this population of students. However, over half of the respondents continued to include academic instruction in students' curricula. Vocational training was not included by 20% of the teachers in school curricula. The finding most pertinent to this paper was that the respondents reported that they were not adequately trained by university teacher training programs to work with individuals having medically fragile conditions

Another researcher found similar results about the perceived preparedness of teachers to serve CSSHN. Krier (1993) developed a survey that was disseminated to general education teachers. The survey involved educators' perceptions about training and preparation for serving such children with medical fragility in educational settings. The researcher used the data gathered to develop descriptive statistics.

The results of the survey indicated that educators have contact with and responsibility for many children with medical complexity of varying degrees and need. Also, educators reported that they did not receive the training necessary to meet the needs of this subset of children they served. The respondents reported that they felt unprepared to meet the medical and educational needs of this population of children. The study represented clear indication of the need for more training for teachers of CSSHN so that they could adequately meet the needs of this population.

Another empirical effort was focused upon the needs of staff members serving CSSHN in early childhood special educational settings (Lowman, 1993). The findings were in accordance with the first two in this group related to preparedness. Dianne Lowman conducted a survey utilizing a questionnaire that was completed by 234 early childhood special education teachers in the state of Virginia. The survey was designed to ascertain the current status of service delivery to preschoolers with special health care needs in early childhood special education programs. The first objective sought to identify basic information such as the size of the locality in which health procedures were delivered, what procedures were being delivered, who was responsible for provision of health procedures, what training procedures were utilized, and what policies or procedures were in place to guide such activities. The second objective of the survey was to determine if a relationship existed between the size of the educational agency and whether or not formal written policies existed. A related question was whether or not a relationship existed between the size of the locality and the type of training procedures utilized. The third objective of the survey was to determine which aspects of receiving a child with special health-care needs were most frightening to teachers and what supports were most helpful. The questionnaire was an iteration of the previously published Preservice Questionnaire and Glossary: Health Maintenance Procedures Severe and Multiple Handicaps/Deaf-Blind (Mulligan-Ault, 1988).

The results of the Lowman survey indicated that a total of 14 health care procedures were occurring in the early childhood special education classes surveyed. Such procedures included, in order of frequency: administration of medication, gastrostomy feeding, provision of humidified air/oxygen, machine suctioning of tracheotomy, changing of tubes or ties of tracheotomy, catheterization, response to asthmatic episodes, administration of nebulizers, emergency care of seizures, nasogastric tube feeding, mechanical ventilation, colostomy/ileostomy procedures, monitoring of blood glucose levels, and provision of nasal cannula. Also noted was the person responsible for administration of the health care procedure. These persons included early childhood special education staff (teachers and paraprofessionals), nurses, and other persons including parents.

About 38% of the teachers reported that their school systems had a formal written policy concerning the administration of medication. In 17.5% of the cases, the teachers reported that the administrator made the decision determining who should deliver health care services; nine percent of those surveyed reported that it was the teachers themselves who decided persons responsible for administration of health care procedures. Half of the teachers reported that they were trained by a health care professional while 28.3% of the teachers reported that they were trained by parents. Urban and suburban school districts tended to have written health care policies to a greater degree than rural districts.

When informed that they were to serve a child with medical fragility, teachers reported a variety of concerns. The fears teachers reported ranged from worry over the child getting germs from other children or the environment, to inability to respond appropriately to a medical emergency (i.e. What if I do something wrong?). Legal liability, disruption of the classroom, and fairness to other children were additional issues for the early childhood special education teachers.

When asked about supports that were most helpful in transitioning CSSHN into their classrooms, the teachers responded that parent input and training were most helpful in allaying their fears. Other helpful supports included gaining information about the child and the medical condition, working with the nurse, speaking with the previous teacher, and meeting the child prior to entry into the class. The surveyed teachers reported that benefits of serving a CSSHN included increased empathy and acceptance on the part of peer classmates and benefits to the child who was being included in the environment.

One year later, Lowman published another study that shed further light on the current status and needs of educational staff members serving CSSHN (Lowman, 1994). In this study, 10 early childhood special education teachers were surveyed to assess trends related to serving children with medical fragility in early childhood education settings. The teachers needed to meet the criteria of: 1) currently serving a child with special health care needs; and 2) teaching in a special education center. The teachers were selected from 10 school districts in the State of Virginia.

Information was gathered through classroom observations and open-ended surveys. Themes became evident upon analysis of the data: 1) CSSHN were a relatively new population to early childhood settings, arriving with little or no teacher preparation or school system policies or procedures; 2) Early Childhood Special Educators reported feeling afraid and unprepared to meet the needs of this population of children; 3) Involved teachers gathered information and supports to increase their ability to meet the needs of children with medical complexities; 4) Following successful inclusion into the early childhood setting, teachers reported increased comfort with serving and meeting the needs of the medically complex child; 5) It was reported that other staff members and children in the school were not given opportunities to become familiar with the child with complex needs; 6) When planned opportunities became available for other staff members and children in the school to become familiar with the child with special health care needs, their comfort level increased; 7) The need for both preservice and inservice training was confirmed by the involved teachers.

The final study related to the current status and needs of school staff members examined the extent that non-medical school personnel were responsible for the delivery of specialized health care procedures for students who need such supports (Heller, Fredrick, Best, Dykes & Cohen, 2000). The purpose of this study was: 1) to determine the extent to which unlicensed assistive school personnel delivered health care procedures to students who need such supports; 2) to determine the extent to which students with special health care needs participated in their own health care procedures; 3) to assess the status of training and supervision provided to unlicensed assistive school personnel; and 4) to assess the type of training provided to unlicensed assistive school personnel to ensure the overall health and safety status of educational environments.

This study was national in scope and targeted members of the Council for Exceptional Children Division for Physical and Health Disabilities (CEC/DPHD). The mailing list of DPHD was used to send members a survey consisting of 4 main categories. The questionnaire queried: 1) demographic data; 2) identification of persons within the educational environment, including staff members and students, who provided students with health care supports; 3) description of training and supervision for persons providing health care supports; and 4) provision of general training for school personnel in order to ensure a safe, healthy environment. Of the 1,063 questionnaires sent to DPHD members, 47% were returned, or a total of 503. The raw data were entered into Version 6 of Epi Info. These data files were exported into an SPSS file that provided statistical analysis including descriptive statistics (frequency counts and percentages). Chi Square analysis was also calculated to determine the significance of differences between states having and not having guidelines for the delivery of specialized health care procedures.

In order to determine the extent to which unlicensed assistive school personnel delivered health care procedures to CSSHN in schools, frequency and percentages were calculated to determine the extent to which non-medical or unlicensed assistive school personnel were involved in the delivery of specialized health care procedures. Of the total respondents, 41.2% reported that health care procedures were performed exclusively by non-medical personnel. These personnel included: teachers, classroom assistants, students, parents, clerical staff, and others. Health care procedures provided by these persons included tube feeding, colostomy/ileostomy care, clean intermittent catheterization (CIC), tracheostomy care, suctioning, ventilator management, administration of medications and diagnostics, dispensing of oral medications, administration of inhaler or nebulizer, oxygen delivery, insulin injections, and testing blood glucose levels.

In determining the extent to which students with special health care needs participated in delivery of their own health care procedures, frequency counts and percentages were again calculated. The results indicated that student self-participation was occurring with very low frequency. In fact, it was determined that only 0.4% to 27.4% of students participated in the various procedures, usually in combination with other school personnel. When both medical and non-medical personnel were queried about who should perform health care procedures for students with complex needs, only 27.2% of these persons thought that students should perform their own procedures.

To assess the status of training and supervision provided to unlicensed assistive school personnel, analysis of collected data indicated that the primary trainer for health care procedures was the school nurse, with the students' parents being the next most frequent source of training. Other sources of training included: health department, hospital staff, physician, other health staff including respiratory and other therapists, teachers, paraprofessionals or aides, and other personnel.

Regarding supervision of non-medical assistive personnel, 56.6% of the respondents did report receiving ongoing supervision in the delivery of health care procedures, whereas 32.4% reported not receiving supervision, and 11.0% of non-medical personnel reported being unsure if they were, in fact, supervised at all. For the 56.6% of respondents who reported being supervised, 17.4% reported receiving supervision monthly, 4.7% were supervised quarterly, 8.1% were supervised annually, and 69.8% were supervised on an "as-needed" basis.

The final research question of the Heller study addressed the training of school personnel in ensuring sound practice in general areas of basic health environments. These areas included such practices as infection control, universal health care procedures, first aid, and cardio-pulmonary resuscitation (CPR). The analysis of the results indicated that the great majority of personnel had been trained in infection control (86.3% non-medical to 86.6% medical). Most personnel had been trained in CPR (87.4% non-medical to 90% medical); far fewer of these reported maintaining a current certification (40% medical to 49.8% non-medical). Similarly, most personnel reported having been trained in first aid (75% medical to 79.5% non-medical), but many fewer persons reported having current training (47.6% medical to 57.9% non-medical).

The survey instrument also asked whether there were written protocols or procedures for emergency management and other areas related to delivery of specialized health care procedures. Most respondents reported that their educational settings had procedures for emergency management (82.5%), first aid (71.8%), dispensing medication (83.4%), and specialized health care procedures (76.4%). A strong majority of respondents (82%) reported that they were interested in receiving additional training, technical assistance, and directives through local policies on the delivery of health care supports to the population of children they served.

The findings of this study have implications for the field, especially those educational entities serving students with special health care needs. The results definitively determined that non-medical personnel were delivering health care procedures to students who need such supports, and, furthermore, that students are rarely, if ever, participating in such activities. The vast majority of the responsible school personnel did not report feeling adequately prepared, trained, or supervised. Additionally, though most of the respondents received training in first aid, universal health care precautions, and/or CPR at some point in their professional development, high percentages of personnel reported that such training was not sustained over time.

a. Summary. In each of the 5 studies reviewed, educators reported that CSSHN were present in classrooms and required care beyond routine educational practice. Educators also reported that they were delivering such care even though feeling unprepared, uncomfortable, uncertain of their practices, or fearful. A universal need for training, support, supervision, and information was indicated by the educators involved in this group of studies

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3. Current Status of Law and Litigation

Of the 18 studies focused on CSSHN in educational settings, only one was conducted specific to the law and litigation (Rapport, 1994). Rapport's research was conducted as a systematic inquiry and analysis using primary, secondary, and tertiary sources of information related to the legal aspects of serving children with specialized health care needs in educational settings. A comprehensive review of federal statutory law and legislation, state statutes, rules, and regulations, and case law generated within the United States Supreme Court, federal appellate court, federal district court, at state levels, and an OCR decision resolving a complaint was conducted. The inquiry led the author to conclude that additional regulations were needed to clarify: funding/cost issues, responsibilities of districts, responsibilities of involved school personnel, and the appropriateness of placement decisions which were thought to reflect free and appropriate education (FAPE) in least restrictive environments (LREs).

It should be noted that this study was conducted prior to the Cedar Rapids Community School District v. Garret F. (526 U.S. 66, 1999) case, settled at the Supreme Court level. This case serves to respond to Rapport's (1994) view that further clarity about responsibilities of schools and personnel are needed. The case clearly sets forth a dictate that nursing services within educational settings are within the purview of the school, and that nursing services do not need to be related to a special education program in order to be provided.

4. Evaluation of an Intervention or Model Program

The literature review gleaned 4 research efforts involving the evaluation of interventions or model programs designed for CSSHN in educational settings. Those research studies included: 1) Project School Care (Palfrey et al., 1992); 2) a study conducted by Robertson, Schloss, Alper, and Wisniewski on teaching self-catheterization skills to a young child (1992); 3) M-FIRST (Smith, 1994); and 4) Healthy CHILD (Bagnato, 1999).

One study represented an effort to provide medical consultation to school systems as they integrated children assisted by medical technology into educational settings. Project School Care (Palfrey et al., 1992) in Boston presented an approach for development of an Individualized Health Care Plan that could be incorporated into a child's Individualized Education Plan. A nurse-physician team from a local hospital provided support and information in the educational planning for medically complex children. The process involved referral of a child, formulation of a health care team, assessment of needs of the child, construction of a health care plan, child-specific training for personnel, development of an implementation and emergency plan, and ongoing monitoring of health care status.

Three groups of children were supported in the development of health care planning: 1) children who were medically complex but did not use medical technology; 2) children who used one medical device; and 3) children who used more than one medical device. Training was either conducted directly by Project School Care Staff or arranged by the Project School Care staff but conducted by another community health care agency. For children who used more than one medical device, direct training by Project School Care staff occurred twice as frequently than by community agencies.

In the Project School Care design, a telephone interview occurred for families 6 months after an initial consultation. A vast majority of families reported a high level of satisfaction with the program, citing the primary reason for satisfaction as smooth transition from hospital to school and preparation of school personnel to serve their children.

Recommendations from the project included training of physicians on the support of school personnel serving CSSHN, and training of school personnel in provision of universal health care and child-specific health care services. Major communication needs existed between educational and medical institutions. Also, funding was found to be a major issue between education, medicine, and health insurers. An outcome from this work was the publication of the manual *Children and Youth Assisted by Medical Technology in Educational Settings: Guidelines for Care* (Porter, S., Haynie, M., Bierle, T., Heintz Caldwell, T., & Palfrey, J., 1997). This guide provides a wealth of hands-on information for use by educators who support CSSHN in school settings.

Another research effort that developed and evaluated an intervention for a child with special health care needs was much smaller in scope than its counterparts reviewed in this section. In this study, a training program was designed to teach a four year old child with myelomeningocele skills in self-catheterization (Robertson et al., 1992). The activities necessitated by the child’s medical condition were task analyzed and organized into three main phases: diapering, cleansing, and catheterization. The training involved initial utilization of a simulation approach in which the child learned to catheterize a doll in his preschool setting. Later, he learned to perform the procedure on himself, in vivo. Edible reinforcers were used to reward the child for successful completion of expectations. The child was assessed to be at mastery level following the intervention. The researcher determined that the skills the child gained as a result of the intervention were maintained during a 3 month follow-up.

The value of the Robertson study was that, though small in scope, it represented a safe, healthy approach to a medical intervention that needed to occur in an early childhood setting. The approach was valuable in that it offered a practical and manageable system for early childhood educators to accomplish a necessary support for a child with special health care needs.

The Medically Fragile Inservice for Related Services Training (M-FIRST) Project was another research effort that evaluated a model program for serving CSSHN within an educational setting (Smith, 1994). The M-FIRST model incorporated recommended practices in training interdisciplinary teams to serve young children with medical fragility. Six sites were chosen which represented rural, urban, and mid-size communities. Subjects from interdisciplinary teams were assessed concerning training needs in 11 competency areas. The fields represented in this interdisciplinary model included occupational therapy, physical therapy, nursing, psychology, education, administration, parents, and Head Start staff. Training events were designed and delivered over the course of 81.5 hours. Targeted skill areas were organized into 3 mega-competency areas: Technical Skills, Service Delivery Issues, and Team Process.

Project evaluation included consideration of best practices in inservice training, measurement of change in competency of staff, team process development, impact upon services, consumer satisfaction, team member assumption of trainer role, validation of instrumentation, project dissemination, and material development. As participants began the process, they completed an assessment scale which required a self-rating of competencies. The measure of where participants perceived themselves at the time of rating was entitled the "AM" scale. The measure of where participants wanted to be following training was entitled the "WANT" scale. Means and standard deviations for each scale were calculated. As participants participated in completion of the scale on 3 occasions over 3 years, significance of change over time was calculated using ANOVAs.

The results of the data analyses demonstrated a strong positive impact for each of the 3 mega-competency areas. Participants perceived themselves as improving in ability to provide interdisciplinary care to children with medical fragility. Participants also reported a significant positive self-perception of change in skill and knowledge. All participants gained in their skills and knowledge throughout the training.

When participants were sorted into the broad categories of "educator" and "related service provider" no significant difference was found in the changes reported over time. Both groups of participants benefited equally in the 3 mega-competency areas. There was, however, a significant difference between the two groups in where they wanted to be in the mega-competency areas. This difference was addressed through on-site technical assistance and training. The M-FIRST model of inservice training was found to be equally effective in both states in which it was piloted. No significant difference was noted in acquisition of the 3 mega-competencies across rural, suburban, and urban groups.

An instrument entitled the Modified Bridge Team Assessment was used to determine change over time in team functioning. There was a statistically significant change on the subscales of Decision-making, and Group Functioning toward improved team functioning. The M-FIRST project demonstrated efficacy in improving team process.

The final research study reviewed that evaluated an intervention or model program was that of Bagnato (1999). This study was similar to the M-FIRST project in that it built the capacity of a local school district to serve CSSHN through a collaborative interdisciplinary approach. This model program was the Healthy CHILD (Collaborative Health Interventions for Learners with Disabilities) Project. This project designed, implemented, and assessed the efficacy of a school-based mobile health care intervention by a collaborative trans-agency developmental health care support team. The research utilized a repeated measures design of an experimental group for some of the outcomes. Additionally, an experimental and contrast group research design was utilized to measure other of the outcomes. Both within group and between group analyses occurred.

There were 40 children with developmental delays and disabilities in the severe range and medical or behavioral health needs served through the pilot Healthy CHILD program. A matched comparison sample of 40 children was selected from children with similar developmental and health conditions who had been seen as patients at Children's Hospital of Pittsburgh in the Child Developmental Unit (CHP CDU). The children from the experimental and control groups were matched across a variety of dimensions including chronological age, developmental disability level, program intensity level, healthcare condition severity index, and complexity of care and support need.

For the Healthy CHILD experimental group, the partners on each team included a parent of a child with special medical needs served in an inclusive early education environment, a developmental psychologist, a pediatric nurse practitioner, a developmental pediatrician from the Children's Hospital of Pittsburgh, a child psychiatrist from Western Psychiatric Institute and Clinic, the child's primary care physician, the child's teacher, and an interagency liaison from Pittsburgh Public Schools. Strategies utilized in the implementation for the experimental group included: development of individualized healthcare plans for CSSHN; tranasagency/transdisciplinary teamwork; nurse coordinated services; mobile, in-vivo classroom based operations; collaborative parent-professional decision making; and frequent follow-up and monitoring.

Program benchmarks were predetermined prior to the onset of the program implementation. There were 14 benchmarks selected. These included outcomes such as: 1) improved hospital/school/agency teamwork; 2) greater teacher confidence and skill level; 3) increased hospital-school cooperation; and 4) improved parent confidence and skill level. The measures used to assess these outcomes included the Developmental Health Care Quality Rating Scale; Developmental Health Care Outcomes Profile: Child and Program Versions; Developmental Health Care Resource Planner; System to Plan Early Childhood Services: Program SPECS; and the Developmental Health Care Time and Activity Monitor.

Outcomes of the project indicated that there was a significant increase in interagency teamwork (44% pre-intervention to 83% post-intervention). Teachers' reported understanding of the condition of the children they served increased to 96% post-intervention. There was also increased hospital-school cooperation as reported by 77.3% of the respondents.

The Healthy CHILD benchmark set for parents was not realized. Unfortunately, families reported ongoing stressors that were not alleviated by the Healthy CHILD model. The extent of care that the children presented to the family milieu did not diminish. Familial stress levels, not unsurprisingly, were not ameliorated, given the severity of health condition of the children.

Desired child outcomes were also determined prior to onset of the Healthy CHILD project. These included such child-specific benchmarks as: 1) decreased absence rates for children; 2) gains in functional skills for children; 3) fewer emergency room visits; and 4) more IEP physical health goals. Instruments used to assess these outcomes were the attendance records of children, the Battelle Developmental Inventory, System to Plan Early Childhood Services: Developmental SPECS, Preschool and Kindergarten Behavior Scale, Temperament and Atypical Behavior Scale (TABS), and Developmental Healthcare Severity Scale. The research design included 2 types of analyses to assess child outcomes. Within group comparisons were used with each child in the experimental group serving as his or her own control. That is, functional levels were compared for each child receiving the supports of the model across various time points. Between group analyses also occurred via a comparison of pre and post intervention data sets for both the experimental and control groups.

To determine whether attainment of child benchmarks occurred, the targeted population was measured at the onset and at the completion of the study. For child benchmarks, the pre and post study scores indicated that: 68.8% of the Healthy CHILD subjects experienced fewer days absent from school; 69.2% of the Healthy CHILD subjects experienced fewer visits to the emergency room; 56.5% of the children demonstrated decreases in atypical behaviors; and

76.9% if the Healthy CHILD subjects had an increased number of health related goals on their IEPs. In general, children in both the experimental and control groups demonstrated similar rates of developmental progress. The children in the Healthy CHILD group showed significant within group progress, given the severity of their delays. Analyses of the data indicated child-specific improvements in 71.6% of the cases for the subject children.

Family benchmarks were also determined and included items such as: 1) decreases in every day parent stress; 2) greater parent knowledge; and 3) increased coping skills. Instruments used to measure these outcomes were the Parenting Stress Index, and the Impact on Family Scale. Participating families were measured with these instruments both at the onset and completion of the study. Research outcomes concerning the needs of families indicated that: 77.3% of the Healthy CHILD families experienced decreases in every day parent stress; 81.8% of the Healthy CHILD families reported a greater level of parent knowledge and coping skills. Unfortunately, some of the indicators of familial stress remained constant or increased across the duration of the project. Families reported a worsening of financial conditions (from 21% to 47%) between the onset and end of the project. Also 80 % of the families reported having trouble with reliable childcare at the onset of the project; this incidence remained constant throughout the life of the grant.

a. Summary. The 4 studies in this section of the literature review focused on model programs or interventions that addressed some of the unmet needs identified earlier, namely that school systems and educators increase their level of preparedness to serve CSSHN by having in place appropriate policies and procedures, providing information and training to school personnel, and improving collaboration with medical professionals.

Three of the studies, Project School Care, M-FIRST, and Healthy CHILD represented interdisciplinary approaches in which educators were given a vehicle for seeking information and training, and ongoing support from medical personnel. Though each of the studies had varying goals, objectives, and measures, the outcomes were consistent in that the capacity of educators improved in serving CSSHN.

Although of great value to the field, these studies have limitations. Each of the studies involved collaboration with the medical or health fields. However, none of the studies incorporated information analyzing cost factors into their data collection. In this era of managed healthcare, and finite levels of educational funding, there are certainly cost and time factors that serve as barriers to educators as they attempt to collaborate with medical professionals.

The study teaching self-catheterization to a young child with myelomeningocele in a preschool setting was significant in that it exemplifies a simple approach to meeting the needs of a CSSHN in the least restrictive environment. The capacity of the educational team was enhanced through demonstration of a systematic approach for teaching a child a functional life skill. Also, the independent functioning of the child, the ultimate goal of special education, was being enhanced.

5. Prediction of Future Trends

One study about CSSHN in educational settings was so unique; it could not be grouped with other related studies (Avery, 1989). This study convened a national panel of experts to consider the impact of medical technology on school health. The members of the panel came from two groups: school nurse consultants and certified school nurses. The Delphi method was used to achieve consensus among this group of experts without face-to-face meetings. Three rounds of questionnaires were sent via U.S. mail to panelists. The first round of query asked for individual forecasts of changes in school health that might occur within the next 15-20 years as a result of the impact of technology on schools. These individual predictions were then sorted and combined into 47 statements of predicted change. The second round of questioning came as the same experts were asked to indicate predictability and desirability for each of the 47 statements of predicted change. The third and final round of questioning gave the panel of experts the opportunity to compare their own round II responses with those of the rest of the total panel on the previous round. Panelists were given the chance to modify their Round II opinions, if desired. Consensus of the experts was reached in 16 of the 47 items. Conclusions from this study emerged as the expert panelists reached consensus around certain predictions along several main themes. Panelists projected that there would be a need for greater funding levels in the future. They also were supportive of the movement toward greater levels of information management, school health screening(s), and health education via computerization. The panel recognized the advent of CSSHN into school environments; they recommended that school nurses be dedicated to provision of the level of practice required by this population. Finally, the panelists voiced a desire for school nurses to be active as partners alongside educators in preparing students for productive lives.

E. Implications for Practice and Further Research

Though much had been written about positions, restrictions, guidelines, and suggested program models for serving children with medical complexity in educational settings, only 30 studies were found that attempted to empirically address the issue. The literature revealed a dire paucity of empirically validated methods to serve CSSHN in educational settings. Nevertheless the children are here and need to be served in a safe, healthy manner. This collective body of research strongly suggests that meaningful steps must be taken to support the population of CSSHN in educational settings now.

When studying families of CSSHN, researchers clearly determine that inordinate levels of stress are present in many arenas for these families (Diehl et al., 1991). As children transition from one educational setting to the next, increased stress commences (Tommett, 1997), most often, with mothers assuming the burden of “boundary spanner,” transferring information from one setting to the other (Myers, 1997). Often families face a forced compromise between obtaining the least restrictive educational environment and a setting that is adequately supportive of the child’s medical needs (Bruns, 1996; Chesler & Barbarin, 1986).

The review of the research focusing upon service to CSSHN in educational settings has major implications for both the medical and educational fields. There are key lessons learned from the conclusions of those studies. For example, the review of the literature reveals that the prevalence of CSSHN ranges from .08 to 18% of the total population of children in the U.S. (Chappell, 1997; Johnson & Asay, 1993; Palfrey et al., 1991; and van Dyke et al., 2002). Though the prevalence rate of CSSHN is highly predicated upon how the population is defined, it is clearly rising (U.S. Department of Education, 2002; van Dyke et al., 2002). The fact that the population of CSSHN is increasing has great implications for educators and the school systems they work within. Though having the obligation and responsibility to serve the population of CSSHN, the resources and knowledge to do so may not be available.

The research also alerts educators that there is little support in determination of the appropriate delegation of nursing duties to UAP, and formation of Individualized Healthcare

Plans (Chappell, 1997; Gardner,1986; Heller et al., 2000; Johnson & Asay, 1993; Josten, Smoot, & Beckley, 1995; Jung, Pearcey, & Phillips, 1994; Wood et al.,1986). However, when training programs in delegation of nursing duties to UAP are applied, confidence of personnel rises (Conger, 1994; Jung, Pearcey, & Phillips, 1994).

Closely related to lack of support for individualized healthcare planning, the literature also evidences that educators have widely varying training experiences and comfort levels in provision of specialized service to CSSHN (Izen & Brown, 1991; Krier, 1993; Lowman, 1993; Lowman, 1994). However, comfort levels improve with training (Lowman, 1993; Lowman, 1994). This has implication for preservice training and professional development activities as well as child-specific training.

Educators have widely varying support through policy and written guidelines regarding the provision of specialized service to CSSHN (Chappell, 1997; Crawford, 1994; Hook, 1992; Johnson & Asay, 1993; Wood, 1986). However, comfort levels of educators rise when policies and procedures are in place (Crawford, 1994; Lowman, 1994). There is a need for statewide standards of school nursing care (Johnson & Asay, 1993) and for policies and procedures to be developed at local levels (Crawford, 1994). If such guidelines did exist, there was a clear need for such policies to be disseminated to involved stakeholders and implemented (Chappell, 1997; Hook, 1992; Johnson & Asay, 1993; Wood et al., 1986).

Increased collaboration needs to exist between healthcare professionals and educators serving CSSHN so that information exchange between the medical and educational entities can occur (Bagnato, 1999; Myers, 1997; and Palfrey et al., 1986). Increased collaboration between education and medicine would result in higher standards of medical care in school settings (Chappell, 1997; Johnson & Asay, 1993; Wood et al. 1986). Increased collaboration between education and medicine could also result in decreased stress for educators and families (Deihl et al., 1991; Lowman, 1993; Lowman, 1994; Lynch et al., 1993; Meyers, 1997; Tommett, 1997).

Local school districts and personnel benefit from very strong and innovative model programs designed to increase capacity to serve CSSHN. Successful interventions have been designed and evaluated to assist educators in serving CSSHN in safe, healthy less restrictive educational environments (Bagnato, 1999; Palfrey et al., 1992; Robertson et al., 1992; Smith, 1994).

Given the rising prevalence of CSSHN, the lack of reported readiness of school systems and personnel to meet their needs, and the Cedar Rapids Community School District v. Garret F. (526 U.S. 66, 1999) determination that nursing services are the obligation of school entities, it becomes a priority to assess the current status of service delivery to CSSHN in ECSE least restrictive environments. It has been 9 years since the Cedar Rapids Community School District v. Garret F. (526 U.S. 66, 1999) determination. It is necessary at this time to assess the progress of the field in service delivery to this population. This study addresses the current status of service delivery for this population in ECSE settings in one state.

III: STATEMENT OF THE PROBLEM

This study assesses the current status of utilization of recommended practices in individualized health care planning in ECSE in one state, in the years subsequent to the Cedar Rapids case. A few researchers have developed models and recommended practices in the delivery of supports and services for CSSHN (Bagnato, 1997; Palfrey et al., 1992; Robertson et al., 1992; Smith, 1994). These practices have produced outcomes demonstrating that, given a collaborative approach between the education and medical fields, CSSHN may be served in typical school environments in a safe, healthy manner. It is notable that these model programs are few and far between. The literature review revealed a mere 3 studies that reported the results of model programs linking the fields of education and medicine. This is especially significant in that the Cedar Rapids Community School District v. Garrett F. case dictates that nursing services are within the purview of the school system and do not need to be related to a special education program to be delivered (526 U.S. 66, 1999). The field is left to wonder if educational entities are floundering within the dynamic tension created between a mandate that is outside of the boundaries of traditional responsibilities assigned to educators and the need to serve CSSHN in least restrictive environs. This is especially true in that some researchers have indicated that most educational entities lack even the most basic policies and procedures for this population (Hook, 1992; Woods et al., 1986). Also, when education entities have developed policies and procedures, these are all too often not understood, or ignored (Hook, 1992). It is of interest to note that these studies were conducted prior to the Cedar Rapids Community School District v.

Garrett F. case when it was unclear whether school districts had the responsibility to deliver nursing services. It remains unknown if the preponderance of policies and procedures related to service to CSSHN has increased given this significant court ruling which has nationwide impact. Likewise, it is also unknown whether those educational entities that do have policies and procedures are practicing fidelity in implementation as set forth in these documents. This is another important issue, given the Cedar Rapids case law.

And yet, it has been shown that the perception of preparedness to serve CSSHN significantly increases given the institutionalization of such policies and procedures. In the study conducted by Crawford, it was concluded that, given Board adopted policies, departmental procedures, and inservice training, the perception of preparedness to serve CSSHN significantly increases for school principals (Crawford, 1994).

A related issue is training for teachers. It has been clearly demonstrated that teachers often are fearful of serving CSSHN. Feeling inept to deliver medically related supports, they view themselves as untrained, unprepared, and reluctant to welcome CSSHN into their classrooms. However, in a study conducted with ECSE teachers, given information, support and exposure to the population, these barriers were largely ameliorated (Lowman, 1994). Once again, it becomes pertinent to wonder whether, subsequent to Cedar Rapids, the preponderance of medical training, information, and supports has increased for educators serving CSSHN.

A few researchers have conducted studies specific to ECSE in the area of individualized health care planning (Bagnato, 1999; Lowman, 1993; Lowman, 1994; Robertson, 1992). None of those occurred before the Cedar Rapids v. Garret F. case. Though empirical evidence does not exist regarding the essential characteristics of individualized health care planning, several authors and agencies have shared forms and formats with the field in an effort to put forward sound practice in support of CSSHN. For example, the Montana Office of Public Instruction (1993) suggested a format for individualized health care planning that was later adopted by the Kansas Department of Education, Office of Special Education (2000). This plan, entitled Serving Students with Special Health Care Needs: Individualized Healthcare Planning, contains the following characteristics of individualized healthcare planning: parent/guardian consultation, physician authorization, staff health training plan, anticipated health crisis plan, and program/transportation planning.

Similarly, the Louisiana Department of Education developed a form for individualized healthcare planning for students with healthcare needs (2000). This form prompts the planning team to solicit input from parents, the school nurse, and involved administrators. It also details a training plan for involved personnel. A medication log is dictated, if applicable (Louisiana DOE, 2000).

The most recent offering in this arena is connected with Healthy People 2010 (Taras, Duncan, Luckenbill, Robinson, Wheeler, & Wooley, 2004). In this publication, Individual Health Service Plans are defined as comprehensive written plans that notify families of their rights, and outline responsibilities of each party. Though specific forms, processes and procedures are not outlined, the text does suggest that a multidisciplinary team is essential in the planning process.

Accumulating the sound concepts and practices put forth by these and other sources, it becomes evident that there are advisable policies and practices involved in sound individualized health care planning for CSSHN. This study involves the content analysis of policies and procedures of agencies delivering early childhood special education in the state of Pennsylvania in order to assess the presence of elements in those documents regarding serving CSSHN.

A. Definitions

Terminology used in the research questions needs to be defined.

Children with Special Health Care Needs (CSHCN). Those children who, due to temporary, or chronic medical condition or illness, require ongoing monitoring, assistance, equipment, devices, or technology to sustain life or health within all environments of daily life.

Children with Special School Health Needs (CSSHN). Those children who, due to temporary, or chronic medical condition or illness, require ongoing monitoring, assistance, equipment, devices, or technology to sustain life or health within school environments.

Early Education Environment. Public and private community settings that serve children from ages 3 to 5 encompassing environments such as preschool, childcare, Head Start programs, and early intervention classrooms, services, and programs.

Individualized Healthcare Planning. This is the process of determining a course of action for the provision of health-related support and service for a CSSHN. The plan is documented in written form and may be found within an Individualized Education Plan, or may be a separate document entitled an Individualized Healthcare Plan (IHP).

Mutually Agreed Upon Written Arrangement. A contract that the Commonwealth of Pennsylvania establishes with agencies accepting the responsibility of delivery of preschool special education programs. There are 34 MAWAs currently in the Commonwealth of Pennsylvania.

Policy. A board-approved set of beliefs, standards, or expectations upon which acceptable program activities are based.

Procedure. An established method of performing in concurrence with a board-approved policy; a process for implementing a policy committed to writing.

B. Research questions

The questions to be answered include:

1) To what extent do PA MAWA local education agencies have policies and procedures in place for CSSHN?

2) What are the elements of the policies and procedures that are in place in PA MAWA local education agencies for serving CSSHN?

IV: METHODOLOGY

Conceptual content analysis is a qualitative methodology involving the process of establishing the existence of concepts as they are represented within text (Colorado State University, 2006). In this methodology, the presence of certain words, phrases, or sentences within text is detected. These text units are then coded according to the concepts that they represent. Following this, inferences can be made about the meaning of the documents.

In the case of this study, the text analyzed was that found in the policies and procedures of Pennsylvania's MAWA agencies regarding service to CSSHN. The unit of analysis was determined to be a line of text. In the content analysis of these documents, the presence of words or phrases within lines of text which represent ideas about serving the population of CSSHN were coded. These coded units provided evidence of concepts about serving CSSHN within the documents.

A. Solicitation of Participants

The participants represented agencies that sign an annual agreement or contract with the Pennsylvania Department of Education (PDE), committing to provide early childhood special education services and supports to 3 to 5 year olds within their local areas. In Pennsylvania, the term Mutually Agreed Upon Written Arrangement or MAWA refers to this annual agreement; the agencies that agree to the provision of Part B early intervention services are termed MAWA agencies. There are 34 such agencies in Pennsylvania serving a statewide total of 21,928 children in the 2005-2006 fiscal year.

Telephone conversations and email communication occurred with PDE officials informing them of the proposed study and requesting permission to appear at the statewide MAWA supervisors' meeting to be held in the autumn of 2006 to solicit participation in the research. While the PDE officials were very supportive of the research and eager for the knowledge that would be contributed to the field, they stipulated that, while participation on the part of the MAWA agencies would be encouraged by PDE officials, it was nonetheless voluntary. The researcher agreed to this stipulation and arranged to be placed on the MAWA agenda for the October, 2006 meeting.

The researcher met with 31 of 34 MAWA supervisors at the statewide meeting held in late October, 2006. One MAWA agency was without representation at the meeting. Two MAWA agency representatives needed to leave the meeting early and did not hear the presentation about the study.

The researcher gave an oral presentation about the study. Some of the points mentioned in the oral presentation included: discussion of the aim of the study; discussion of the research questions; definition of CSSHN and other relevant terminology; and request for MAWA participation in the study. Participation was described as provision of any policy or procedure that the MAWAs may have regarding serving CSSHN.

Written information was also provided to the MAWA supervisors concurrent with and parallel to the oral presentation. A one page letter was issued describing the study (Appendix A). The letter contained the details discussed in the oral presentation (Appendix B). In addition, a form was provided to each MAWA representative to return to the researcher (Appendix C). The form required a check-off indicating the following conditions: a) the MAWA has no policies or procedures at this time; b) enclosed are the policy(ies) the MAWA uses regarding service to

CSSHN; c) enclosed are the procedure(s) the MAWA uses regarding service to CSSHN; or d) enclosed are the policies and procedures the MAWA uses regarding service to CSSHN. The MAWA supervisors were asked to return this sheet with the requested documents, indicating the contents on the check-off sheet. The researcher provided a self-addressed postage-paid envelope to each MAWA supervisor, also informing them that she would reimburse them for postage, or bulk mailing if the documents were too numerous to be returned in the envelope provided.

Additionally, an incentive for participation was included. A $5.00 gift certificate at a chain store coffee shop was enclosed in each self-addressed envelope. The MAWA supervisors were informed that this gift card was provided in hopes that they would participate. However, it was understood that participation was entirely voluntary. If they chose not to participate, they should enjoy the coffee anyway!

Following the meeting, written requests for information were mailed to MAWAs who were not in attendance for the October presentation.   In January, 2007, if responses were not yet received, the researcher called each MAWA supervisor, reminding them of the project and requesting participation. Some messages were left on the Voicemail service of the MAWA supervisor. In other cases, direct conversations with MAWA Supervisors were held via telephone.

B. Data Collection and Preparation

The data were received from the MAWA supervisors in one of 2 ways: 1) Paper copies were sent via US mail in the postage-paid envelopes provided by the researcher; or electronic documents were sent via email correspondence by the MAWA supervisors to the researcher.

In cases where “hard copies” of documents were sent via US mail, optical character recognition (OCR) scanning software was used to scan the documents and import them into a qualitative data analysis software package. In these cases, each page of "hard copy" documents needed to be handled as a separate file. In cases where documents were sent electronically, multiple page documents were imported via the clipboard and handled as a unified file.

A naming convention was developed in which each file was assigned an identifier. The naming convention consisted of the agency of origin first, the title of the document, then the page number, if a multi-page file. Using this naming convention, an example of a multipage file name is, "IU #7 Confidentiality Guidelines, page 1."

Single page files were named using the agency identifier first, followed by the document name. No page identifier was used. An example of a single page file is: "IU #14 Child Abuse Policy."

C. Selection of Coding Software

Tesch (1990) notes that defensible qualitative data reduction systems represent the richness of qualitative data, but do not become overwhelming with the amount of detail. It is therefore essential that through the iterative research process the researcher develop a system of coding that detects relevant ideas and logically links them to one another without becoming lost in voluminous concepts contained in the data. The system must allow for seemingly unrelated documents to serve as evidence of themes to be organized into a logical, relevant conceptual framework.

The collected documents were analyzed using the N-6 software package for qualitative research. N-6, or QSR NUD*IST revision 6, using its full name, was developed for qualitative management and analysis of text data (Qualitative Solutions and Research Pty. Ltd. (QSR), 2004). The term NUD*IST stands for Non-numerical Unstructured Data * Indexing Searching and Theorizing. As its full name implies, N-6 allows the researcher to make meaning from text data that are diverse and unstructured. This software is a toolkit for code-based inquiry and searching which allows the researcher to remain close to the data and to shape emergent interpretations. Use of this software involves a process in which the researcher analyzes information, by importing or transcribing data, coding, classifying, and sorting text into a conceptual framework. The power of N-6 allows for the rich data analysis that Tesch (1990) calls for.

The data analyzed in this study included text from policy and procedures for serving CSSHN of MAWA agencies in Pennsylvania. As each document was coded, new ideas, trends, or concepts were detected. In N-6, these ideas are called nodes. Nodes may be stand-alone, or have sub-ideas. In N-6, these sub-ideas are entitled "children." The evolution of ideas and their associated ideas may be thought of as a coding tree with associated branches. For example, the node "authorization" might evolve as having the branches of "parent authorization," "physician authorization," and "administrator authorization" as sub-categories.

Within the N-6 software system, a description is required for each node. In this way, the researcher clearly defines the meaning of terminology utilized in the research. Nodes discovered in the policies and procedures about serving CSSHN were thus defined within N-6 in order to ensure that the interpretation of meaning of the text remained clear, and were consistently applied throughout the study. These emerging definitions provided the foundation for development of a data dictionary.

D. Developing the Data Dictionary and Rules Guide

Neuendorf (2001) refers to a researcher-developed guide as a content analysis codebook. This specialized dictionary or codebook defines the words and phrases pertinent to the study.

In order to limit the subjectivity of the coder throughout the coding process, coding definitions of the nodes were developed as they emerged in the data. These definitions evolved into a specialized dictionary containing a definition of each node. This guide is contained in Appendix D and is entitled *Content Analysis Data Dictionary and Rules Guide for Documents Related to Service to CSSHN* .

By way of example, one node used in the research was entitled "Individualized Planning/Service." The definition of this node, as developed for the *Data Dictionary and Rules Guide for Documents Related to Service to CSSHN* was as follows:

> This node represents the aspects of planning and service for a CSSHN. Individualized planning is evidenced when a document lists a child's name, birth date, and other unique identifiers, or when a policy or procedure dictates that planning or a service will occur for individual children (e.g. health screenings, Chapter 15 Service Agreements, ISTs, IEPs, administration of medication, Individual Healthcare Plan, etc.) NOTE: General Training or information dealing with specific diagnoses (e.g. AIDS, tracheotomy, catheterization, etc.) are not evidence of individualized planning or service.

Note that definitions also included exclusionary criteria, as appropriate, if they proved useful in coding the documents consistently. Such definitions became the reference for the coder to help in deciding which code to assign to specific text or if a new node needed to be identified.

The data dictionary may also define synonymous terms. In the case of this study, some documents in the collected data used the term "educational administrator." The *Data Dictionary and Rules Guide for Documents Related to Service to CSSHN* defines other terms synonymous with "educational administrator" as "MAWA Supervisor," "Executive Director," or "Preschool Service Coordinator." Referring to this definition, a coder would receive guidance on how to code words or phrases which were tantamount to previously established nodes.

Similarly, a set of rules were developed to assist the coder in decision-making while coding the text. During the coding process, the coder is confronted with decision-making dilemmas as certain text may serve as evidence of multiple nodes. An example of such a dilemma might be in determination for a node assignment for the term “parent signature.” The coder is faced with a conundrum: Does the phrase “parent signature” constitute “parental input” and/or “parental authorization,” two nodes that have evolved in the coding process? Following consideration, the researcher decided that the presence of a parent signature signifies *both* that the parent had opportunity for input *and* provided authorization for the plan to be implemented. Referring to the *Data Dictionary and Rules Guide for Documents Related to Service to CSSHN,* the researcher thus made the following entry:

> **SIGNATURES-** signify BOTH input for parents, physicians, administrators, and public officials, AND constitute authorization or permission by those stakeholders.

E. Coding Process

As the researcher embarks upon content analysis of documents, a decision must be made about the unit of analysis. The unit of analysis may be at various levels including, the sentence, line, or paragraph levels. In this study, the researcher chose to analyze documents using a “line of text” as the unit of analysis. That is, the coder considered the text in each document, line by line.

Upon commencement of the coding process, the researcher discovered that one line of text could contain multiple concepts, and thus, multiple codes. An example is the following line of text:

> “each case will be individually and periodically reviewed by a…”

Upon reflection during the coding process, the researcher coded this text as: 1) relevant to its base or source (i.e. the specific MAWA that contributed the document); 2) evidence of individualized planning, and 3) evidence of periodic review. This line of text, therefore, received multiple coding assignments.

At the onset of the project, the coding scheme entered into the N-6 software contained concepts that the researcher expected to be included as central to the policies and procedures for CSSHN children. These preliminary expectations were shaped by the literature review, documents used in the researcher's agency, and the researcher's experience as a MAWA administrator. Those original concepts include the following: a.) provision of generalized health care training for personnel (e.g. first aide, CPR, universal healthcare precautions, etc.); b) input from parents in the process of individualized health care planning for CSSHN; c) authorization from parents prior to the delivery of individualized health care for CSSHN; d) input from physicians in the process of individualized health care planning for CSSHN; e) authorization from physicians prior to the delivery of individualized health care plans for CSSHN; f) input from administrator(s) in the process of individualized health care planning for CSSHN; g) authorization from administrator(s) prior to the delivery of individualized health care for CSSHN; h) input from nurses prior to the delivery of individualized health care for CSSHN; i) use of a log to record health care procedures; j) periodic review and update individualized healthcare plans; k) on-going monitoring of health care services; l) provision of child-specific training to persons administering individualized health care procedures to CSSHN; m) development of emergency procedures in individualized health care planning for CSSHN; and n) development of back-up plans for provision of service to CSSHN

Throughout the process of reviewing and coding the documents provided by Pennsylvania's MAWA agencies, the researcher's understanding of the concepts contained in the documents deepened. Additional key concepts and their inter-relatedness to other concepts emerged. It became clear that much of the text being coded did not fit within the conceptual framework of 14 original nodes. Additional concepts and related concepts were detected, necessitating the development of additional nodes within the N-6 software. Furthermore, new definitions and new rules for coding the data needed to be developed in the course of this iterative process. As the original framework of 14 nodes grew, this emergent understanding needed to be reflected in the *Content Analysis Data Dictionary and Rules Guide for Documents Related to Service to CSSHN* (Appendix D) as well as the *Node System for Analysis of Documents Related to Service to CSSHN* (Appendix E).

A subsequent task in this iterative process is that documents that were coded prior to the detection of newly detected nodes, needed to be re-examined for the presence of the new nodes. Each document included in this study was reviewed for compliance with updated coding strategies, nodes, and the *Content Analysis Data Dictionary and Rules Guide for Documents Related to Service to CSSHN* at least twice prior to the inter-rater reliability study.

1. Establishing Inter-coder Reliability

In order to establish the degree of inter-coder reliability, a random sample of 20% of the lines of text, or 52 pages were randomly selected for study of the degree to which the researcher's codings were in alignment with a colleague inter-rater. The researcher utilized a social psychology website to randomly generate a list of 52 numbers within the range of numbers from 1 to 262 (Urbaniak and Scott, 2008). The 262 pages received from the MAWA agencies were each assigned a number and the 52 randomly selected pages were set-aside for the inter-rater reliability study. The list of randomly generated numbers and their associated document names is contained in Appendix F. The randomly selected documents represented a total of 1,983 lines of text collected for the project. The researcher also printed out the queries from N-6 reporting the coding she had previously assigned to each of the randomly selected pages.

A colleague inter-rater was identified. The colleague was a retired Ph. D. in mathematics who was a former chair of a California university's Geometry Department. She had served as advisor to countless Ph. D. candidates. Having an earnest interest in education, she was serving as a Board Member for a local school entity at the time of the study. A training process and rubric for decision-making were developed. The researcher and colleague inter-rater met for 2 hours at the onset of the reliability study. During the initial meeting, instruction ensued regarding the study. Along with verbal discussion, instructional tools utilized during this session included presentation of the *Node System for Analysis of Documents Related to Service to CSSHN* and the *Content Analysis Data Dictionary and Rules Guide for Documents Related to Service to CSSHN.* Several practice documents were coded by the colleague to assess her initial level of comfort and understanding of the study and the coding process.

Following the initial session, the colleague inter-rater reviewed the documents and notes from the initial session, returning to conduct the reliability study two weeks following the initial training. During this 4 hour session, the colleague inter-rater and researcher worked side-by-side. The colleague asked a few questions to increase clarity about the study, referred frequently to the *Node System for Analysis of Documents Related to Service to CSSHN* and the *Content Analysis Data Dictionary and Rules Guide for Documents Related to Service to CSSHN.* Following 4 hours of work, she reported that she felt confident in her understanding of the task and could complete the remainder of the work independently.

When the researcher and inter-rater colleague re-convened, the coding of the researcher was compared with that of the inter-rater. The reader may recall that multiple codings could, and most often did, appear on a single line of text. In comparing the coding of the researcher with the inter-rater colleague, if all codings within one line of text were not 100% in agreement, the researcher considered this as a disagreement for that line. The inter-coder reliability formula was calculated as follows: Number of Lines of Agreements/Total Number of Lines Reviewed X 100 = % of inter-rater reliability.

The number of lines of text reviewed by the inter-rater colleague was 1,983, or 21.29% of the total number of lines coded in the project. Of those 1,983 lines of text, there was agreement on 1,535 lines; thus, the researcher and inter-rater colleague had an initial agreement of 77.4%. Said another way, there was a dispute between the researcher and the colleague/inter-rater on a total of 438 lines of text.

Following calculation of the initial reliability statistic, the two colleagues negotiated differences, as stipulated in the Methodology. Upon analysis, the researcher determined that the differences between the inter-rater colleague and the researcher encompassed 4 main areas. Those involved: 1) whether there was a relationship between input, participation, and responsibility of involved stakeholders and permission of involved stakeholders; 2) whether there should be an addition of a category or node addressing Input, Participation, and/or Responsibility of Public Officials; 3) whether there should be an addition of a category or node addressing Input, Participation, and/or Responsibility of CSSHN; and 4) whether there was a distinct difference between Prevention and Safeguards.

The first area of negotiation addressed the relationship between input, participation, and responsibility of involved stakeholders (e.g. parents, physicians, and administrators) and permission of involved stakeholders. The node schema was designed to consider input, participation, and responsibility to be distinct from permission or authorization. Following discussion, the researcher and the inter-rater colleague however ultimately agreed that any party who gave permission or authorization always had opportunity for input. The researcher, therefore, adjusted the node schema to make permission or authorization of stakeholders a sub-node of input, authorization, and or responsibility. The data dictionary, node schema, and coding of documents thus were subsequently altered to reflect this change.

The second area of negotiation addressed whether there should be a node addressing the input, participation, and/or responsibility of public officials. Several of the collected documents addressed the role of public officials in event of the outbreak of communicable diseases, or child abuse or neglect. As the input and authorization of public officials is juxtaposed to that of school administrators in such events and the response of school officials is sometime predicated upon the authorization of public officials, it was agreed that there was indeed a need to add nodes for input, participation, and/or responsibility of public officials, as well as their authorization. Once again, the data dictionary, node schema, and coding of documents were altered to reflect this change.

The third area of negotiation between the researcher and the inter-rater colleague was whether there should be an addition of a category or node addressing Input, Participation, and/or Responsibility of CSSHN. Though there were citations in the collected documents that referenced the roles of children, initially, the researcher was reluctant to add a node about the responsibility of children as the study focused on preschool-age children. Upon reflection, however, the researcher and colleague agreed that certain levels of participation are identified and appropriate for preschool-age CSSHN. Some of those may include a preschool-age CSSHN: reporting discomfort; holding supplies or equipment; or assisting in positioning his or her body to facilitate a healthcare procedure. As in the 2 examples described above, the data dictionary, node schema, and coding of documents were altered to reflect this change.

The fourth and final area of negotiation between the researcher and colleague was whether there was a distinct difference between the nodes Prevention and Safeguards. The 2 referred to the data dictionary and ultimately decided that there was indeed a distinction between the two areas. There were therefore no changes made to the data dictionary, node schema, or coding of documents following this negotiation.

The possibility of one of three post-negotiation conditions existed: 1) following negotiation, the colleagues agreed and changes were made to either the researcher's or the colleague's coding; 2) following negotiation, the data dictionary and node schema within N-6 were modified, then the colleagues agreed; or 3) following discussion, the colleagues continued to disagree. Subsequent to the negotiations process, the following occurred: Agreements = 1,969 lines of text; Disagreements = 14 lines of text.   Therefore, inter-coder reliability was calculated at a final rate of 99.29%. The researcher and inter-rater colleague agreed that the differences in coding on these 14 remaining lines of text were a function of fatigue, or simple human error, and did not represent real disagreements about the nodes, coding schema, or data dictionary.

V: FINDINGS

In response to the request for policies and procedures for serving CSSHN, 163 documents were returned in the self-addressed envelopes by January 15, 2007. Follow-up calls or emails were placed to MAWA supervisors who had not yet responded, giving a gentle reminder that documents had not yet been received and would be appreciated if sent. By February 15, 2007, 181 documents were received. Another 52 documents were received during the ensuing months, making the total number of documents received 233.

There were 262 pages contained within the 233 documents that were received. During the period from December, 2006 through January, 2008, the researcher imported and coded the 262 pages of text. In the case of this project, it was anticipated that the policies and procedures about serving CSSHN would contain 14 nodes or central ideas. During analysis, a total of 159 nodes were detected; 54 nodes emerged that were non-agency identifiers.

A. Agency Identifiers: Base Data

Every document received needed to be linked to its source, or have an agency identifier. In N-6 the term for data source is “base data.” Each of the 34 MAWA agencies was assigned a node, or “address” within the N-6 structure so that individual documents could be linked with their agency of origin. Each document was first coded with its source, or base data. In addition, if a MAWA agency did not respond to the request for documents, a node was developed for this situation so that inquiry could occur to discover those agencies that elected not to respond. Some

MAWA agencies did respond, indicating that they did not have policies or procedures to share with the researcher. The following is a synopsis of the findings regarding base data. The analysis of these data answered the first research question 1): To what extent do PA MAWA local education agencies have policies and procedures in place for CSSHN?

Of the 34 MAWA agencies in Pennsylvania, a total of 23 MAWA agencies (67.6%) responded to the request for policies and procedures. Among those, 11 (32.3%) indicated that they had no written policies or procedures to share with the researcher. One MAWA supervisor in this group wrote, “Though we have no written policies or procedures, we follow physicians’ directives in serving children with special health needs.” Another MAWA supervisor indicated that her agency had no written policy or procedure, but that she and her contracted nurse would be willing to speak with me about their procedures when presented with the need to serve a CSSHN. An additional MAWA supervisor indicated that her program was in the process of developing procedures to serve CSSHN, but had nothing to share at the time of the request. Several of the MAWA supervisors apologized for not being in a position to help with the study, and others indicated that they were anxious for the results of the study so that they could improve their practice in service to CSSHN. The remaining 12 of the 23 responding MAWA agencies provided 233 documents containing a total of 262 pages of text. There were a total of 9,314 lines of text in the documents submitted by MAWA agencies.

As mentioned earlier, the researcher did follow-up with reminders to the request for written policies or procedures to guide service to CSSHN in least restrictive environments. Nevertheless, 32.4% percent of the agencies (11) failed to respond to the request and reminders.

The MAWA agencies were further defined in N-6 by size (small, medium, or large). For the purposes of this study, small MAWA agencies were defined as serving 1-499 children in the

2005-2006 fiscal year. Medium-sized MAWA agencies were defined as serving 500-999 children in the same fiscal year. Lastly, large MAWA agencies were defined as serving more than 1,000 children during that time period. In Pennsylvania, there were 14 small MAWA agencies, 14 medium size agencies, and 6 large agencies at the time of the study. When asked to supply the researcher with policies and procedures about service to CSSHN, 2 of the 14 small MAWA agencies provided a combined total of 30 pages of text, while 7 of the 14 medium-size MAWA agencies provided a combined total of 179 pages of text. Of the 6 large MAWA agencies, 3 provided a combined total of 53 pages of text. Half of the large and medium providers supplied policies and/or procedures as data for the study, while only 14.3% of the small providers supplied data.

Another relevant characteristic of the participating MAWA agencies was region. In Pennsylvania, the Office of Child Development and Early Learning (OCDEL) divides their statewide training and technical assistance network for early childhood (i.e., Keystone Stars) into 6 regions: 1) Central Regional Key; 2) Northeast Regional Key; 3) Northwest Regional Key; 4) South Central Regional Key; 5) Southeast Regional Key; and 6) Southwest Regional Key. All regions were represented in the study in that members of each region supplied data. There were, however, no regional differences in the amount of data contributed. The region of Southwestern Pennsylvania was the sole region with a 100% response rate. A map of Pennsylvania's counties and their associated regional key may be found in the Pennsylvania Key Resource Directory (Pennsylvania Key, 2006), or by accessing http://www.pde.state.pa.us/early_childhood/lib/early_childhood/PA_Key_Resource_Directory_Ver_4-06.pdf. Table 1 provides a listing of the MAWAs by size, county, regional key, and response to the study. The reader should note that 3 of the 34 MAWA agencies are located within 2 Regional Keys.

Table 1. Pennsylvania MAWAs by size, counties, regional keys, and response status

MAWA	**SIZE (CHILD COUNT)***	**COUNTIES**	**OCDEL REGIONAL KEY**	**RESPONSE STATUS**
1. Altoona	S(248)	Altoona Area SD	Central	DID NOT RESPOND
2. Chester-Upland (Elwyn)	S(109)	Chester	Southeast	12 documents/ 12 pages
3. Erie City SD	S(294)	Erie City	Northwest	18 documents/ 18 pages
4. Farrell	S(30)	Farrell Area SD	Northwest	Responded, “No Policies”
5. Hazelton ASD	S(472)	Wyoming & Luzerne	Northeast	Responded, “No Policies but we do follow physician’s directives”
6. IU # 1	M(536)	Washington, Greene, & Fayette	Southwest	Responded, “No Policies,”
7. IU # 2	M(585)	City of Pittsburgh	Southwest	Responded, “No Policies but do have procedures that we may discuss by phone…”

Table 1 (continued).

8. IU # 3	L(1,440)	Allegheny	Southwest	13 documents/ 41 pages
9. IU # 4	M(609)	Mercer, Lawrence, & Butler	Northwest	DID NOT RESPOND
10. IU # 5	M(827)	Erie, Crawford, & Warren	Northwest	8 documents/ 8 pages
11. IU # 6	M(506)	Venango, Clairion, Forest, & Jefferson	Northwest	2 documents/ 2 pages
12. IU # 7	M(608)	Westmoreland	Southwest	76 documents/ 76 pages
13. IU # 8	M(800)	Cambria, Somerset, Blair, & Bedford	Central	Responded, "No Policies"
14. IU # 9	S(270)	McKean, Potter, Elk, & Cameron	Northwest	Responded, "No Policies"
15. IU # 10	S(375)	Clearfield, Clinton, & Centre	Central & Northwest	DID NOT RESPOND
16. IU # 11	S(306)	Huntingdon, Juniata, Mifflin, & Fulton	Central	Responded, "No Policies"
17. IU # 12	L(1,023)	Franklin, Adams, & York	South Central	6 documents/ 6 pages
18. IU # 13	L(1,073)	Lebanon, & Lancaster	South Central	DID NOT RESPOND
19. IU # 14	M(700)	Berks County	Northeast	9 documents/ 10 pages

Table 1 (continued).

20. IU # 15	M(787)	Cumberland, Perry, Dauphin, and Northern York	Central & South Central	67 documents/ 67 pages
21. IU # 16	M(503)	Union, Snyder, Northumberland, Columbia, & Montour	Central	5 documents/ 5 pages
22. IU # 17	S(361)	Tioga, Bradford, Lycoming, & Sullivan	Central & Northeast	DID NOT RESPOND
23. IU # 19	S(442)	Susquehanna & Lackawanna	Northeast	Responded, "No Policies"
24. IU # 20	M(674)	Monroe, Northampton	Northeast	11 documents/ 11 pages
25. IU # 21	M(978)	Carbon & Lehigh	Northeast	DID NOT RESPOND
26. IU # 22	L(1,160)	Bucks County	Southeast	DID NOT RESPOND
27. IU # 23	L(1,082)	Montgomery	Southeast	6 documents/ 6 pages
28. IU # 24	M(898)	Chester	Southeast	Responded, "No Policies"
29. IU # 25	M(750)	Delaware	Southeast	DID NOT RESPOND

Table 1 (continued).

30. IU # 26 (Elwyn)	L(2,339)	Philadelphia (Elwyn)	Southeast	Responded, “Documents are currently being developed.”
31. IU # 27	S(360)	Beaver	Northwest	DID NOT RESPOND
32. IU # 28	S(349)	Armstrong & Indiana	Northwest	DID NOT RESPOND
33. IU # 29	S(332)	Schuylkill	Northeast	Responded, “No Policies”
34. Western Wayne Consortium	S(102)	Wayne & Pike	Northeast	DID NOT RESPOND
* Legend: Small (S) serving 1-499 children; Medium (M) serving 500-999 children; Large (L) serving 1,000 + children				

The following sections provide the findings regarding the elements of the policies and procedures that are in place in PA MAWA local education agencies for serving CSSHN. Analysis of these data addressed the second research question: What are the elements of the policies and procedures that are in place in PA MAWA local education agencies for serving CSSHN?

B. Element I: Training and Information

One theme that emerged from the documents supplied by the MAWA agencies was that of *Training and Information*. Across the Commonwealth, agencies have designed processes for training and providing information to staff about serving CSSHN. Some of this training may be delivered within the context of scheduled professional development; other training may be delivered on a consultative basis. There were 9 sub-categories or types of Training and Information identified in the statewide documents. Those were: 1) General Training and Information; 2) Child-specific Training and Information; 3) Training and Information about Confidentiality ; 4) Training and Information about Medical Records; 5) Training and Information about Team Approaches; 6) Training and Information about Prevention; 7) Training and Information about Follow-up activities; 8) Training and Information about Safeguards; and 9) Training and Information about Transportation Planning. In the area of Child-specific training, 3 sub-categories were identified. Those were: 1) Nurse/Medical trainer; 2) Parent trainer; and 3) Non-medical trainer.

The data revealed that although 61.8% of the text related to training and information of a general nature, a mere 4.6% of the text addressed training and information about child-specific matters. The remaining 7 sub-nodes together comprised 12.9% of the total lines of text with any one sub-node representing fewer than 5% of the total lines of text. The findings related to Training and Information are summarized in Table 2.

Table 2. Findings related to Training and Information

NODE: **Training & Information (2.0)**	**# LINES**	**% LINES**	**# PAGES**	**% PGS.**
General (2.1)	5756	61.8%	160	61.1%
Child-Specific (2.2)	428	4.6%	23	8.8%
Nurse Trainer (2.2.1)	4	.04%	1	.04%
Parent Trainer (2.2.2)	2	.02%	1	.04%
Non-Medical Trainer (2.2.3)	4	.04%	1	.04%
Confidentiality (2.3)	184	2.0%	19	7.3%
Medical Records (2.4)	19	.2%	3	1.1%
Team Approaches (2.5)	278	3.0%	16	6.1%
Prevention (2.6)	445	4.8%	37	14.1%
Follow-up (2.7)	57	.6%	7	2.7%
Safeguards (2.8)	200	2.2%	20	7.6%
Transportation (2.9)	11	.1%	3	1.1%

C. Element II: Input, Participation, or Responsibility

The node entitled *Input, Participation, and/or Responsibility* described the contributions that others made prior to and during provision of service to a CSSHN. The collected documents provided evidence of 7 groups of persons who provide input, participation, or have responsibility in the healthcare planning and implementation process. Those stakeholders included: parents, physicians, nurses, administrators, staff members, public officials, non-school child services personnel, and children including CSSHN. Table 3 summarizes the findings of the study regarding Input, Participation, or Responsibility.

Table 3. Findings related to Input, Participation, and Responsibility

NODE: Input, Participation & Responsibility (3.0)	**# LINES**	**% TOTAL LINES**	**# PAGES**	**% TOTAL PAGES**
Parent Input, Participation & Responsibility (3.1)	619	6.7%	120	45.8%
Parent Permission or Authorization (3.2.1)	376	4.0%	52	19.8%
Physician Input, Participation & Responsibility (3.2)	378	4.1%	52	19.8%
Physician Permission or Authorization (3.2.1)	363	3.9%	53	20.2%
Nurse Input, Participation, & Responsibility (3.3)	412	4.4%	66	25.2%
Administrative Input, Participation, & Responsibility (3.4)	197	2.1%	31	11.8%
Administrative Permission or Authorization (3.4.1)	78	.8%	23	8.8%
Staff Input, Participation & Responsibility (3.5)	507	5.4%	72	27.5%
Public Official Input, Participation & Responsibility (3.6)	72	.8%	11	4.2%
Public Official Permission or Authorization (3.6.1)	45	.5%	5	1.9%
Non-school Child Services Personnel Input, Participation, & Responsibility (3.7)	19	.2%	2	.8%
Child Input, Participation, & Responsibility (3.8)	104	1.1%	27	10.3%

Of the 8 stakeholder groups, 4 of those were found to give permission or authorization for a procedure to occur. Those were: 1) parents; 2) physicians; 3) administrators; and 4) public officials. Parents and physicians were found to be responsible for providing permission for the administration of medication or medical procedures during the school day for a CSSHN. Administrators also were found to give permission which served as assurance of their awareness of the need for a CSSHN and that staff would be trained and dispatched to follow-through on the medically necessary tasks. Public health officials were found to give permission only in the event of an outbreak of a pandemic event such as AIDS, or methicillin-resistant Staphylococcus aureus (MRSA), or in the case of child abuse or neglect. In such cases, public officials over-ride the authority of school officials in education settings. Of the total lines of text, 9.5% addressed stakeholders who gave permission or authorization for service to CSSHN.

There were 12 sub-nodes in the area of input, participation, and responsibility. Text relating to medical personnel comprised 12.4% of the total lines of text, with 8% addressing physician input, participation, responsibility, or permission and 4.4% addressing nurse input.

Of the total lines of text, 11.8% was related to children and families. Parents were found to have responsibilities including provision of medical records or other information, and participation in meetings. CSSHN were found to be required to participate in the healthcare process by performing such activities as: assuming a desired position to enable a procedure to occur; assisting with donning or doffing clothing before or after a medical procedure; and holding a syringe during gastrostomy feeding. Other text evidenced that CSSHN may assist caring adults through their report of discomfort or irritation during a healthcare procedure, or auras indicating that a seizure or anaphylactic reaction was forthcoming.

There were 8.3% of the total lines of text related to the roles and responsibilities of school personnel. This text addressed both school staff and administrators. School staff members were found to be in a participatory role and were given responsibility in the healthcare process. Administrators were one of the groups with the added responsibility of giving permission to assure that CSSHN received necessary services while in school.

Fewer than 1% of the total lines of text analyzed in the study addressed the input, participation, responsibilities and permission of public officials and non-school child services personnel.

D. Element III: Logging, Documentation or Record Keeping

The node *Logging, Documentation or Record Keeping* represented the record keeping of activities provided to CSSHN. Often, activities such as the administration of medications or feeding through a gastrostomy tube were logged to serve as a record of healthcare activities that took place while the CSSHN were in school. Table 4 summarizes the findings related to logging, documentation or record keeping.

Table 4. Findings related to Logging, Documentation, or Record Keeping

NODE	**# LINES**	**% of TOTAL LINES**	**# PAGES**	**% TOTAL PAGES**
Logging, Documentation, or Record Keeping (4.0)				
Child's Name Log (4.1)	5	.05%	3	1.1%
Activity Log (4.2)	5	.05%	4	1.5%
Date Log (4.3)	7	.07%	4	1.5%
Time Log (4.4)	3	.03%	3	1.1%
Administering Personnel (4.5)	2	.02%	2	.8%
Log with Non-specified Elements (4.6)	26	.3%	16	6.1%

The data revealed 5 elements that were specified on logs, documentation, or record keeping forms. Those 5 elements included: 1) child's name; 2) activity or medication administered; 3) date administered or delivered; 4) time administered or delivered; and 5) name or names of administering personnel. Fewer than 1% of the total lines of text reviewed in the study were related to these logging elements. There were, however, some documents reviewed that referenced "documentation" or record keeping, but did not specify the elements of the documentation; this was termed "log with non-specified elements" in the data dictionary and comprised .3% of the total lines of text reviewed.

E. Element IV: Individualized Planning and Services

The node *Individualized Planning and Services* represented the aspects of planning and service for specific CSSHN. Individualized planning was evidenced when a procedural document listed a child's name, birthdate, and/or other unique identifiers, or when a policy or procedure dictated that planning or a service would occur for individual children (e.g. via health screenings, Chapter 15 Service Agreements, ISTs, IEPs, administration of medication, Individual Healthcare Plan, etc). General training or information that dealt with specific diagnoses (e.g. AIDS, Tracheotomy, catheterization, etc.) were not considered evidence of individualized planning or service.

There were 1,789 lines of text coded as related to individualized healthcare planning of the 9,314 total lines coded. This represented 19% of the coded text and the second largest category of text analyzed in the study. These references were found in 83 of the 262 pages reviewed, or on 31.7% of the total number of pages supplied by the MAWA agencies. Table 5 summarizes the findings related to individualized healthcare planning and delivery of services.

Table 5. Findings related to Individualized Healthcare Planning and Services

NODE	# LINES	% TOTAL LINES	# PAGES	% TOTAL PAGES
Individualized Planning and Services (5.0)	1,789	19.2%	83	31.7%
Ongoing Monitoring for Fidelity of Implementation (5.1)	0	0%	0	0%
Emergency Planning (5.2)				
Community or School Disaster (5.2.1)	8	.08%	1	.04%
Change in Health Status of CSSHN (5.2.2)	466	5.0%	40	15.3%
Change for another child (5.2.3)	0	0%	0	0%
Plan for the rest of the children (5.2.4)	1	.01%	1	.04%
Emergency Planning, other (5.2.5)	340	3.7%	33	12.6%
Transportation Emergency Planning (5.2.6)	36	.4%	3	1.1%
Back-up Planning (5.3)				
Staff Absences (5.3.1)	17	.2%	5	1.9%
Alterations in Schedule (5.3.2)	15	.2%	4	1.5%
Clothing or Equipment (5.3.3)	16	.2%	6	2.3%
Periodic Review of Plan for Appropriateness (5.4)	5	.05%	2	.7%
Periodic Review based on Frequency (5.4.1)	4	.04%	2	.7%
Periodic Review based on Reason (5.4.2)	11	.1%	4	1.5%
Individualized planning using Team Approaches (5.5)	183	2.0%	17	6.5%
Individualized planning including Prevention (5.6)	137	1.5%	19	7.3%

Table 5 (continued).

Individualized planning including Follow-up (5.7)	38	.4%	8	3.1%
Individualized planning including Safeguards (5.8)	102	1.1%	8	3.1%
Individualized Planning Including Transportation Planning (5.9)	12	.1%	10	3.8%

The content of the lines coded as evidence of individualized healthcare planning was varied in both format and theme. There was evidence of individualized planning documents that were forms for generic healthcare planning, individualized planning for children with seizure disorders, and individualized planning for children with asthma.

Within the node *Individualized Healthcare Planning and Services*, there were major themes and sub-sections of each major theme. In the area of individualized healthcare planning, the major themes included were: a) ongoing monitoring for fidelity of implementation; b) emergency planning; c) back-up planning; d) periodic review of plans for appropriateness; e) team approaches; f) prevention; g) follow-up; h) safeguards; and i) transportation. A total of 20 sub-nodes were detected related to individualized planning.

It was found that 9.2% of the total lines of text analyzed related to emergency planning for a CSSHN. The greatest attention in the documents was spent on emergency planning for a change in health status (5.0% of the total lines of text analyzed). Such changes in health status included a seizure or allergic reaction. The second largest category in emergency planning included “emergency planning-other.” This category comprised 3.7% of the total lines of text and represented text that mentioned emergency planning, but did not specify the elements of such planning. The other nodes related to emergency planning represented less than 1% of the total lines of text and included emergency planning for a community or school disaster; planning for the rest of the children in the event of an emergency; and emergency transportation planning.

Remaining nodes and sub-nodes related to individualized planning included: 1) back-up planning for staff absences, alterations in schedules, or need for back-up clothing or equipment; 2) periodic review of an individualized plan due to as a specified reason or due to a prescribed timeframe; 3) follow-up subsequent to a medical event for a CSSHN; and 4) transportation planning. Less than 1% of the text addressed these nodes.

It was discovered that there was an absence of text that related to ongoing monitoring of an individualized healthcare plan for fidelity of implementation. There was also an absence of text related to planning for a CSSHN in the event of a medical emergency for another child in the classroom.

VI: DISCUSSION

The data provided by Pennsylvania's MAWA agencies represented a collective body of documents used in Pennsylvania to guide service for CSSHN. The analysis of this information pointed to a pathway for MAWAs to improve practice and to ensure safety and optimal health for CSSHN while in school settings.

A. Status of Current Practice in Serving CSSHN in Pennsylvania

The analysis of Pennsylvania MAWA documents represented a snapshot of the current policies and procedures about service to preschool-age CSSHN in the state. The coding of the text using base data nodes enabled the analysis of the documents with respect to their origin, the size of the agency, and the region of the state in which the agency was located. The analysis of base data nodes provided data needed to answer the first research question: *To what extent do PA MAWA local education agencies have policies and procedures in place for CSSHN?* There were 105 nodes describing the base data, or source of the documents.

An additional 54 nodes emerged as the content of the documents became evident. These represented major themes or elements of the policies and procedures. As the elements of the documents became salient in the iterative coding process, the second research question was answered: *What are the elements of the policies and procedures that are in place in PA MAWA local education agencies for serving CSSHN?* Those major themes or elements emerged as:

Training and Information; Input, Participation and Responsibility; Logging, Documentation, & Record Keeping; and Individualized Planning and Services.

The largest categories of coded text occurred in the areas of General Training and Information (61.8% of total lines coded) and Individualized Healthcare Planning (19.2% of total lines coded). This relative weight demonstrates that while general healthcare training appears to be the subject of procedural documents in Pennsylvania, training about individual CSSHN is not, which suggests that training about individual CSSHN is perhaps being ignored. This is in spite of the fact that delivery of sound individualized healthcare practice is clearly the legal responsibility of educational entities (Cedar Rapids Community School District v. Garrett F. 526 U.S. 66, 1999).

No one entity supplied policies and procedures containing all the elements that were detected statewide for service to CSSHN. The collective body of documents, however, represented the aggregate efforts of providers in one state.

1. Base Data

The results indicated that small providers were less likely to have policies and procedures in place for the service to CSSHN. Although 50% of medium and large MAWA providers contributed policies and procedures about service to CSSHN, only 14.3% of the small providers contributed to the body of collected documents. It may be that small providers react to the school health needs of individual children as they present themselves, but do not feel a need to create a state of preparedness through the formulation of policies or procedures. Furthermore, due to the low incidence of this population, small providers are faced with proportionately fewer of these CSSHN to serve. In the Chappell research (1997), the largest California school districts reported having proportionately more children with physical disabilities. Possibly, the large school entities are the districts in closer proximity to hospitals, diagnostic supports, and service providers to meet the needs of CSSHN. It would then follow that larger providers may be more likely to have policies and procedures in place to serve this population. Conversely, smaller providers may have less pressure to provide service to CSSHN, and thus, a reduced need to develop policies and procedures about this topic.

A recently published Section 619 Profile (Danaher, Kraus, Armijo, & Hipps, 2003) noted that just "2.2% of all preschool age children receiving early intervention services are eligible under the eligibility category of "other health impairment."' The need for formal policies and procedures for small MAWAs serving fewer than 500 children may thus be perceived as unnecessary due to the low incidence of the population.

A review of the findings indicated that there was no correlation between contribution of policies and procedure and the location of the Regional Keys. Though Lowman (1993) found that urban and suburban school districts tended to have written health care policies to a greater degree than rural districts, Pennsylvania's Regional Keys were not easily sorted by the categories of urban, rural, and suburban; each Regional Key comprised a larger swath of the state, most regions containing each of these geo-structures.

Statewide, only 12 MAWA agencies demonstrated evidence of planning for service to CSSHN through the development of policies or procedures; this is a worrisome rate of just 35.3%. Similarly, Lowman (1993) found that about 38% of the teachers reported that their school systems had a formal written policy concerning the administration of medication. It is interesting that the Lowman research occurred 15 years prior to the current study. The degree to which policies and procedures exist is nevertheless at virtually the same level. Progress has remained stagnant during this time period in spite of the fact that research has shown that policies and procedures increase the preparedness of school entities to serve CSSHN.

It must also be noted that it is unknown how many of the non-participating Pennsylvania MAWAs do, in fact, have policies and procedures about care of CSSHN. It is possible that the non-participating MAWAs did have data to share, but simply neglected to do so. The findings of Wood, Walker and Gardner (1986) advised that increased attention must be paid on a state level toward construction of policies and guidelines to assist school districts to serve the population of CSSHN; this recommendation must be given consideration by Pennsylvania.

2. Training and Information

A key content area of the policies and procedures about safe and healthy care of CSSHN in least restrictive environments was in the area of Training and Information. This finding is aligned with a study conducted by Heller et al (2000) which indicated that a strong majority of respondents (82%) reported that they were interested in receiving training, technical assistance, and directives through local policies on the delivery of health care supports to the population of CSSHN they served. The high proportion of Pennsylvania MAWA documents evidencing provision of training and information demonstrated that MAWAs seem to be responding to training needs similar to those alluded to in the Heller study. It is nevertheless concerning that these healthcare training materials were supplied by just 12 of the 34 MAWA agencies.

Most of the lines of text about Training and Information were within the subset of text addressing General Training and Information. In fact, 62% of the lines of text reviewed dealt with general training and information. The 160 pages within this section most often addressed issues pertinent to the healthy care of all children. These Pennsylvania documents encompassed topics such as universal healthcare precautions, first aide, and cardiopulmonary resuscitation (CPR).

This finding is also in alignment with the Heller et al (2000) study which addressed the need for training of school personnel in ensuring sound practice in general areas of basic health environments. Heller and colleagues deemed these areas to include training on such practices as infection control, universal health care procedures, first aid, and cardio-pulmonary resuscitation (CPR); this is commensurate with the content of the PA MAWA documents provided.

Unlike the Heller study, however, the reader must note that this area additionally comprised documents addressing low incidence conditions. That is, general training and information about care of tracheotomies, gastrostomy feeding, clean intermittent catheterization, and other procedures fell within this coding area unless the information was part of individualized planning for specific CSSHN.

Regarding child-specific training and information, the researcher found that fewer than 5% of the total lines of text focused on training staff on child-specific information. It is notable that although 62% of the lines of text addressed general training and information, only 4.6% of the lines of text addressed child-specific training. And yet, research (Lowman, 1993) shows that Early Childhood Special Educators who reported feeling afraid and unprepared to meet the needs of this population of CSSHN, acknowledged feelings of increased competence given information and supports to increase their ability to meet the needs of children with medical complexities. The fact that fewer than 5% of the lines of text addressed child-specific training and information may indicate lack of consideration of child-specific issues or a dearth of training around child-specific issues. Conversely, it could be that MAWA supervisors neglected to contribute evidence of child-specific training as they viewed “policies and procedures” did not encompass child-specific data, or they feared that confidentiality could be compromised.

Interestingly, the data showed that reference was made to nurse trainers, parent trainers, and non-medical trainers with relatively similar frequency (.4% of documents or 1 of 233 pages for each trainer category). While Heller (2000) found that the primary trainer for health care procedures for CSSHN was the school nurse, the analysis of collected documents in this study revealed that just 1 document of the 233 documents referred to the school nurse as a trainer. This is a surprising result, especially in that the Garrett Decision rendered nursing as clearly within the purview of the schools (Cedar Rapids Community School District v. Garrett F. 526 U.S. 66, 1999).

There could be several reasons for this result. As MAWAs are LEAs but not school entities, they may not have school nurses on staff. Due to the cost, nursing shortage, and low incidence of the population of CSSHN, large MAWAs may be the only entities that have the capacity to employ nursing expertise. It may also be that additional information was available on this topic, but MAWA supervisors thought it irrelevant and neglected to supply it for the study.

Just one of the documents contained reference to the parent as the provider of training for a CSSHN. These findings may be due to growing concerns about litigation, and the clearly defined responsibility of school entities to deliver health services under the direction of the school nurse (Cedar Rapids Community School District v. Garrett F. 526 U.S. 66, 1999).

Similarly, just one document evidenced training provided by non-medically trained MAWA personnel. This medium-sized MAWA published a procedure in which the MAWA secretary collected medical information from parents, physicians, and other sources and, in turn, provided training to school personnel. The finding that this procedure was evidenced in just one document hopefully indicates that MAWAs, for the most part, are utilizing trainers with medical credentials subsequent to the clearly defined responsibility outlined in the Cedar Rapids case (1999). A clear recommendation stemming from this study is that training for the care of CSSHN be conducted by properly qualified medical personnel.

Training and information on confidentiality was found to be an essential ingredient for planning and service delivery rooted in the legal strictures of FERPA (1974) and HIPAA (1996). Two percent of the text reviewed made reference to the need for confidentiality when serving a CSSHN. Though the results of the study do not indicate this, it is probable that MAWAs are providing additional training and information about confidentiality, FERPA and HIPAA as part of their mandatory annual staff training. MAWA Supervisors, however, may not have supplied this information as they did not think of it as within the context of service to CSSHN.

Medical records provide the basis for sound individualized planning in healthcare for CSSHN. There was, however, very little text addressing procurement and use of medical records (3 documents comprising 19 lines of text). This is concerning in that sound individualized planning must be based upon authentic information found within medical records. Once again, it may be that practices in Pennsylvania do utilize information from medical records, but these practices are not reflected in the policies and procedures. An additional recommendation of this study is therefore that medical records are procured and utilized in the individualized healthcare planning process for CSSHN.

As made salient in the Bagnato study (1999), transdisciplinary team approaches were essential in the effective planning and delivery of services to support CSSHN. Concurrent with this, the finding in this study evidenced that training in team approaches are referenced in the Pennsylvania documentation. This Pennsylvania research further evidenced that the policies and procedures included team approaches in individualized planning for CSSHN.   This finding will be discussed later in this section.

With the advent of AIDS, and methicillin-resistant Staphylococcus aureus (MRSA) into early education settings, and the recent rise in childhood food and environmental allergies and seizure disorders, it is indeed imperative that Pennsylvania MAWAs provide training in preventative measures to control these undesirable health conditions for children (Center for Disease Control and Prevention, Emergency Preparedness and Response, 2008). In this study, there was evidence in the documents that PA MAWA entities were aware of this need in that 4.7% of the lines of text demonstrated that these agencies identified training on preventative measures to thwart the spread of communicable diseases and the onset of allergic and/or seizure episodes in their procedures.

Subsequent to a health related episode such as a seizure or anaphylactic reaction, there was evidence that follow-up activities were required. In the collected documents, follow-up activities often involved notification of parents or school administrators that a health episode had occurred, or sending a used Epi-pen or Diastat cartridge to the hospital subsequent to an episode for a CSSHN. Such follow-up activities are imperative in that the success of service delivery and future planning are predicated upon the full disclosure of health information by all team members (Center for Disease Control and Prevention, Emergency Preparedness and Response, 2008).

In this study, the area of safeguards involved training or information for staff and other constituents about activities that should or must take place to prevent errors and hold the agency or individuals employed or contracted by the agency harmless from litigation. As Rapport noted (1994), there is clearly litigation surrounding the provision of care to CSSHN, thus, safeguards must be strictly enforced for the benefit of CSSHN, staff, and school entities alike. The findings of the study indicated that training about safeguards in the health care planning process were noted in procedural protocols; this valued emphasis needs to continue on a statewide basis.

There were 2 MAWA agencies which submitted documents evidencing the provision of training and information about transporting CSSHN. Though there were few lines of text, it must be noted that additional mention of procedures related to transportation were evidenced in individualized planning for CSSHN in the area of transportation planning. Though general training was sparsely identified in the documents, there was greater evidence that information relating to transportation is shared during the process of planning for specific CSSHN.

3. *Input, Participation, and Responsibility*

The findings related to input, participation and responsibility reveal the stakeholders involved in the process of service delivery to CSSHN. The findings indicated that 8 such stakeholder groups existed. Those were: parents, physicians, nurses, administrators, staff, public officials, non-school child services personnel, and the CSSHN themselves. Among these 8 stakeholder groups there were 4 groups which, in addition to provision of input, participation, and responsibility also were in a position to provide permission or authorization. Those were: parents, physicians, administrators, and public officials.

The findings revealed that the documents call for parents to be involved on behalf of their CSSHN. This finding was in alignment with one study (Myers, 1997) in which the researcher sought to identify the boundary spanners in support of CSSHN transitioning from hospitals to schools. The Myers results indicated that, in virtually all cases, it was the mother who was responsible for transferring information between hospital and school. Another study making salient the meaningful participation of parents was that conducted by Lightfoot et al. (1999). In that study, school-age CSSHN who were interviewed reported that their parents were very helpful in rectifying a lack of knowledge on the part of school staff, and that parental knowledge was best utilized in school when accompanied by a physician's verification. The findings in the present study echoed the importance of parent input, participation, and responsibilities and are concurrent with the findings of a number of additional researchers (Lynch, Lewis, & Murphy, 1993; Tommett, 1997; Division of Services for Children with Special Health Care Needs, 2001).

In addition to providing essential input and participation, and having responsibility, the documents revealed that parents were one of the stakeholder groups from whom permission was needed for healthcare planning and implementation to occur. The findings indicated that parental permission was required during the healthcare planning and implementation process. Another study (Hook, 1992) commensurate with this finding was one that indicated that in 90% of cases studied, parents were required to submit written authorization in order for health care procedures to take place, as per state law.

Previous researchers (Palfrey et al., 1986; Palfrey et al, 1992; Myers, 1997; Bagnato, 1999) have noted that improved collaboration and communication were needed between the health and education systems, and that there was a need for procurement of health services in school settings. The findings of the present study are in concert with these conclusions of earlier researchers. In this study, 4.1% of the coded text evidenced that physician input and participation, or physician responsibility was important in the process of delivering supports and services for CSSHN. Collaborative efforts between the medical and educational communities are essential in the effort to service CSSHN in least restrictive school settings.

Continued collaboration must occur on a local and state level between educational and medical entities. On a state level, Pennsylvania's OCDEL must work with the Pennsylvania

Chapter of the American Academy of Pediatrics to strengthen the care of CSSHN in educational settings.

In addition to having a role in provision of input and participation, and having responsibilities in the healthcare process for CSSHN, the documents indicated that physicians were one of the stakeholder groups who were required to give permission or authorization for some of the healthcare activities to occur. It was unearthed that 3.9% of the total lines of text reviewed served as evidence for this point. Once again, this echoes the conclusion reached by another researcher. In a previously reviewed work (Hook, 1992), 92% of school administrators surveyed reported that a written physician prescription was required in order to provide a medical procedure in school. The requirement of obtaining physician authorization in the healthcare process is an essential procedure that ensures the safety of CSSHN in school settings and must continue.

School nurses comprised another stakeholder group that provided input, participation, and had responsibility in the delivery of healthcare for CSSHN. Analysis of the coded text demonstrated that 4.4% of the documentation revealed that nurses had such roles. These data are comparable to the data about the roles of physicians when considering the total number of lines of text coded.

These findings existed in contrast to the conclusions of other researchers. The secondary-age students interviewed in the Lightfoot et al. study (1999) reported that the role of the school nurse was perceived as dealing only with collecting and maintaining records of height, weight, and immunization. The school nurse was reported as not available during times when students needed supports. It may be that the apparent difference in the findings is because the Lightfoot study investigated the role of nurses in the perception of students, while this research alludes to the role of nurses as revealed in public documents.

In another related study by Avery (1989), the panel recognized the advent of CSSHN into school environments and recommended that school nurses be dedicated to the level of service required by this population. The panelists voiced a desire for school nurses to be active as partners alongside educators in preparing students for productive lives. The current findings are in concert with Avery's recommendation in that nurses are evidenced as having essential roles in the healthcare process for CSSHN.

In spite of the importance of the input of the school nurse, there was no node that emerged for nurse authorization or permission. This is appropriate to the PA Nurse Practice Act, and because the nurse works under the direction of or from the orders of a physician (PA Board of Nursing, 2008). Though nurses have vital input, participation and responsibility in the healthcare planning and implementation process, it is the physician who provides the authorization prescribing a medication, health treatment, or procedure.

Administrators were another stakeholder group found to have an important role in the healthcare process for CSSHN as evidenced by the text within the collected statewide documents. As the local agency representatives, it is imperative that this stakeholder group has an integral role in this process. The work of Crawford (1994) in which school principals were surveyed about their perception of preparedness in serving CSSHN emphasizes this point. Crawford reported that administrative perceived preparedness to serve CSSHN increased with Board of Education policies and procedures in place, and availability of training supports for staff. It is essential that administrative input and participation continue to occur during the individualized healthcare planning and implementation process.

Administrators were another of the stakeholder groups that provided permission or authorization in addition to input, participation and responsibility, as revealed by the collected text. Such administrative permission or authorization served as assurance of sound procedures from the local educational agency perspective. In another study (Lowman, 1993), when teachers were interviewed about service to CSSHN, 17.5% of the teachers reported that the administrator made the decision determining who should deliver health care services. It is imperative that such decisions are sound and involve a representative of the agency who has authority to make such decisions.

Another key stakeholder group was that of staff members. The findings of this study are concurrent with those of Heller et al. (2000), which indicated that health care procedures were often performed by non-medical personnel such as teachers, classroom assistants, students, parents, and clerical staff. This study indicated that staff members have input, participation, and responsibilities in the healthcare planning process and in implementation of services and supports for CSSHN in Pennsylvania. Meaningful staff input and participation appear to be valued as essential in this process. As several researchers have indicated (Izen & Brown, 1991; Krier, 1993), when surveyed, teachers perceived they were not adequately trained by university teacher training programs to work with individuals having medically fragile conditions. It is therefore vital that staff members have opportunities to participate in the review of records, planning, and training process prior to service to CSSHN.

There was a mere .8% of the total lines of text coded which referenced public official input, participation or responsibility. These references pertained to necessary interface of education and public health in the event of two conditions: an outbreak of communicable disease; or child abuse and/or neglect. This result indicated that Pennsylvania's MAWAs need to increase collaboration and communication with public health and welfare officials as they move forward in creating policies and procedures about service to CSSHN, especially when considering communicable diseases and child abuse and/or neglect.

Within the coded text, only .5% of the coded text contained passages related to public official permission or authorization. This text made reference to the authority of the public health or welfare official to make a determination about things such as: when CSSHN may or may not attend school due to a health condition; actions that school officials must take to prevent the transmission of communicable diseases; and when public record will be maintained or expunged relevant to the identity of a perpetrator. This finding evidences the importance of the clear line of authority that a health or welfare official has which supersedes that of a school administrator even within educational settings. It is imperative that Pennsylvania’s MAWA agencies become aware of this, and create policies and procedures that are reflective of this authority.

In this study, non-school child services personnel included such persons as child care workers, community social service personnel, or a family’s religious minister. The findings indicated that .2% of the text addressed such persons. The fact that so few lines of text in the collected documents referred to non-school child services personnel indicates that MAWAs have a need to strengthen communication and collaboration with supportive entities. In addition, policies and procedures must be created that delineate the roles and responsibility of persons and agencies that are closely aligned with education entities, especially in the areas of resources and referrals for CSSHN, and child abuse and neglect.

Initially, it seemed that little or no participation or responsibility could be assigned to a preschool-age CSSHN. In fact, in the Heller (2000) study, the results indicated that student self-participation occurred even in a school-age population with very low frequency: it was determined that only 0.4% to 27.4% of students participated in the various procedures, usually in combination with other school personnel.   And yet, this Pennsylvania analysis of policies and procedures indicated that CSSHN were being called upon to exercise emergent independence by participating in necessary healthcare activities.

There were 1.1% of the total lines of text reviewed that indicated that CSSHN had input, participation or responsibility in self-care. Similar to another study which involved a 4 year old child being taught skills in self-catheterization (Robertson et al., 1992), Pennsylvania's CSSHN were participating in elementary ways in their own self-care. For example, the documents indicated that policies and procedures for CSSHN were encouraging self-participatory skills. This information may raise the awareness of stakeholders involved in individualized planning for CSSHN; independence should be maximally fostered by allowing the CSSHN to assume as much responsibility in the process as is medically sound.

4. Logging, Documentation, or Record Keeping

In this study, the log referred to written documentation of the medication or health procedure administered to a CSSHN. Within the collected documents, there were 5 elements of documentation identified. Those were: child's name; activity; date of administration; time administered; and administering personnel. Another category emerged in which a policy or procedure referenced or required a log, however, the elements of the log were unidentified. A total of 5 MAWA agencies supplied information referring to documentation or logging health procedures or administration of medication. There were 3 agencies which supplied sample logs.

The greatest segment of the text referring to logs stated that documentation must occur but did not specify the elements of the log. Similarly, the Hook study (1992) reported on record keeping indicating that 86% of the involved personnel kept a written log of administration of health procedures, the elements of the log also being unspecified. A medication log was likewise dictated by the Louisiana Department of Education (Louisiana DOE, 2000); however, no elements of the Louisiana documentation were identified.

There were 3 sample logs provided by Pennsylvania MAWAs. While 27% of the respondents in the Hook study require that a witness sign the log for verification that a procedure has taken place, there was no evidence of witnesses being required to sign a log in the sample logs provided by MAWAs.

It may be true that MAWA supervisors neglected to think about a log as part of the procedure for service delivery for CSSHN. It is probable that there are many more logs in place across the state than these findings indicate. Every health-related procedure, treatment, or administration of medication that occurs during the school day must be recorded with specificity including name of child, date, time, description of activity or medication including dosage; a witness's signature should be required as appropriate.

5. Individualized Planning and Services

The data regarding individualized planning for CSSHN indicated that, in the Pennsylvania documents, such planning is prescribed, using a variety of sound practices. And yet, no one MAWA provider was found to be requiring usage of all of the elements of individualized planning evidenced in the study. As early as 1992, a model was put forth for individualized health care planning for CSSHN, within the context of the IEP process (Palfrey et al). In the same time period, the Montana Office of Public Instruction (1993) suggested a plan for individualized healthcare planning that was more recently adopted by the Kansas Department of Education, Office of Special Education (2000). Similarly, the Louisiana Department of

Education developed a form for individualized healthcare planning for students with healthcare needs (2000). This form prompted the planning team to solicit input from parents, the school nurse, and involved administrators.

It seems that an essential aspect of individualized planning for CSSHN would be ongoing monitoring of the plan to assure fidelity of implementation. Earlier in this paper, the research of delegation of nursing duties to unlicensed assistive personnel (UAP) was discussed. One piece of literature reviewed (Hansten & Washburn, 1992) emphasized the imperativeness of ongoing monitoring and adjusting of the delegated nursing duties in order to ensure maintenance of skills by the delegate, as well as responsiveness to changing patient needs. The Hansten and Washburn model of delegation of nursing duties to UAP views delegation of nursing duties as a dynamic process as opposed to a singular event, that is, it is a process that is ongoing. Similarly, another previously discussed study indicated that 56.6% of respondents reported being supervised for ongoing fidelity of implementation, either monthly, quarterly, annually, or on an "as needed" basis (Heller et al, 1991). And yet, none of the collected data evidenced that this process is required in Pennsylvania. The essential component of ongoing monitoring must be added to the individualized healthcare planning process.

Analysis of the collected documents indicated that a critical aspect of individualized planning was found to be emergency planning. Some of the sub-nodes of emergency planning included emergency planning in the event of: 1) community or school disaster; 2) change in the health status of a CSSHN; 3) change for another child; 4) care is needed for the rest of the children; 5) transportation emergency; and 6) emergency planning (other).

In the Heller study (2000), the vast majority of teacher respondents reported that their educational settings had procedures for emergency management posted. In alignment with this finding, the Hook study (1992) indicated that 65% of the administrators surveyed reported that emergency procedures were posted in a location accessible to the staff. There was, nevertheless, very little evidence of requirements to post emergency procedures in the Pennsylvania MAWA documents. There was just one participant who provided evidence of planning for a school or community disaster.

Vigilant administrators must take heed: policies and procedures for school lockdowns; shelter-in-place procedures; school evacuations; movement of children to alternate sites; mobile communication devices; and GO Kits containing food and water supplies, medications, diapers and updated emergency lists must be provided within early education settings. Once such overall school and community disaster planning occur, attention must be paid to planning for individual CSSHN within the context of such catastrophic situations. To do otherwise is clearly negligent on the part of school administrators.

There was evidence in the collected documents of individualized planning for a change in health status of a CSSHN. Many of the documents evidenced templates for planning in the event of a seizure, anaphylactic reaction, or other change in health status for a CSSHN. It is advisable that such planning occur with consideration of each of the individualized health care plan elements contained in this study, at minimum.

There were no documents that evidenced plans for a CSSHN in the event that another child experienced a healthcare emergency. Similarly, there was minimal evidence (1 document) that planning was occurring for the remainder of the children in the class during a health emergency for a CSSHN. Unless thoughtful anticipation and sound planning occur for such events, panic is likely to ensue on the part of staff members. Consideration should be given in the healthcare planning process for what needs to occur for a CSSHN in the event of a change in health status of another child. Likewise, consideration must be given to managing other preschoolers in the class during health emergencies for their classmates.

As the MAWA agencies are the local education agencies (LEAs) for eligible CSSHN, and transportation may be a related service listed within the IEP, transportation emergency planning is vital. There was evidence in the data that such planning is required in some locations in Pennsylvania, although, detail about emergency transportation planning was not detected within the supplied documents; that is, the elements of such planning were non-specified. This leaves the researcher to wonder whether: driver and/or bus monitor training is required; drivers must become aware of ways to detect changes in health status of a CSSHN; drivers must keep abreast of changes in healthcare plans or health status of CSSHN; or emergency medication, interventions, or equipment are required to be available during transportation. Are children as safely cared for while in transit as they are in the educational setting? Transportation emergency planning is undeniably difficult. Emergency transportation planning must occur with great caution and attention to detail, in spite of its inherent challenges.

The issue of back-up planning is a crucial one. Staff absences, alterations in the preschool schedule, and the need for back-up clothing or equipment are certain occurrences in a preschool program. Adequate attention must be focused on planning for these certain eventualities to occur while caring for a preschooler with CSSHN.

The changing needs of CSSHN make the individualized healthcare planning process a dynamic one. Individualized Healthcare Plans (IHPs) must therefore be periodically reviewed to assess their continuing appropriateness. There was, however, minimal evidence of the continual review of IHPs (just 20 lines of text made reference to IHP review). Reviews were supposed to occur based upon 1 of 2 conditions: due to a stated frequency; or due to a stipulated reason.

When the IHP comprised a portion of an IEP, the frequency for review was commensurate with the review of the IEP. This timeline may or may not be responsive to the changing health needs of the CSSHN.

Conversely, and more appropriately responding to the dynamic needs of CSSHN, a few examples of procedures required that IHP reviews be initiated at any time for a variety of appropriate reasons. Individualized healthcare planning must contain a stipulation about conditions that will initiate a review of the IHP. Examples of such conditions may include a change in the health status of the child, a change in responsible staff members, or alterations in the school schedule or environment that would impact the CSSHN.

Individualized healthcare planning necessitates a team approach. Both the case study conducted by Bruns (1997) and the model program developed by Bagnato (1999) punctuated the need for interdisciplinary systems to be developed and available for schools with the advent of a child with medical fragility. The collected documents evidence use of team approaches when planning for a CSSHN. In this study, the data evidenced that members of transdisciplinary teams included stakeholders ranging from parents, and administrators, to representatives of the medical field and responsible staff members. Staff member participants included teachers, related service providers, and even bus monitors and drivers. It is only through the meaningful participation of the full array of stakeholders that support a CSSHN that effective planning may occur.

Preventative measures are very important in planning especially for CSSHN with a seizure disorder, and environmental or food allergies. Other conditions that may warrant preventive measures might include dermatitis or neurological disorders. A review of medical records and interviews with parents and others who know the child will reveal known triggers and/or allergens. The data revealed that planning for prevention of health episodes is occurring in Pennsylvania. Preventative measures must be considered as an integral part of the healthcare planning process. All stakeholders must be aware of their responsibility in the prevention process. For example, a teacher may be aware of a child's dust allergy, but this condition would be equally important for a school janitor to understand.

Another node revealed in the collected documents was that of follow-up activities subsequent to a health event for a CSSHN. Such activities encompassed communication with all stakeholders subsequent to a health episode, or construction of reports describing a health incident. Little evidence existed that planning for follow-up occurred for CSSHN within the individualized healthcare planning process. As attention must be paid to changing health status of this population, and full disclosure and communication among all stakeholders, it is essential that follow-up activities be intentional, prescribed in the IHP, and result in appropriate accommodations for CSSHN.

Safeguards were also found to be essential for inclusion into the individualized healthcare planning process. In Healthy People 2010 (Taras, Duncan, Luckenbill, Robinson, Wheeler, & Wooley, 2004), the Individual Health Service Plan was defined as outlining the responsibilities of each stakeholder. These authors stated the importance of clear delineation of the roles and responsibilities as one safeguard in the care of CSSHN. The data provided by Pennsylvania MAWAs evidenced that safeguards were incorporated into the individualized healthcare planning process. This is an essential element of planning for the care of CSSHN.

The National Highway Traffic Safety Administration has researched transportation of preschool-age children and of children with disabilities (NHTSA, 2008). This agency, along with the American Academy of Pediatrics (AAP), offers updated research-based recommendations about the safe transport of this vulnerable population of CSSHN. It is concerning that there was, nevertheless, very little evidence that MAWAs are requiring individualized planning for the safe transport of CSSHN in Pennsylvania. Educational agencies must become familiar with the revised strictures of the NHTSA and the AAP, and incorporate these into procedures along with medically necessary protections for individual CSSHN.

B. Limitations of the Study

In spite of the fact that the MAWA supervisors received both verbal and written explanation about the study, their interpretations about which documents were relevant to the study may have been wide-ranging. Some MAWA administrators may not, therefore, have provided all pertinent documents available within their program.

At the onset of the study, the Pennsylvania Office of Child Development and Early Learning (OCDEL) officials made it clear that participation in the study was voluntary. In turn, the researcher made this clear to the MAWA supervisors. This may have been taken as a message that the study was non-essential resulting in differing levels of commitment on the part of the 34 MAWA Supervisors to participate in the study.

The findings demonstrated that 11 MAWA agencies chose not to participate. It is unknown whether this choice was made due to lack of agency policies or procedures about serving CSSHN or because participation was not mandated by OCDEL. Though the study did receive 67% participation from MAWA providers, some important data and concepts may have been missed due to the non-participation of 33% of the agencies.

The inter-rater reliability effort within this study demonstrated agreement between the researcher and the colleague-rater at a post-negotiation rate of 99.3% across 21.3% of the total lines of text analyzed. It is possible, nevertheless, that further disagreements could have been unearthed if additional lines of text were analyzed.

C. Implications for Future Research

Though the research demonstrates that the existence of policies and procedures was important for the comfort of staff and the perception of preparedness of administrators (Lowman, 1993; Crawford, 1994), the existence of such documents represents just part of the story. Future study is needed to determine the degree to which policies and procedures about service to CSSHN are applied to practice. A field-based inquiry is needed to reveal whether policies and procedures are indeed implemented in service of CSSHN.

Another area of great interest might be to research the effectiveness of various pre-service and post-service professional development approaches in increasing the preparedness of teachers to serve CSSHN. CSSHN will be well-served only when their teachers and other staff members feel comfortable and competent in this service. Such professional development efforts need to include each of the healthcare planning elements found in the Pennsylvania documents.

VII: SUGGESTED FRAMEWORK FOR PRACTICE

The analysis of the statewide data from Pennsylvania MAWA agencies highlights the need for each entity to embark upon a journey considering issues germane to safe, healthy service delivery for CSSHN. Issues to be considered include: adoption and implementation of policies and procedures to ensure use of medically safe and recommended practices; emergency planning to ensure maximal safety; access to and use of nurses; and consideration of the use of a series of taxonomies as tools in individualized planning for CSSHN. As the confidence and competence of administrators, staff, and parents rises due to this initiative, liability for entities will wane given well-coordinated, comprehensive planning.

A. Policies and Procedures Necessary to Ensure Healthy Early Education Environments

The policies and procedures necessary to ensure general health conditions in early education environments are applicable to all children in early education settings. Such policies and procedures would include provision of annual training in universal healthcare precautions; the recognition of common childhood illnesses and referring those to proper stakeholders or authorities; annual provision of training in universal healthcare precautions; the recognition of common childhood illnesses and referring to proper stakeholders or authorities; annual first aide training; annual cardiopulmonary resuscitation (CPR) certification or re-certification; annual training in confidentiality; and training in classroom or program accommodations for short-term or temporary illnesses or medical conditions. A checklist of these policies and procedures for consideration and development is contained in Figure 1.

Policies and Procedures Needed to
Ensure Healthy Early Education Environments

1. _____General Training and Information (applicable to all children in educational setting)
2. _____Universal Healthcare Precautions
3. _____Recognizing Common Childhood Illnesses and referring to proper authority
4. _____First Aide
5. _____Cardiopulmonary Resuscitation (CPR)
6. _____Confidentiality
7. _____Classroom accommodations for short-term temporary illnesses or medical conditions

Figure 1. Policies and Procedures Needed to Ensure Healthy Early Education Environments

To help with this formidable task, the Pennsylvania Chapter of the American Academy of Pediatrics has developed a manual entitled Model Child Care Health Policies, 4th edition (Aronson, 2002). The policies are available for adapting or adoption according to the needs of entities. The editor does recommend that prior to approval of a policy, entities procure the advisement of their solicitor and in-house health professional in order to be certain that the policy does meet the needs of the entity, funding source(s), and population served.

The manual provides an array of available model policies ranging from general policies on confidentiality, admissions, enrollment, and discipline, to policies specific to serving CSSHN. An example of a general policy offered within this manual is contained in Appendix G, addressing Admissions. This policy applies to service to all children.

B. Policies and Procedures Needed to Ensure Sound Practice for CSSHN

The second category of policies and procedures for consideration are those needed to ensure the comprehensive and medically sound practice for CSSHN. These are child-specific practices. Such policies and procedures would include provision of training in: procurement and use of medical records within education entities; use of team approaches in planning for and serving CSSHN (stakeholders include parents, physicians, nurse, administrators, staff, pubic officials, non-school child service personnel, and CSSHN); procuring authorization of key stakeholders (i.e. parents, physicians, administrators, and public officials, as appropriate); logging, documentation, & record keeping for a CSSH; and ongoing monitoring for fidelity of implementation of Individualized Healthcare Plans. Procedures must be created which incorporate emergency planning for CSSHN in the event of: community or school disaster; change in health status of CSSHN; changes in health status of another child; planning for the rest of the children in the event of an emergency for a CSSHN; and emergency transportation planning for CSSHN. Furthermore, back-up planning for staff absences; alterations in schedule; back-up equipment or clothing are imperative. Other necessary elements of procedures must include periodic review of individualized plans for appropriateness according to a prescribed frequency; or periodic review of plan for appropriateness for a prescribed reason. Procedures must consider strategies for the prevention of allergic reactions, seizures, or other medically-related events; follow-up activities subsequent to a medical event for a CSSHN; safeguards in the delivery of healthcare services in the educational setting; and transportation planning for CSSHN. A checklist of these policies and procedures for consideration and development is contained in Figure 2.

Policies and Procedures Needed to Ensure Comprehensive Medically Sound Practice for CSSHN

1) _____Child-specific planning for CSSHN

2) _____Procurement and Use of Medical Records within Education Entities

3) _____Use of Team Approaches in Planning for and Serving CSSHN (Stakeholders include parents, physicians, nurse, administrators, staff, pubic officials, non-school child service personnel, and CSSHN)

4) _____Procuring Authorization of Stakeholders (i.e. parents, physicians, administrators, and public officials as appropriate.)

5) _____Logging, documentation, & Record Keeping of healthcare services and supports for a CSSHN

6) _____Ongoing Monitoring for Fidelity of Implementation

7) _____Emergency Planning for:
    7a) _____Community or School disaster;
    7b) _____Changes in Health Status of CSSHN;
    7c) _____ Changes in Health Status of Another Child;
    7d) _____ Plan for the Rest of the Children;
    7e) _____Emergency Planning (other needs)
    7f) _____ Emergency Transportation Planning

8) _____Back-up Planning
    8a) _____For Staff Absences
    8b) _____For alterations in schedule
    8c) _____Back-up Equipment or clothing

9) _____Periodic Review of Plan for appropriateness
    9a) _____Frequency
    9b) _____Reason

10) _____Strategies for the Prevention of Allergic Reactions, Seizures, or other Medically-Related events

11) _____Follow-up Activities Subsequent to a Medical Event for Children

12) _____Safeguards in the Delivery of Healthcare Services in the Educational Setting

13) _____Transportation planning for CSSHN

Figure 2. Policies and Procedures Needed to Ensure Comprehensive Medically Sound Practice for CSSHN

As mentioned above, the guide Model Child Care Health Policies, 4th edition (Aronson, 2002) is an available resource in formulation of such policies. An example of a policy contained in this book which addresses the needs of CSSHN is contained in Appendix H and is entitled Feeding Children with Nutritional Special Needs.

C. Emergency Planning

As analysis of the data in this study indicated, attention must be given to development of policies about emergency planning for CSSHN. The Emergency Information Form (EIF) is one resource that may be adopted or adapted for this purpose (AAP, 2000). This form provides a concise summary of a CSSHN's medical condition and history, medical contacts, common presenting problems and suggested medical management. It is a standardized "at-a-glance" tool from which medical personnel quickly gain meaning and the ability to react appropriately with maximal efficiency. Completion of this tool provides a "passport" to appropriate responses by personnel in the event of an emergency. Copies of the plan should be kept in easily accessible locations and updated by the family frequently (Committee on Pediatric Emergency Medicine, 1999). Needless to say, though the EIF must be readily accessible, confidentiality must also be ensured.

As the results of this study make salient, emergency planning during community or school disasters is essential for CSSHN. One resource provides checklists for emergency and disaster planning for CSSHN (Texas DSHS, 2008). This helpful manual offers basic tips for disaster response; internet resources for families; a checklist for preparatory activities pertinent to a CSSHN during a disaster; instructions for creating a disaster kit including first aid and medial supplies; and a list of important documents to be kept close at hand in the event of an emergency. School entities should use this resource as a reference tool in their own disaster response planning.

A related resource is a manual for physicians in preparing their practices to respond to disasters or emergencies (Needle, 2008). This guidebook was written subsequent to Hurricane Katrina and benefits from lessons learned by pediatricians in that weather-related disaster. Though the manual is addressed to pediatricians and the response of their practices during a disaster, school entities could learn much from the advisements made in this work. For example, educators can adapt recommendations made by Dr. Needle on evacuation, basic supplies to have available, creation of a disaster kit, medical supplies, maintaining communications, maintaining alternate energy supplies, service delivery in alternate spaces, preserving data and records, ensuring the safety of essential documents, employee and consumer contact information and contact strategies. In disaster preparation, it is important that consideration is given to contact of fire departments, local emergency response teams, hospitals, municipalities, and emergency management agencies.

D. Access to and Use of Nurses

Educational administrators may neither dictate medical practice to nurses in their employ, nor may they assign nursing duties to unlicensed assistive personnel (UAP). The scope of practice for nurses in school settings is prescribed by physician’s orders. It is the role of the school nurse in turn to assign prescribed nursing duties to UAP. The role of the nurse in the education setting is articulated in each state’s nurse practice act.

Some entities may be too small or geographically remote to have a full-time nurse on staff. In those situations alternate strategies must be explored. Contracted agency nurses, county public health nurses, community hospital nurses, Elks or other society nurses, and adjacent school entity nurses may be made available through a partnership agreement, or contract. A solicitor’s assistance would be necessary to examine agreements and assure that collaborative arrangements are sufficiently protective of all parties.

Regardless of the training level or experience of the nurse, sufficient supports must be available to assure that the nurse is able to respond to the needs of the diverse population of CSSHN. School nurses report feelings of isolation from the medical community as they work in school settings; sometimes this isolation is coupled with a feeling of inadequacy in their ability to meet every health need that the school community presents (Josten, Smoot & Beckley, 1995). In order to sufficiently support nurses working in school settings, arrangements must be made for them to interface with physicians via a contractual arrangement between the medical and educational entities. In this way, nurses are able to access expert medical consultation in educational settings. It is furthermore imperative that nurses are able to establish relationships with primary care physicians and sub-specialists with whom CSSHN are associated. These professionals are the persons dictating medical orders and nurses need to dialogue with them as they plan for implementation of care in school settings.

General informational supports must be made available to school nurses. For example, manuals such as Children and Youth Assisted by Medical Technology in Educational Settings: Guidelines for Care, *Second Edition* (Porter, Haynie, Bierle, Heintz-Caldwell, & Palfrey, 1997) must be readily accessible as a resource to nurses serving children with a wide array of diagnoses. This work contains directives on the care of CSSHN with conditions necessitating clean intermittent catheterization, use of a ventilator, gastrostomy feeding, or maintenance of a tracheotomy.

Standards of care are outlined in Caring for Our Children: National Health and Safety Performance Standards: Guidelines for Out-of-Home Child Care Programs, Second Edition.

This volume is helpful to the school nurse as it serves as a guide to the establishment of conditions that need to be present in the school environment. This comprehensive volume provides standards ranging from establishing and maintaining confidentiality, to maintenance of health records for all children, and individualized planning for healthcare for medically needy children in schools.

Another useful tool for nurses in school settings is a series of concise, easily utilized, practical health fact sheets published by the PA Chapter of the American Academy of Pediatrics (ECELS, 2008).   These fact sheets address a variety of health conditions, define them, and provide simple directions for caregivers about recommended service to CSSHN with those diagnoses. Examples of ECELS Fact Sheets include: Immunizations; Prevention of Lead Poisoning; Asthma; Promoting Oral Health; Injury Prevention for Preschoolers; and Food Allergies.

The American Academy of Pediatrics also publishes a newsletter entitled Health Link Online. This periodic publication offers advice on ensuring playground safety, risk management of administration of medication, emergency preparedness, and safe transport of children. Regular email alerts may be procured by accessing www.ecels-healthychilcarepa.org.

E. Taxonomies

The creation of policies sets the stage for safe and medically sound care of CSSHN. It is, however, just part of the response that needs to occur. The early education system must consider the individual needs of the children in its care. As the stories of Habeeth, Krista, Tamoyya, and Charlie indicate, children within the population of CSSHN vary widely in their conditions, health status, stability, equipment needs, and requirements for school health support. In planning for and responding to their individual needs, we must take an analytical approach informed by: 1) the health status of the CSSHN; 2) level of risk of procedure(s) required; 3) level of training required by the developers/trainers on the individualized healthcare planning team; and 4) level of training required by the caretakers or implementors of the individualized healthcare plan. Thus, decisions must carefully and individually be made regarding care of CSSHN within school settings. Scheduling, placement, environment, and personnel assignments must be thoughtfully considered. This is never a "one size fits all" proposition. In an effort to edify conversations about children within the population of CSSHN, further titration may occur. A series of 4 taxonomies support deliberations and sound planning for service to the population of CSSHN in schools.

1. Taxonomy of CSSHN by Health Status

The first taxonomy considers CSSHN in view of their health status (see Figure 3). Health status may occur in varying degrees along a continuum from stable to unstable health status. A continuum of care requirement usually correlates with the level of stability in health status. In fact, stability of health status and care requirements are often inversely related. That is, as stability of health status declines, care requirements rise. Stable health status for a CSSHN may be accompanied by care requirements that are predictable, simple, temporary accommodations within the school setting and/or preventative, or non-intrusive measures in health care. This is often easily arranged and causes minimal disruption in educational settings. An example of this would be Habeeth, the child who has broken his arm. This situation involves a child who has a stable health status, and minimal need for accommodations in the educational environment. Accommodations may include modifications for his participation in gross motor activities, and efforts to ensure that Habeeth does not get jostled by other children on the playground and in other less structured settings. Minor temporary accommodations will need to be made for Habeeth in view of his broken arm.

If the health status of a CSSHN is less stable, the care requirement becomes more intensive, perhaps requiring intermittent monitoring or minimal care. At this stage, parents may begin to express concern about the child in the educational environment; teachers need information in order to ensure a sufficient level of care. An example of this would be Krista, who experiences anaphylactic reaction to bee stings and specific food items. Krista possesses a relatively stable health status, however intermittent monitoring, especially during the warm weather is required. If Krista falls prey to a bee sting, immediate administration of an Epi-Pen is necessary. This is a minimally invasive procedure. Also, monitoring and adjustment of the preschool menu is in order. It will be necessary to offer Krista food choices free of shellfish, nuts, and eggs.

Moving along the continuum of progressing destabilization of health status, even greater care requirements may be indicated by some children. Care requirements at this juncture may involve daily monitoring of health status and perhaps minimal but daily non-invasive care. An example is Tamoyya, the child with ichthyosis, a disease that causes the skin to become dry, thick and scaly. This child has a chronic skin condition requiring lubrication every two hours.

Because of the fragility of the skin and risk of breakage, the school environment must be sanitary at all times to avoid potential infection. Also, thought must be given to the social aspects of the condition. With parent permission, planning should occur to explain the condition to other children in the early education setting so that Tamoyya's differing appearance can be understood by the other children. Thus, this CSSHN requires special attention and care for health needs, and yet, the care requirements are non-invasive.

Finally, consider Charlie, the child with a significantly unstable health status. This is a child whose care requires vigilant monitoring and multiple invasive procedures. Assistance is needed to conduct range of motion activities, monitor and clear the child's tracheotomy and ventilator, administer food through the PEG feeding tube, and to clean and diaper. This unstable health status requires vigilant monitoring and multiple invasive care procedures.

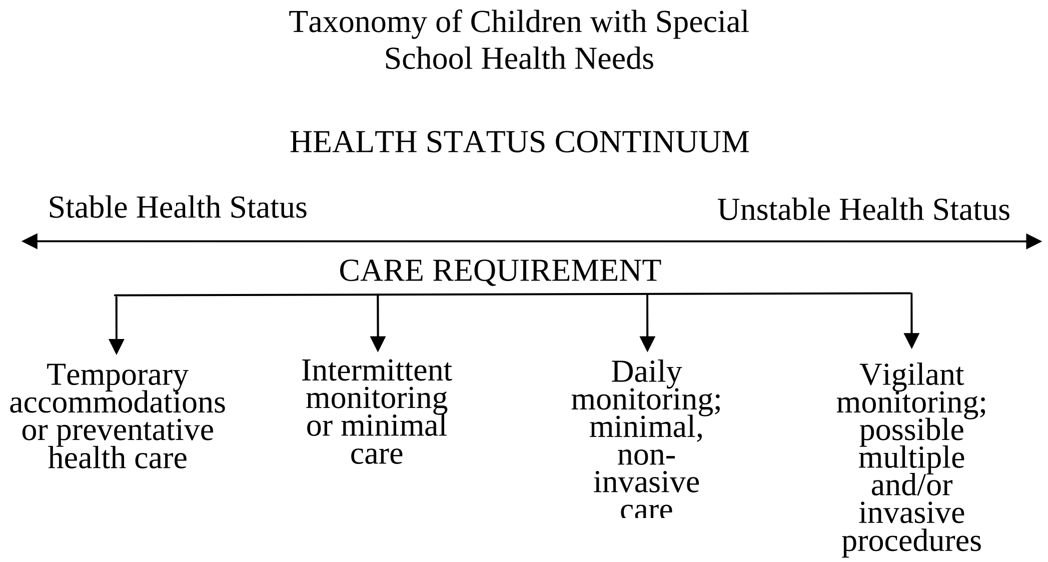


Figure 3. Taxonomy of CSSHN

2. Taxonomy of Procedural Risk

Another taxonomy has been developed to assist the school-based team in thinking about a continuum of risk associated with required procedures. (See Figure 4.) Care requirements occur along a continuum from low procedural risk to high procedural risk. If a child requires care with low procedural risk, the possible consequence of neglecting to perform this procedure properly will simply result in suboptimal care. For example, if planning does not occur for Habeeth to offer his alternate activity during gym time, the result may be he does not participate in gross motor time. This is certainly suboptimal care; every effort must be made to ensure that the child is included in all educational settings in spite of his medical dilemma. However, no deleterious effect will occur on his health status if he is not included with an alternate activity during gross motor area.

Moving along this continuum toward increasing risk, some procedures if improperly performed have increased negative consequence; these are the procedures with moderately low procedural risk. For example, if the Tamoyya, with CIE, does not receive proper skin care on one occasion, the child may suffer a possible temporary deleterious effect such as breakage and infection of the skin. Though an educator would not want this to occur, the effect would be temporary and could be remediated with resumption of proper care and medication.

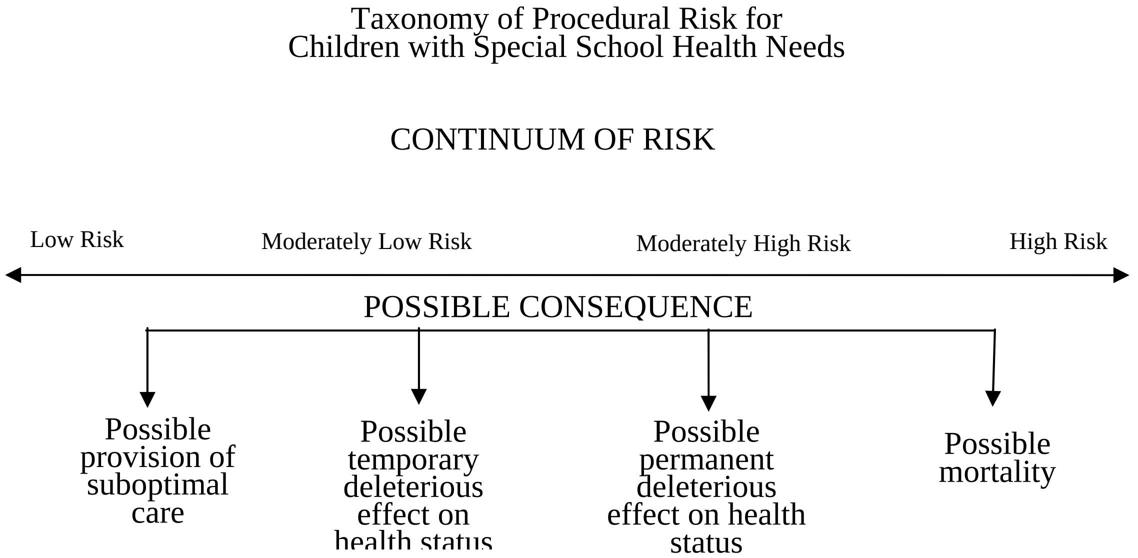


Figure 4. Taxonomy of Procedural Risk

The continuum then moves to health procedures with a moderately high risk. If not performed properly, these procedures have consequences that may result in a possible permanent deleterious effect on health status. One example of this situation relates to Charlie, the child with DMD. If the food is improperly prepared or inserted into the PEG tube, this error could result in aspiration, anoxia and permanent brain damage. This is a permanent deleterious effect from improperly delivering a moderately high risk procedure properly to a CSSHN.

Finally, there are health procedures in which high risk is inherent. The possible consequence of neglecting to properly administer a high risk procedure would be possible mortality. An example of this is Charlie, and his tracheotomy and ventilator. If the vent system is not monitored for proper functioning and fails to produce sufficient air supply to the CSSHN, and the Charlie’s oxygen level is monitored, mortality could result.

3. Taxonomy of Personnel Developing IHPs and Providing Training and Information

The third taxonomy for consideration relates to personnel contributing to the development of an individualized healthcare plan (IHP) for a CSSHN and/or to provision of training or information about the child's care. Personnel qualified to assess, plan for, and train others to meet the needs of a CSSHN occur along a continuum of training levels ranging from untrained through highly trained (see Figure 5). This taxonomy includes the CSSHN themselves; educated lay persons; certified nursing assistants; licensed practical nurses; registered nurses; nurse practitioners; public health officials; and primary care or subspecialty medical doctors.

Educated lay persons may include parents, administrators, teachers, and non-school child services personnel such as social workers or behavioral health specialists. These are persons who have no formal medical training, but who have received training or information through their association with or responsibilities to the CSSHN.

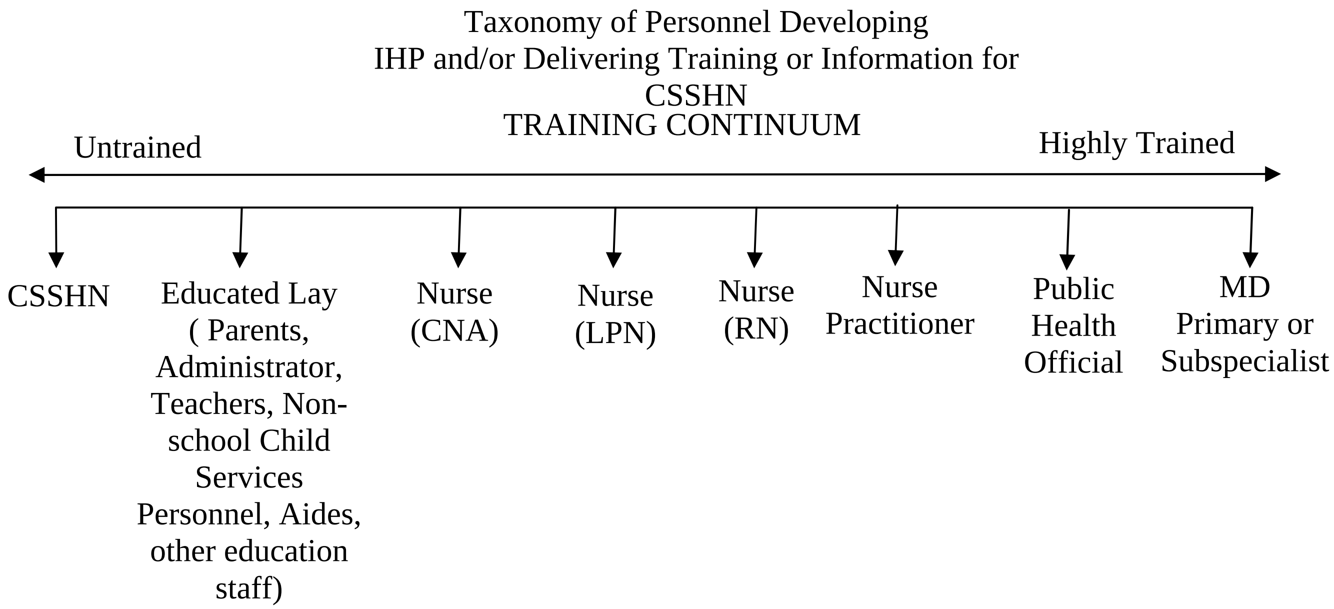


Figure 5. Taxonomy of Personnel Planning/Training

Moving along this continuum, certified nursing assistants are persons sometimes referred to as CNA's, nurses aides, orderlies, patient care technicians, or home health aides. The classes needed to become a certified nursing assistant may be offered at a health institution such as a hospital or nursing home, or at the local community college. These persons must take such classes in preparation of passing a state administered exam.

Licensed practical nurses are trained and licensed to have a basic level of nursing skill. The training is in accordance with the requirements of the Nurse Practice Act of the state in which the training took place. To earn a LPN license, the person must take and pass a state certified training program and pass a state administered test.

The scope of practice for a registered nurse is wider than that of a licensed practical nurse. This is because the level and content of education is broader and more rigorous. Registered nurses are often assigned to a supervisory role in oversight of tasks performed by LPNs, CNAs, and unlicensed assistive personnel (UAPs). Registered nurses may possess a hospital diploma, a two year college degree, or a Bachelor of Science in Nursing. Registered nurses must take and pass a state administered test for licensure.

Advanced education in nursing may be completed at the masters and doctoral levels. A Master of Science in Nursing requires approximately three years of full-time study and prepares the graduate for specialization as a nurse practitioner.

Further along the continuum, public health officials have formalized education and training in medical or healthcare fields. These persons also have authority to oversee healthcare situations, especially in situations when public health may be at risk. Such circumstances may include a CSSHN with AIDS, or MRSA, or in other pandemic situations.

Finally, the highest level of training on the continuum is possessed by the physician or medical doctor. For the purposes of this paper, this category encompasses primary and/or subspecialist medical doctors. Physicians have extensive training requirements. They must take entry level medical training followed by supervised practiced or an internship, then a residency at a health care institution. Physicians must be licensed to practice. Some move further in their education, earning the license to additionally practice a specialization in the medical field. All nurses work under the direction of doctor's orders.

The children portrayed in this paper need different levels of training in the personnel involved in their healthcare planning and training. For his broken arm, Habeeth needs a team which is able to address behavioral and minimal health-related issues related to his broken arm. Conversely, Charlie needs a team which can address, plan for and train staff about his progressive Duchenne Muscular Dystrophy, and its effective on his musculature systems and school activities.

4. Taxonomy of Personnel Implementing Individualized Healthcare Plans

As teams move forward in implementation of service to CSSHN, the training levels of personnel assigned to support the child must be considered. The fourth and final taxonomy was developed for use in this deliberation (see Figure 6.) The health status and care requirements of Habeeth, Krista, Tamoyya, and Charlie require different levels of trained personnel. Though it is inadvisable to assign untrained personnel to support the health needs of CSSHN, many health supports are able to be performed by educated lay persons. Educated lay personnel may include building principals, teachers, or aides. School-based health-related professionals may also be engaged in the implementation of an individualized healthcare plan. Such health-related professionals include: speech language therapists, occupational therapists, or physical therapists.

These supports should be described in a written Individualized Health Care Plan (IHP) and training must be provided to lay personnel by a qualified medically-trained person, appropriate to the needs of the CSSHN.

Certified nursing assistants may have increased skills and comfort levels with the assignment of delivery of some health procedures than educated lay persons. It may be advisable to assign LPN or RNs to more invasive high risk procedures. Nurse Practitioners may be used to design, provide training and information for, and oversee Individualized Health Care Planning. Though health plans are operational under the direction of a medical doctor, the medical doctor will participate through the diagnostic process, prescription of treatment and medication, and input and approval of the Individualized Health Care Plan. The medical doctor does not participate in its implementation in the school setting.

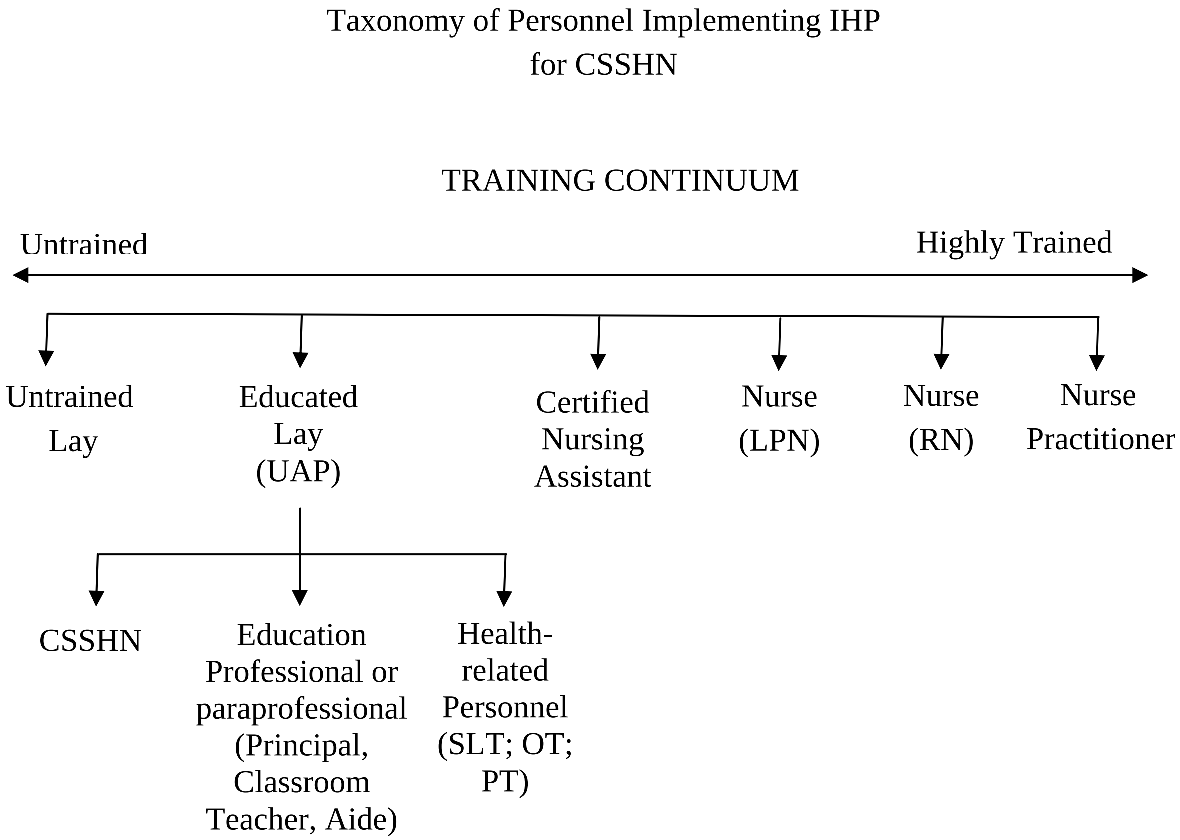


Figure 6. Taxonomy of Implementation Personnel

Thinking about the children discussed in this study, Habeeth simply requires the support of educated lay personnel such as the teacher or aide in the care of his broken arm. They need to be trained on restriction of his activities in preschool and how to manage these restrictions in view of his over-activity.

Tamoyya's diagnosis of congenital ichthyosiform erythroderma (CIE) and its impact upon her activities of daily living necessitate a higher level of training in the personnel who care for her. Tamoyya has severe heat intolerance, need for frequent skin lubrication, high risk for infection, and social issues. These conditions indicate that Tamoyya needs a personal care aide with some medical training. A registered nurse or nurse practitioner needs to develop, train, and provide information to a certified nursing assistant who will remain with Tamoyya in all preschool environments throughout the day.

Charlie needs the care of multiple personnel. His need for daily stretching and manual cough assist could be performed by a Physical Therapist or Physical Therapist Assistant. Charlie also has a need for feeding via a PEG tube, maintenance of his tracheostomy, portable ventilator, aerosol therapy, nebulizer, and oximeter. This indicates that he needs personnel to be assigned further along on the training continuum, such as an LPN or RN.

F. Conclusion

It is known that teachers of young CSSHN understandably report feeling afraid and unprepared to meet the needs of CSSHN. It is also known that their level of comfort and competence increase given appropriate training, information, and supports (Lowman, 1993; Lowman, 1994). And yet, there is evidence that the policies and procedures of Pennsylvania’s MAWAs lack certain essential elements in the individualized healthcare planning process. The findings of this study have been extrapolated into a suggested framework for practice; these are considerations for the state and local agencies for the development of policies and implementation of these into sound procedures in the care of CSSHN. A template for effective and defensible services for CSSHN, their families, and those dedicated to their support, must emerge from this work.

This research represents a call to action in Pennsylvania. The push toward including CSSHN into typical preschool environments must be coupled with the development of statewide tools for the formulation of sound policies and procedures to support this work. The 4 taxonomies presented earlier in this paper should be utilized within the framework of sound policies and procedures for the service of CSSHN. OCDEL must develop training and technical assistance so that local capacity may be developed in MAWA agencies. The suggested framework for practice presented in this paper should serve as the impetus for this work.

Individualized health care planning for CSSHN must be deliberate and thorough. General training must occur relative to creating safe, healthy educational environments for all children in the care of MAWAs. Moreover, child-specific training must occur for the most challenging population of CSSHN. Practices must include: anticipatory planning based upon valid medical data; use of team planning including all stakeholders on the team; a clearly delineated logging or documentation procedure, emergency planning; and periodic review of individualized healthcare plans. Consideration must be given to each of the elements included in this research. Using this comprehensive approach, Pennsylvania may rest assured that children such as Habeeth, Krista, Tamoyya, and Charlie will be included in less restrictive early education settings with maximal health and safety.

APPENDIX A

LETTER OF EXPLANATION TO MAWA SUPERVISORS

October, 2006

Dear Colleague,

I would appreciate your help in participating in this study for my dissertation research. My research will focus on the population of children with special school health needs (CSSHN). For the purpose of this research, Children with Special School Health Needs (CSSHN) are defined as: those children who, due to a temporary, or chronic medical condition or illness, require ongoing monitoring, assistance, equipment, devices, or technology to sustain life or health within school settings. Examples of such children range from children with asthma, allergies, or heart conditions, to children who require life-support systems. These are children for whom you may have made some accommodations, or may have conducted health care planning, in order to maintain them safely in your early education environment.

I am hoping that you will consider the following:
1) Provision of policies your program or agency may have regarding services to children with special school health needs. (Policies are Board-approved documents that serve as guiding statements about a topic, in this case, CSSHN.)
2) Provision of procedures your program or agency may have regarding service to CSSHN. (These are documents that outline steps you and your staff take in planning to serve CSSHCN.)
3) Participation of you or your designee in a brief survey;
4) A sample of MAWA supervisors will be asked to participate in an interview at a later time.

I know that you are concerned, as I am, about confidentiality of information you provide. There is no risk to you or your agency for participation in this study. You and your agency will not be identified or singled out in any way. All data analysis will be in aggregate form. The origin of all data sources will be unidentifiable. The benefit to you and your agency will be the knowledge gained from the findings of the study.

You have no obligation to participate in this study. You have the right to withdraw at any time, though I would be very grateful for your continued support and participation in this study. Upon request, I will be happy to share the findings of the study and answer your questions following analysis of the data.

At this time, I hope you will ask your secretary to send me any policies or procedure you have about serving CSSHN. If you do not have any such policies, please let me know that via the form I have provided. If the documents are too numerous to enclose in the envelope, please let me know that as well.

Your secretary may email this information to me at barbara.minzenberg@aiu3.net, or send it to me in the self-addressed envelope provided to you today. I would appreciate receipt of these documents on or before November 15, 2006.

Please call me at anytime if you have any questions regarding this study at (412)848-8498. Once again, I truly appreciate your participation in this study.

Sincerely,

Barbara G. Minzenberg
Doctoral Student
University of Pittsburgh
Department of Instruction and Learning

APPENDIX B

TALKING POINTS USED WITH MAWA SUPERVISORS

Fall, 2006

1) As a student at the University of Pittsburgh, I am focusing my work on the topic of service to Children with Special School Health Needs (CSSHN) in preschool special education programs.

2) For the purpose of this research, Children with Special School Health Needs (CSSHN) are defined as: those children who, due to temporary, or chronic medical condition or illness, require ongoing monitoring, assistance, equipment, devices, or technology to sustain life or health within school settings.

3) The purpose of the study is to assess the current status of service delivery for this population of children in early education settings in Pennsylvania.

4) Please send the following in the self-addressed stamped envelope:
   a) Any policy(ies) that your agency or department have for service to CSSHN.
   b) Any procedures that your agency or program have for CSSHN. This could include: information from staff manuals; IHPs with personally identifiable information expunged; staff training information; parent brochures or correspondence; nursing records, and so on.

5) I will send reminder emails or call each of you who need such a reminder.

6) There is no risk to you or your agency for participation in this study. The origin of all data sources will be unidentifiable. The benefit to you and your agency will knowledge gained from the findings of the study.

7) You have no obligation to participate in this study. You have the right to withdraw at any time.

8) A coffee card is enclosed as an incentive for participation. If you choose not to participate, enjoy the coffee as a thank you for your hard work!

9) I am happy to answer questions related to this study. My contact information is:
   a) e-mail: barbara.minzenberg@aiu3.net; or
   b) VM: (412)394-5739.

Thank you so much!

APPENDIX C

FORM USED FOR MAWA RESPONSE

Dear Barb,

Please check one:

○ I am having our policies and procedures for service to Children with Special School Health Needs (CSSHN) emailed to you at barbara.minzenberg@aiu3.net.

○ Enclosed are the policies and procedures we use in serving Child with Special School Health Needs (CSSHN).

○ We have no policies or procedures that we use in serving Children with Special School Health Needs (CSSHN).

○ Our policies and procedures for serving Children with Special School Health Needs (CSSHN) are too numerous to mail; please contact me for other options for sharing them with you.

Sincerely,

Name: ____

MAWA: ____

APPENDIX D

DATA DICTIONARY AND RULES GUIDE

DATA DICTIONARY (ALPHABETICAL ORDER)

A

Activity Log (4.2)-Documentation or record keeping specifying the health-related support services, administration of medication, or other health activities were provided to a CSSHN.

Administering Personnel (4.5)-This node represents notation of the person who administered the health related service or medication to the CSSHN. This may include medical or non-medical personnel, employed by the MAWA or not employed by the MAWA.

Administrative Input, Participation, Responsibility (3.4)-Written, verbal, or active contribution made by a responsible school administrator prior to or during service to a CSSHN. This input may be in the form of a suggestion, information, training, opinion, or guidance. Administrators may include persons with varying titles such as "supervisor," "director," "service coordinator," or "principal." Some documents refer to entities such as "the school" or "the Intermediate Unit." Such references were also coded as administrative.

Administrative Permission, Authorization (3.4.1)-Written permission or authorization of responsible school administrator prior to service to CSSHN, usually in the form of a signature. Administrators may include persons with varying titles such as "supervisor," "director," "service coordinator," or "principal." Some documents refer to entities such as "the school" or "the Intermediate Unit." Such references will also be coded as administrative.

Alterations in Schedule (5.3.2)-This node represents planning for the safe and healthy care of CSSHN during instances when changes in routine or alterations in schedule occur. Examples may include: classroom celebrations, field trips, unanticipated visitors, and so on.

Authorization (4.0)-This node represents authorization or permission provided prior to service for a CSSHN.

B

Back-up Planning (5.3)-This node represents planning for back-up or alternative systems to ensure the safe care of CSSHN during non-routine or unplanned events. These non-routine or unplanned events may include staff absences, alterations in schedules, or planning for back-up equipment or clothing.

Back-up Equipment/Clothing (5.3.3)-This node represents planning for back-up equipment for a CSSHN in the event that the equipment for a CSSHN becomes inoperative; also applies to back-up clothing if needed subsequent to a health care procedure.

Base Data (1.0)-34 MAWA Agencies. Definition includes counties included in each MAWA, MAWA Supervisor and contact information, Region as per the Pennsylvania Regional Key, and Size per the December 1, 2006 Child Count.

C

Change for Another Child (5.2.3)-This node represents planning to ensure the safety of a CSSHN in the event that a change in behavioral or health status of another child occurs. This planning occurs in order to assure and maintain the safe care of the CSSHN during an event that represents a change for another child.

Change in Health Status for CSSHN (5.2.2)-This node represents planning in the event of a change in health status for a CSSHN while the child is in school or under the care of school personnel.

Child Input, Participation, Responsibility (3.8)-This node represents input, participation, or responsibility that a CSSHN, or other children take in the provision of healthcare services. For preschoolers, some examples may include rinsing mouth as a part of dental hygiene, self-care during clean intermittent catheterization, assistance with the self-feeding process, or report of irritation or illness.

Child's Name Log (4.1)- Documentation or record keeping specifying the CSSHN for which service was provided.

Child-Specific Training or Information (2.2)-This node represents child-specific training or information. This is individualized training or information for staff about a particular child which is designed to inform staff so that they may meet the needs of a CSSHN. This training may be delivered to persons administering individualized health care procedures or to a general group of school stakeholders. The recipients of this training may include staff employed by the MAWA agency, or contracted staff, who deliver services to CSSHN.

Child's Name Log (4.1)- Documentation or record keeping specifying the CSSHN for which service was provided.

Community or School Disaster (5.2.1)- This node represents emergency planning that considers action to be taken for a CSSHN in the event of a community or school disaster. Examples of community disasters may include: flooding, weather-related emergencies while children are in schools, a violent community or school event, school lock-downs, school evacuations, school closings, water failures, bomb threats, and so on.

D

Date Log (4.3)-Documentation or record keeping specifying the month, day, and year that health-related support services, administration of medication, or other activities were provided to a CSSHN.

E

Emergency Planning (5.2)- This node represents planning that takes potential emergency situations into account. These could include community or school-related emergencies, changes in health status of the CSSHN, health or behavioral changes in other children, or emergencies occurring during transportation. Planning may also occur for the care of other children in the event the CSSHN has an emergency. Additional types of emergency planning were coded under the heading of Emergency Planning-Other.

Emergency Planning-Other (5.2.5)-Emergency Planning that is NOT related to a community or school disaster, change in the health status of the CSSHN, change for another child, plan for the rest of the children, or transportation planning.

F

Follow-up (5.7)- This node represents individualized planning for activities following a health episode for a CSSHN or follow-up activities subsequent to information learned or collected about the health condition of a CSSHN.

Frequency (5.4.1)-This node represented planning which dictated the frequency of periodic review of health care for a CSSHN. Examples of review/revisions due to frequency included: 1) IEP review; 2) due to a prescribed timeline as stipulated within an Individualized Healthcare Plan (IHP).

G

General Training or Information. Generalized healthcare training, and procurement and dissemination of information. Not specific to an individual child; applicable to the healthy care of all children or children with specified diagnoses. Examples may include training in first aid, universal healthcare precautions, cardiopulmonary resuscitation (CPR), tracheotomy care, or catheterization.

H

I

Individualized Planning/Service (5.0)-This node represents the aspects of planning and service for a CSSHN. Individualized planning is evidenced when a document lists a child's name, birthdate, and other unique identifiers, when a policy or procedure dictates that planning or a service will occur for individual children (e.g. individualized health screenings, Chapter 15 Service Agreements, Individualized Service Plans (ISPs), Individualized Education Programs (IEPs), administration of medication, Individual Healthcare Plans (IHPs), etc) NOTE: General

Training or Information dealing with specific diagnoses (e.g. AIDS, Tracheostomy, catheterization, etc.) are not evidence of individualized planning or service.

Input, Participation, Responsibility (3.0)- This node describes the contributions that others make or are required to make prior to and during provision of service to a CSSHN. This node includes the input, participation, and/or responsibilities of parents, physicians, nurses, administrators, staff members, public officials, non-school child services personnel, and children including CSSHN.

J

K

L

Log (4.0)-This node represents the record keeping or documentation of activities provided to a CSSHN.

Log with Non-Specific Elements (4.6)-This node represents procedures or policies that mention a log, documentation, or record keeping of health procedures, but do not specify the elements of such records.

M

N

No Policies or Procedures (6.0)-This node represents MAWA participants who did respond to the request for policies or procedures about the safe and healthy care of CSSHN, but indicated that they had no policies or procedures for service to this population of children.

No Response Group (7.0)-This node represents MAWAs who were asked to provide health care policies and procedures for service to CSSHN, but did not respond to the request.

Non-Medical Trainer (2.2.3)-This node represents persons with no medical credentials who may conduct the training for service to CSSHN and may include personnel such as a teacher, secretary, administrator, janitor, and so on.

Non-School Child Services Personnel (3.7)- This node represents the persons who deliver services and supports for a CSSHN who are non-school personnel. These are persons who may work within, but have limited authority in representing the health, welfare or public justice systems. Examples of persons in this category include persons such as a home health care aide, human services personnel, social worker, foster care worker, peace officer, law enforcement officer, therapeutic staff support personnel, or day care worker.

Nurse Input, Participation, Responsibility (3.3)-Written, verbal, or active contribution made by a school nurse, nurse practitioner, registered nurse, licensed practical nurse, or other school health official, or authorized medically credentialed person prior to or during service for a CSSHN. The nurse may be an employee of the MAWA agency or contracted agent. This input may be in the form of a suggestion, information, training, opinion, or guidance. This is also descriptive of the activities, roles, and responsibilities of the nurse in care of the CSSHN.

Nurse/Medical Trainer (2.2.1)-This node represents the persons who conduct the training for service to CSSHN and may include a registered nurse, school nurse, private duty nurse, or licensed practical nurse. This category could also include otherwise credentialed medical personnel such as a physician. Nurse/medical personnel may be employed by the MAWA or contracted through an agency.

O

Ongoing Monitoring for Fidelity of Implementation (5.1)-This node represents health care planning that includes some type of ongoing monitoring to assure that the plan continues to be followed as written.

P

Parent Trainer (2.2.2)-This node represents the persons who conduct the training for service to CSSHN and may include a biological parent, grandparent, foster parent, adult sibling, or guardian.

Parental Input, Participation, Responsibility (3.1)-Written, verbal, or active contribution made by a parent or guardian prior to or during service to a CSSHN. This input, participation, or responsibility may be in the form of a suggestion, information, opinion, mandated or voluntary activity, or guidance. In this case, the term ”parent” may be used in reference to a biological parent, grandparent, foster parent, adult sibling, or guardian.

Parental Permission, Authorization (3.1.1)-Written permission or authorization, usually in the form of a signature, provided by parent or guardian regarding service to their CSSHN. In this case, the term “parent” may be used in reference to a biological parent, grandparent, foster parent, adult sibling, or guardian.

Periodic Review of Plan for Appropriateness (5.4)-This node represents planning that includes periodic inspection and/or alteration of the plan for continuing appropriateness. There were 2 situations that resulted in the periodic review of individualized plans for appropriateness: 1) Review/revision due to dictated frequency (i.e. annually, twice per year, etc); and 2) Review/revision for a specific reason (e.g. change in staff, change in health status of a CSSHN).

Physician Input, Participation, Responsibility (3.2)-Written, verbal, or active contribution made by the child's primary care physician, sub-specialist, dentist, or an agency contracted physician prior to or during service for a CSSHN. This input may be in the form of a suggestion, training, diagnosis, information, opinion, or guidance. For the purpose of this study, the term “physician” also includes emergency room care, as this is a location where physician input may be immediately accessed.

Physician Permission, Authorization (3.2.1)-Written authorization of child's primary care or subspecialist, dentist, or agency contracted physician prior to service to CSSHN, or readmission to school. A pharmacy label or a doctor's prescription constitutes physician permission.

Plan for the Rest of the Children (5.2.4)- This node represents planning for provision of activities or care of the other children in the educational setting in the event that the CSSHN has an emergency while in their proximity.

Prevention (2.5)-This node represents training and information on preventative measures that staff or other responsible adults may take to prevent spread of infection, allergic reaction, or other health difficulties for the CSSHN or other parties including other children and staff members.

Prevention (5.6)-This node represents preventative measures that staff or other responsible adults plan to take to prevent spread of infection, allergic reaction, or other health difficulties for the CSSHN or other parties including other children and staff members.

Public Official Input, Participation, Responsibility (3.6)- This node represents input, participation, or responsibility of a public health or child welfare official such as a coroner, public health nurse, representative of child protective services, or other designee of the Health or Welfare Departments. Public officials may act in a consultative manner for school officials given an outbreak of infectious diseases such as Methicillin-resistant Staphylococcus aureus (MRSA), Acquired Immune Deficiency Syndrome (AIDS), and other challenging health conditions.

Public Official Permission, Authorization (3.6.1)-This node represents written permission or authorization of responsible public officials regarding service to CSSHN. Public Officials may include persons with varying titles and roles such as coroner, public health nurse, representative of child protective services, or other designee of the Health or Welfare Departments. Such authorization is usually in the form of a public policy upon which a school health policy is based. Other forms of public official authorization are those protective strictures related to child abuse and neglect.

Q

R

Reason (5.4.2)-This node represented planning which dictated that periodic review take place given a certain circumstance or reasons. Examples of those included: plan review/revision due to change in health status of a child; due to parent request; or due to teacher or staff request.

S

Safeguards (2.6)-This node represents training and information for staff and other constituents on safeguards that prevent errors and hold the agency harmless. Safeguards include such activities as: medication contained in original containers, dosage, frequency, and other physician directives, medication kept in locked area, hold harmless clauses to protect medical and non-medical school personnel, etc.

Safeguards (5.8)-This node includes safeguards within an individualized plan for a CSSHN designed to prevent errors and hold the agency or involved staff member harmless. Safeguards include such activities as: medication contained in original containers; written physician orders for dosage, frequency, and other directives; medication kept in locked area; hold harmless clauses to protect medical and non-medical school personnel, etc.

Staff Absences (5.3.1)-This node represents planning that ensures staff coverage in the event of unanticipated absences for staff who provide care or services for a CSSHN.

Staff Input, Participation, Responsibility (3.5)- Written, verbal, or active contribution made by the staff supporting a CSSHN. Staff may include teacher, paraprofessional, speech therapist, Occupational Therapist, Physical Therapist, personal care aide, bus driver or monitor, and so on. This input, participation, and responsibilities may be in the form of a suggestion, active support on a daily or emergency basis, information, logging, reporting, or opinion.

T

Team Approach (5.5)-This node represented a multi-disciplinary approach in including, informing, and encouraging input from all stakeholders including staff members of various disciplines, medical personnel, parents, administrators, the CSSHN, and other public officials and non-school personnel, as appropriate.

Time Log (4.4)-Documentation or record keeping noting the time of day that health-related support services, administration of medication, or other activities were provided to a CSSHN.

Training and Information (2.0)-This node represents the training, professional development, or consultation staff receive regarding service to CSSHN.

Training and Information regarding Confidentiality (2.3)-This node represents training or information about confidentiality or the right to privacy for CSSHN and their families. This is mandated via the strictures of Family Educational Rights & Privacy Act (FERPA) and/or Health Insurance Portability Accountability Act (HIPAA). This node does not represent confidentiality about an individual child.

Training and Information regarding Follow-up (2.7)-This node represents training or information regarding follow-up activities that should or must take place subsequent to a health-related incident. This does not represent individual planning for preventative measures for a specific CSSHN.

Training and Information regarding Medical Records (2.4)-This node represents training or information about the procurement, interpretation, handling, or use of medical records. This node does not represent the medical records of an individual child.

Training and Information regarding Prevention (2.6)-This node represents training or information about general techniques that staff or other responsible persons must use to assure the prevention of spread of infection, allergic reaction, disease, illness, or other health difficulties for a CSSHN, other children, family, and staff members. This node does not represent planning for prevention of the spread of illness for an individual CSSHN.

Training and Information regarding Safeguards (2.8)-This node represents training or information for staff and other constituents about safeguards that should or must take place to prevent errors and hold the agency or individuals employed or contracted by the agency harmless from litigation. Safeguards include such activities as: medication contained in original containers, dosage, frequency, and other physician directives, medication kept in locked area, hold harmless clauses to protect medical and non-medical school personnel, etc. This node does not represent activities planned for individual CSSHN.

Training and Information regarding Team Approaches (2.5)-This node represents training or information about the roles and responsibilities of various members of the team planning and providing care for a CSSHN. This node does not represent a team of an individual child.

Training and Information regarding Transportation Planning (2.9)-This node represents training or information about transportation planning that assures safe and healthy transport of CSSHN. This node may include information about the roles and responsibility of drivers, bus monitors, and other personnel, appropriate positioning, handling and vehicular restraints, response to change in health status while in transport, and so on. This node does not represent activities planned for individual CSSHN, but rather general training and information on this topic.

Transportation Emergency (5.2.6)-Emergency planning specific to emergencies occurring when a CSSHN is being transported.

Transportation Planning (5.9)-This node represents individualized planning for the safe transport of a CSSHN to and from school and home, on field trips, and other school events.

U

V

W

X

Y

Z

DATA DICTIONARY (CODING ORDER)

1.0

Base Data (1.0)-34 MAWA Agencies. Definition includes counties included in each MAWA, MAWA Supervisor and contact information, Region as per the Pennsylvania Regional Key, and Size per the December 1, 2006 Child Count.

2.0

Training and Information (2.0)-This node represents the training, professional development, or consultation staff receive regarding service to CSSHN.

General Training or Information (2.1)-This node represents generalized healthcare training, and procurement and dissemination of information. This training is not specific to an individual child, but applicable to the healthy care of all children or children with specified diagnoses. Examples may include training in first aid, universal healthcare precautions, cardiopulmonary resuscitation (CPR), tracheotomy care, or catheterization.

Child-Specific Training or Information (2.2)-This node represents child-specific training or information. This is individualized training or information for staff about a particular child which is designed to inform staff so that they may meet the needs of a CSSHN. This training may be delivered to persons administering individualized health care procedures or to a general group of school stakeholders. The recipients of this training may include staff employed by the MAWA agency, or contracted staff, who deliver services to CSSHN.

Nurse/Medical Trainer (2.2.1)-This node represents the persons who conduct the training for service to CSSHN and may include a registered nurse, school nurse, private duty nurse, or licensed practical nurse. This category could also include otherwise credentialed medical personnel such as a physician. Nurse/medical personnel may be employed by the MAWA or contracted through an agency.

Parent Trainer (2.2.2)-This node represents the persons who conduct the training for service to CSSHN and may include a biological parent, grandparent, foster parent, adult sibling, or guardian.

Non-Medical Trainer (2.2.3)-This node represents persons with no medical credentials who may conduct the training for service to CSSHN and may include personnel such as a teacher, secretary, administrator, janitor, and so on.

Training and Information regarding Confidentiality (2.3)-This node represents training or information about confidentiality or the right to privacy for CSSHN and their families. This is mandated via the strictures of Family Educational Rights & Privacy Act (FERPA) and/or Health

Insurance Portability Accountability Act (HIPAA). This node does not represent confidentiality about an individual child.

Training and Information regarding Medical Records (2.4)-This node represents training or information about the procurement, interpretation, handling, or use of medical records. This node does not represent the medical records of an individual child.

Training and Information regarding Team Approaches (2.5)-This node represents training or information about the roles and responsibilities of various members of the team planning and providing care for a CSSHN. This node does not represent a team of an individual child.

Training and Information regarding Prevention (2.6)-This node represents training or information about general techniques that staff or other responsible persons must use to assure the prevention of spread of infection, allergic reaction, disease, illness, or other health difficulties for a CSSHN, other children, family, and staff members. This node does not represent planning for prevention of the spread of illness for an individual CSSHN.

Training and Information regarding Follow-up (2.7)-This node represents training or information regarding follow-up activities that should or must take place subsequent to a health-related incident. This does not represent individual planning for preventative measures for a specific CSSHN.

Training and Information regarding Safeguards (2.8)-This node represents training or information for staff and other constituents about safeguards that should or must take place to prevent errors and hold the agency or individuals employed or contracted by the agency harmless from litigation. Safeguards include such activities as: medication contained in original containers, dosage, frequency, and other physician directives, medication kept in locked area, hold harmless clauses to protect medical and non-medical school personnel, etc. This node does not represent activities planned for individual CSSHN.

Training and Information regarding Transportation Planning (2.9)-This node represents training or information about transportation planning that assures safe and healthy transport of CSSHN. This node may include information about the roles and responsibility of drivers, bus monitors, and other personnel, appropriate positioning, handling and vehicular restraints, response to change in health status while in transport, and so on. This node does not represent activities planned for individual CSSHN, but rather general training and information on this topic.

3.0

Input, Participation, Responsibility (3.0)- This node describes the contributions that others make or are required to make prior to and during provision of service to a CSSHN. This node includes the input, participation, and/or responsibilities of parents, physicians, nurses, administrators, staff members, public officials, non-school child services personnel, and children including CSSHN.

Parental Input, Participation, Responsibility (3.1)-Written, verbal, or active contribution made by a parent or guardian prior to or during service to a CSSHN. This input, participation, or responsibility may be in the form of a suggestion, information, opinion, mandated or voluntary activity, or guidance. In this case, the term "parent" may be used in reference to a biological parent, grandparent, foster parent, adult sibling, or guardian.

Parental Permission, Authorization (3.1.1)-Written permission or authorization, provided by parent or guardian regarding service to their CSSHN, usually in the form of a signature. In this case, the term "parent" may be used in reference to a biological parent, grandparent, foster parent, adult sibling, or guardian.

Physician Input, Participation, Responsibility (3.2)-Written, verbal, or active contribution made by the child's primary care physician, sub-specialist, dentist, or an agency contracted physician prior to or during service for a CSSHN. This input may be in the form of a suggestion, training, diagnosis, information, opinion, or guidance. For the purpose of this study, the term "physician" also includes emergency room care, as this is a location where physician input may be immediately accessed.

Physician Permission, Authorization (3.2.1)-Written authorization of child's primary care or subspecialist, dentist, or agency contracted physician prior to service to CSSHN, or readmission to school. A pharmacy label or a doctor's prescription constitutes physician permission.

Nurse Input, Participation, Responsibility (3.3)-Written, verbal, or active contribution made by a school nurse, nurse practitioner, registered nurse, licensed practical nurse, or other school health official, or authorized medically credentialed person prior to or during service for a CSSHN. The nurse may be an employee of the MAWA agency or contracted agent. This input may be in the form of a suggestion, information, training, opinion, or guidance. This is also descriptive of the activities, roles, and responsibilities of the nurse in care of the CSSHN.

Administrative Input, Participation, Responsibility (3.4)-Written, verbal, or active contribution made by a responsible school administrator prior to or during service to a CSSHN. This input may be in the form of a suggestion, information, training, opinion, or guidance. Administrators may include persons with varying titles such as "supervisor," "director," "service coordinator," or "principal." Some documents refer to entities such as "the school" or "the Intermediate Unit." Such references were also coded as administrative.

Administrative Permission, Authorization (3.4.1)-Written permission or authorization of responsible school administrator prior to service to CSSHN, usually in the form of a signature. Administrators may include persons with varying titles such as "supervisor," "director," "service coordinator," or "principal." Some documents refer to entities such as "the school" or "the Intermediate Unit." Such references will also be coded as administrative.

Staff Input, Participation, Responsibility (3.5)- Written, verbal, or active contribution made by the staff supporting a CSSHN. Staff may include teacher, paraprofessional, speech therapist, Occupational Therapist, Physical Therapist, personal care aide, bus driver or monitor, and so on.

This input, participation, and responsibilities may be in the form of a suggestion, active support on a daily or emergency basis, information, logging, reporting, or opinion.

Public Official Input, Participation, Responsibility (3.6)-This node represents input, participation, or responsibility of a public health or child welfare official such as a coroner, public health nurse, representative of child protective services, or other designee of the Health or Welfare Departments. Public officials may act in a consultative manner for school officials given an outbreak of infectious diseases such as Methicillin-resistant Staphylococcus aureus (MRSA), Acquired Immune Deficiency Syndrome (AIDS), and other challenging health conditions.

Public Official Permission, Authorization (3.6.1)-This node represents written permission or authorization of responsible public officials regarding service to CSSHN. Public Officials may include persons with varying titles and roles such as coroner, public health nurse, representative of child protective services, or other designee of the Health or Welfare Departments. Such authorization is usually in the form of a public policy upon which a school health policy is based. Other forms of public official authorization are those protective strictures related to child abuse and neglect.

Non-School Child Services Personnel (3.7)- This node represents the persons who deliver services and supports for a CSSHN who are non-school personnel. These are persons who may work within, but have limited authority in representing the health, welfare or public justice systems. Examples of persons in this category include persons such as a home health care aide, human services personnel, social worker, foster care worker, peace officer, law enforcement officer, therapeutic staff support personnel, or day care worker.

Child Input, Participation, Responsibility (3.8)-This node represents input, participation, or responsibility that a CSSHN, or other children take in the provision of healthcare services. For preschoolers, some examples may include rinsing mouth as a part of dental hygiene, self-care during clean intermittent catheterization, assistance with the self-feeding process, or report of irritation or illness.

4.0

Log (4.0)-This node represents the record keeping or documentation of activities provided to a CSSHN.

Child's Name Log (4.1)- Documentation or record keeping specifying the CSSHN for which service was provided.

Activity Log (4.2)-Documentation or record keeping specifying the health-related support services, administration of medication, or other health activities were provided to a CSSHN.

Date Log (4.3)-Documentation or record keeping specifying the month, day, and year that health-related support services, administration of medication, or other activities were provided to a CSSHN.

Time Log (4.4)-Documentation or record keeping noting the time of day that health-related support services, administration of medication, or other activities were provided to a CSSHN.

Administering Personnel (4.5)-This node represents notation of the person who administered the health related service or medication to the CSSHN. This may include medical or non-medical personnel, employed by the MAWA or not employed by the MAWA.

Log with Non-Specific Elements (4.6)-This node represents procedures or policies that mention a log, documentation, or record keeping of health procedures, but do not specify the elements of such records.

5.0

Individualized Planning/Service (5.0)-This node represents the aspects of planning and service for a CSSHN.   Individualized planning is evidenced when a document lists a child's name, birthdate, and other unique identifiers, when a policy or procedure dictates that planning or a service will occur for individual children (e.g. individualized health screenings, Chapter 15 Service Agreements, Individualized Service Plans (ISPs), Individualized Education Programs (IEPs), administration of medication, Individual Healthcare Plans (IHPs), etc) NOTE: General Training or Information dealing with specific diagnoses (e.g. AIDS, Tracheostomy, catheterization, etc.) are not evidence of individualized planning or service.

Ongoing Monitoring for Fidelity of Implementation (5.1)-This node represents health care planning that includes some type of ongoing monitoring to assure that the plan continues to be followed as written.

Emergency Planning (5.2)- This node represents planning that takes potential emergency situations into account. These could include community or school-related emergencies, changes in health status of the CSSHN, health or behavioral changes in other children, or emergencies occurring during transportation. Planning may also occur for the care of other children in the event the CSSHN has an emergency. Additional types of emergency planning were coded under the heading of Emergency Planning-Other.

Community or School Disaster (5.2.1)- This node represents emergency planning that considers action to be taken for a CSSHN in the event of a community or school disaster. Examples of community disasters may include: flooding, weather-related emergencies while children are in schools, a violent community or school event, school lock-downs, school evacuations, school closings, water failures, bomb threats, and so on.

Change in Health Status for CSSHN (5.2.2)-This node represents planning in the event of a change in health status for a CSSHN while the child is in school or under the care of school personnel.

Change for Another Child (5.2.3)-This node represents planning to ensure the safety of a CSSHN in the event that a change in behavioral or health status of another child occurs. This planning occurs in order to assure and maintain the safe care of the CSSHN during an event that represents a change for another child.

Plan for the Rest of the Children (5.2.4)- This node represents planning for provision of activities or care of the other children in the educational setting in the event that the CSSHN has an emergency while in their proximity.

Emergency Planning-Other (5.2.5)-Emergency Planning that is NOT related to a community or school disaster, change in the health status of the CSSHN, change for another child, plan for the rest of the children, or transportation planning.

Transportation Emergency Planning (5.2.6)- Emergency planning specific to emergencies occurring when a CSSHN is being transported.

Back-up Planning (5.3)-This node represents planning for back-up or alternative systems to ensure the safe care of CSSHN during non-routine or unplanned events. These non-routine or unplanned events may include staff absences, alterations in schedules, or planning for back-up equipment or clothing.

Staff Absences (5.3.1)-This node represents planning that ensures staff coverage in the event of unanticipated absences for staff members who provide care or services for a CSSHN.

Alterations in Schedule (5.3.2)-This node represents planning for the safe and healthy care of CSSHN during instances when changes in routine or alterations in schedule occur. Examples may include: classroom celebrations, field trips, unanticipated visitors, and so on.

Back-up Equipment/Clothing (5.3.3)-This node represents planning for back-up equipment for a CSSHN in the event that the equipment for a CSSHN becomes inoperative; also applies to back-up clothing if needed subsequent to a health care procedure.

Periodic Review of Plan for Appropriateness (5.4)-This node represents planning that includes periodic inspection and/or alteration of the plan for continuing appropriateness. There are 2 situations that result in the periodic review of individualized plans for appropriateness: 1) Review/revision due to dictated frequency (i.e. annually, twice per year, etc); and 2) Review/revision for a specific reason (e.g. change in staff, change in health status of a CSSHN).

Frequency (5.4.1)-This node represents planning which dictates the frequency of periodic review of health care for a CSSHN. Examples of review/revisions due to frequency included: 1) IEP review; 2) due to a prescribed timeline as stipulated within an Individualized Healthcare Plan (IHP).

Reason (5.4.2)-This node represents planning which dictates that periodic review take place given a certain circumstance or reasons. Examples of those included: plan review/revision due to change in health status of a child; due to parent request; or due to teacher or staff request.

Team Approach (5.5)-This node represents a multi-disciplinary approach in including, informing, and encouraging input from all stakeholders including staff members of various disciplines, medical personnel, parents, administrators, the CSSHN, and other public officials and non-school personnel, as appropriate.

Prevention (5.6)-This node represents preventative measures that staff or other responsible adults plan to take to prevent spread of infection, allergic reaction, or other health difficulties for the CSSHN or other parties including other children and staff members.

Follow-up (5.7)- This node represents individualized planning for activities following a health episode for a CSSHN or follow-up activities subsequent to information learned or collected about the health condition of a CSSHN.

Safeguards (5.8)-This node includes safeguards within an individualized plan for a CSSHN designed to prevent errors and hold the agency or involved staff member harmless. Safeguards include such activities as: medication contained in original containers; written physician orders for dosage, frequency, and other directives; medication kept in locked area; hold harmless clauses to protect medical and non-medical school personnel, etc.

Transportation Planning (5.9)-This node represents individualized planning for the safe transport of a CSSHN to and from school and home, on field trips, and other school events.

6.0

No Policies or Procedures (6.0)-This node represents MAWA participants who did respond to the request for policies or procedures about the safe and healthy care of CSSHN, but indicated that they had no policies or procedures for service to this population of children.

7.0

No Response Group (7.0)-This node represents MAWAs who were asked to provide health care policies and procedures for service to CSSHN, but did not respond to the request.

RULES GUIDE

Introduction:

Most scanning software programs treat a scanned document as a graphic (PICT or JPEG). The scanning software used for this work has optical character recognition (OCR) capability. That is, this software scans documents, and recognizes those files as text. The individual characters are translated as letters in the scanned document. Using OCR software, scanned files can be manipulated as Microsoft Word documents.

When one works with scanned documents using this software, the user will become aware that, at times, the OCR erroneously translates a character or character as the wrong set of letters in text. For example, the characters “VV” may be translated as a “W.” Likewise, the characters “li” may be translated as “k.”

ADMINISTRATIVE INPUT/PARTICIPATION/RESPONSIILITY. Some documents contain text such as “the school shall notify…” or “the Intermediate Unit shall disseminate…” As these passages do not specify which persons in the educational entity will assume these responsibilities, such passages are coded as “Administrative Input/Participation/Responsibility.” If it is more likely that another category would more appropriately suffice (e.g. Nurse, or staff), then that may be used.

ASSUMPTION. The researcher must assume that the form or document is used for its stated purpose. That is, if a procedure uses the term “Physical Health Team” it is to be assumed that team approaches are used in the process. If “teacher’s name” is listed, it is assumed that the teacher has some input, or responsibility in the process.

GENERAL TRAINING AND INFORMATION. A document that deals with overall practices or dissemination of general information is evidence of general training and information (2.1).

If the document evidences that each child receive an individualized service (e.g. health screening), it may therefore evidence general training and information (2.1) AND individualized planning/service (5.0).

IMPLICIT MEANINGS. Some text must be coded for its’ implicit meaning. For example, the question “List Triggers for Allergic Reactions” implies that preventative measures will be taken to avoid the allergic reaction and should be coded “prevention” (5.6).

INDIVIDUALIZED PLANNING. A document that states that an activity occurs for each child (e.g. health screening), or a specific child (e.g. catheterization) is evidence that individualized service or planning occurs and therefore should be coded individualized planning (6.0).

INPUT. Input cannot be assumed unless participation occurred, or information was considered from the stakeholder (e.g. parent (3.1), physician (3.2), nurse (3.3), administrator (3.4), staff member(s) (3.5), public official (3.6), or non-school child services personnel (3.7), or child (3.8).

MULTIPLE CONCEPTS WITHIN ONE LINE OF TEXT. Each concept occurring on a line should be coded. For example one line of text could be about individualized planning (6.0) and parent input (4.1).

MULTIPLE SIGNATURES. When multiple signatures are required, this indicates Permission (Parent (3.1.1), Physician (3.2.1), etc., AND a Team Approach (6.5).

PHYSICIAN PERMISSION. A note on a prescription pad, or a pharmacy label on prescribed medication constitutes physician permission (3.4.1).

SIGNATURES = both input and permission for authorizing persons.

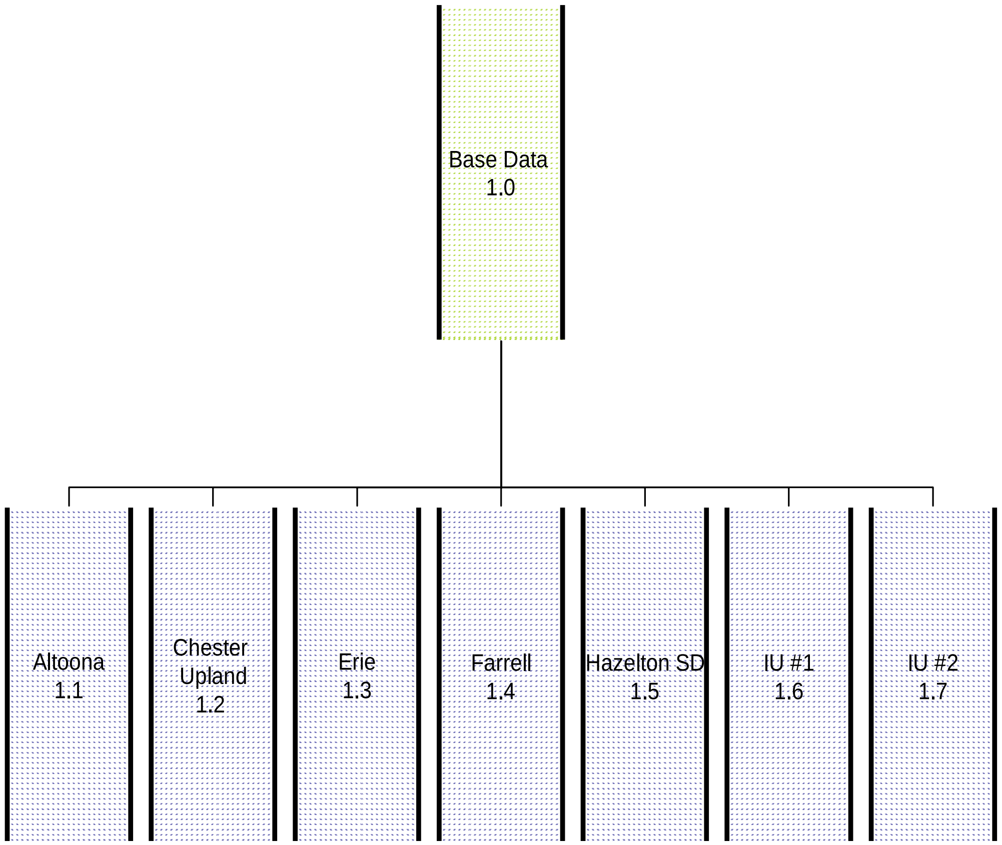
TEAM APPROACH. A ‘team’ constitutes two or more persons. Therefore a meeting with a parent and a staff member, for example, constitutes a team approach (6.5). When other members of the child’s health care team are listed (e.g. dentist, subspecialist(s), team approaches are assumed.

UNIT OF ANALYSIS AND WORDS IN CONTEXT. The unit of analysis for this project is a line. That is, coding takes place on a line by line basis. It us understood, however, that in most cases, the meaning of words and phrases (node) extend beyond the line into a sentence or paragraph. Thus, coding will extend to those lines where the node exists.

APPENDIX E

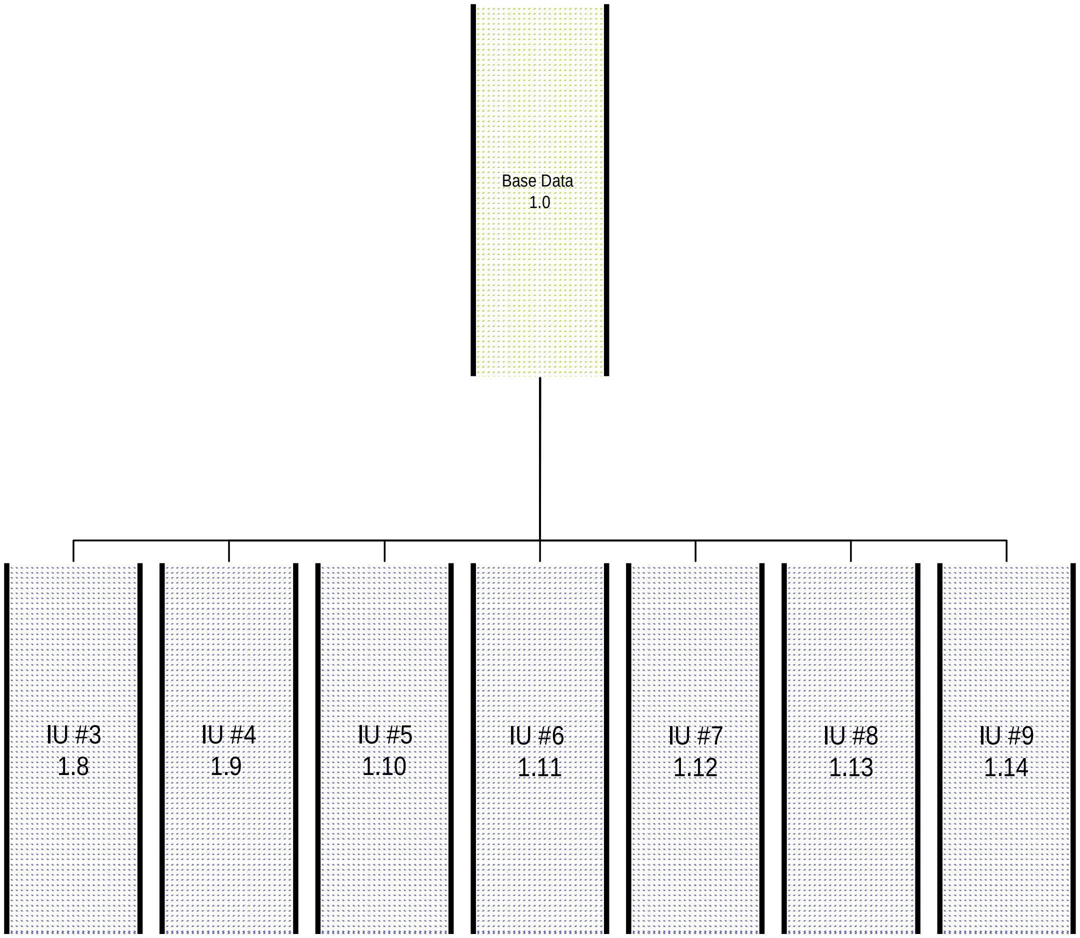
NODE SYSTEM FOR SERVING CSSHN IN LRES

Node: Base Data



- Base Data 1.0
  - Altoona 1.1
  - Chester Upland 1.2
  - Erie 1.3
  - Farrell 1.4
  - Hazelton SD 1.5
  - IU #1 1.6
  - IU #2 1.7

Node: Base Data



Base Data
1.0

IU #3
1.8

IU #4
1.9

IU #5
1.10

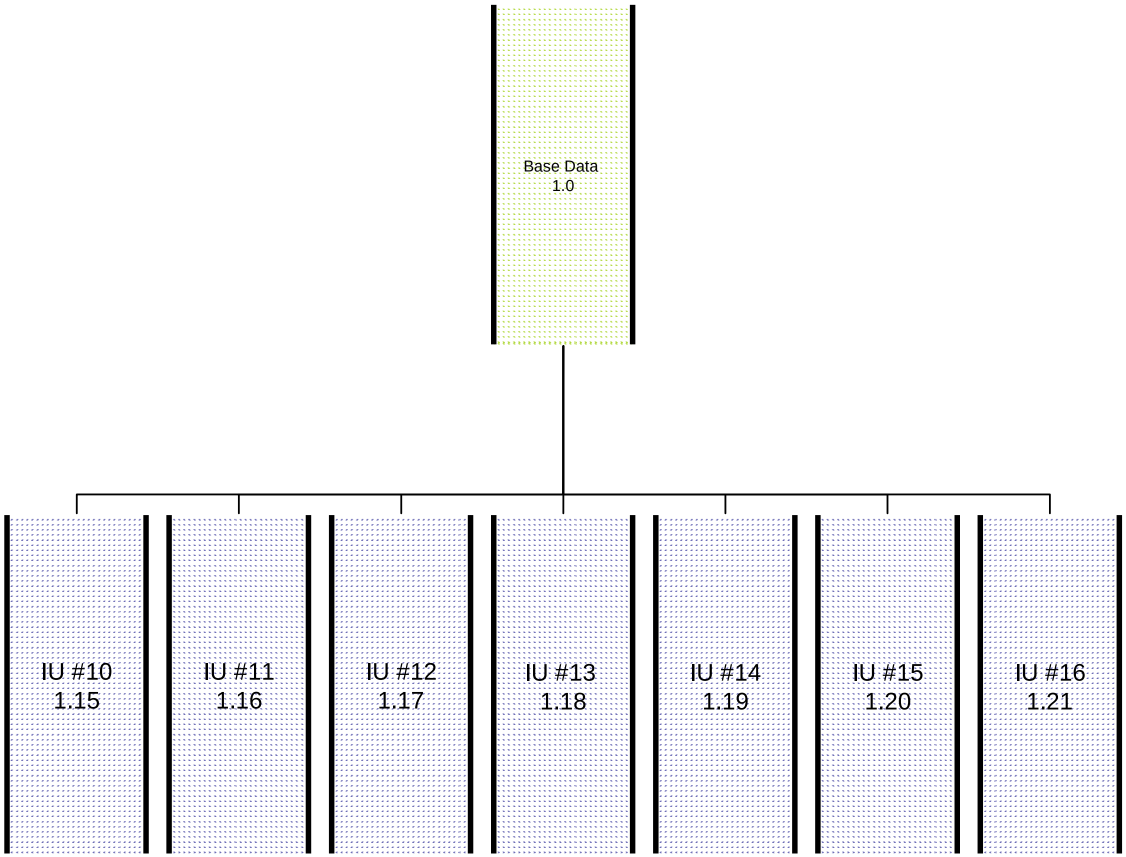
IU #6
1.11

IU #7
1.12

IU #8
1.13

IU #9
1.14

Node: Base Data



Base Data
1.0

IU #10
1.15

IU #11
1.16

IU #12
1.17

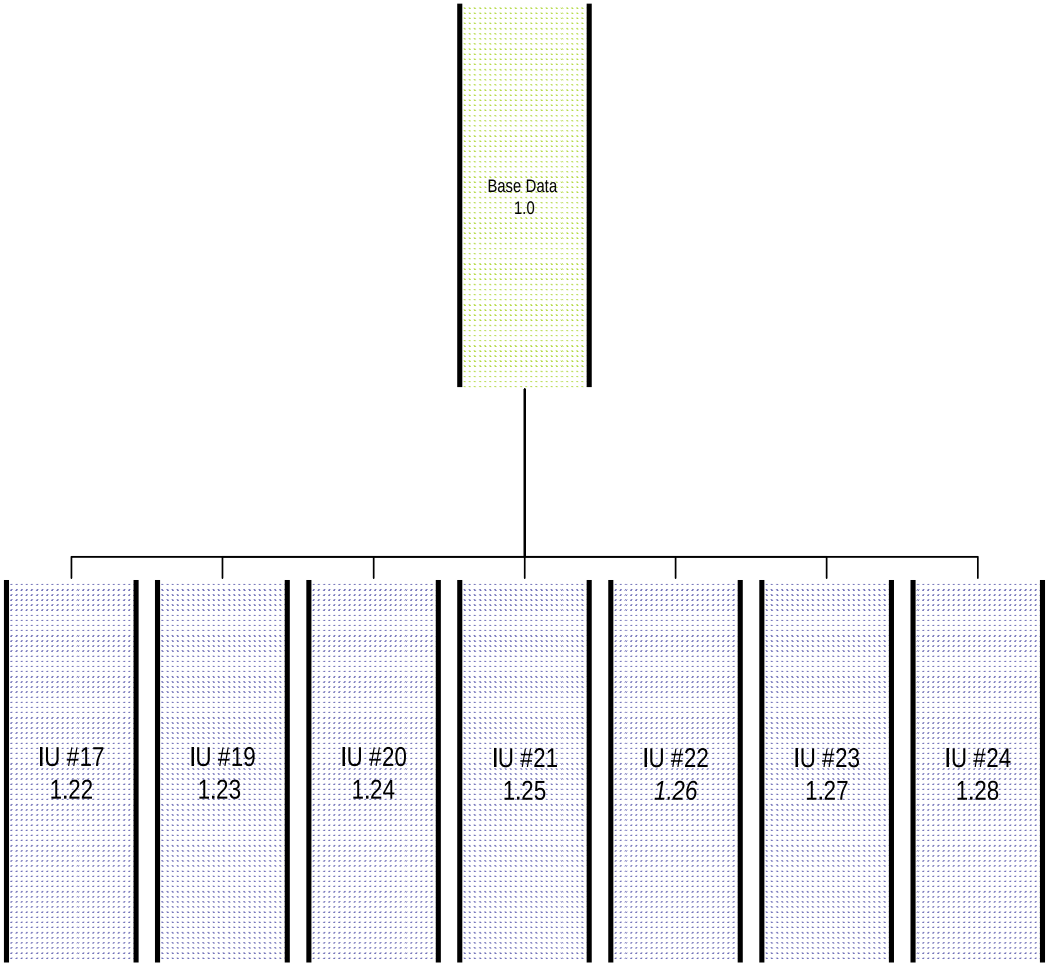
IU #13
1.18

IU #14
1.19

IU #15
1.20

IU #16
1.21

Node: Base Data



Base Data
1.0

IU #17
1.22

IU #19
1.23

IU #20
1.24

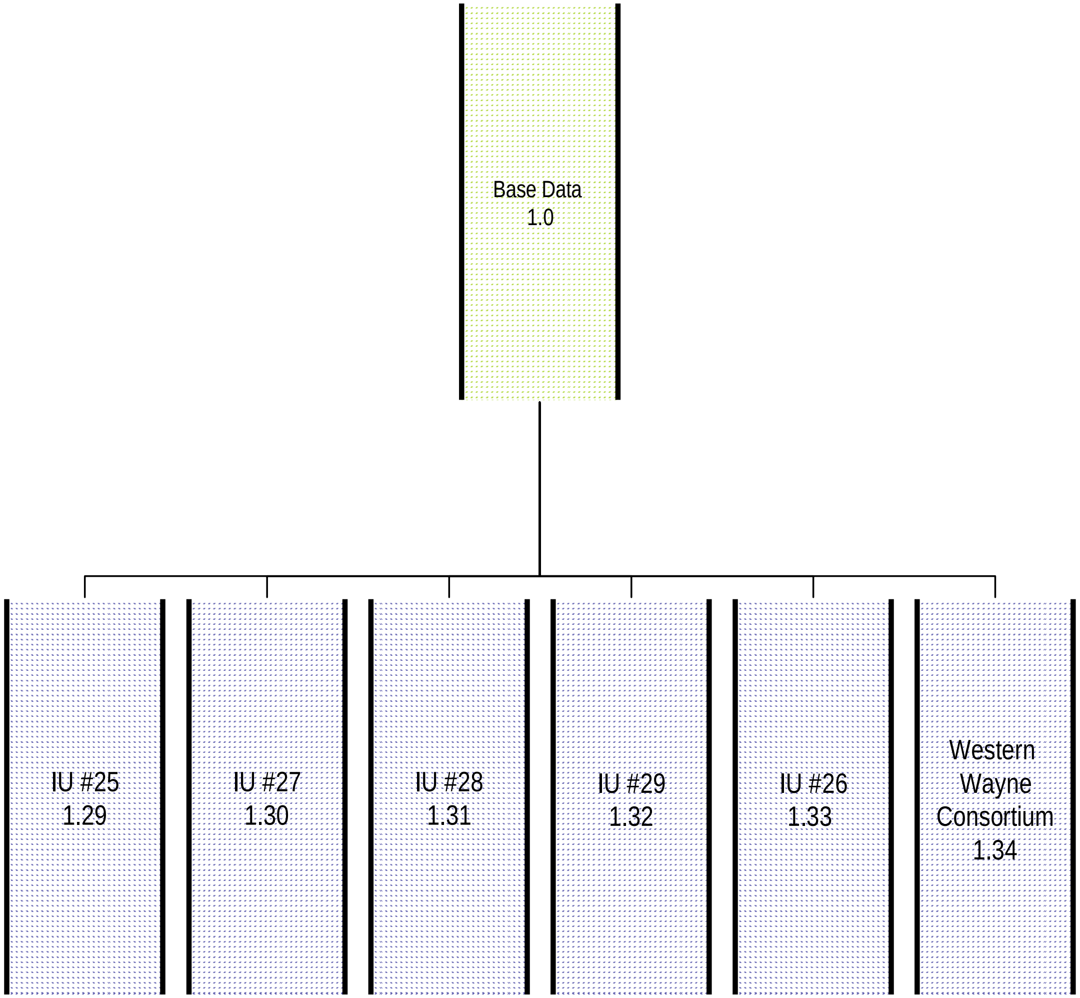
IU #21
1.25

IU #22
1.26

IU #23
1.27

IU #24
1.28

Node: Base Data



Base Data
1.0

IU #25
1.29

IU #27
1.30

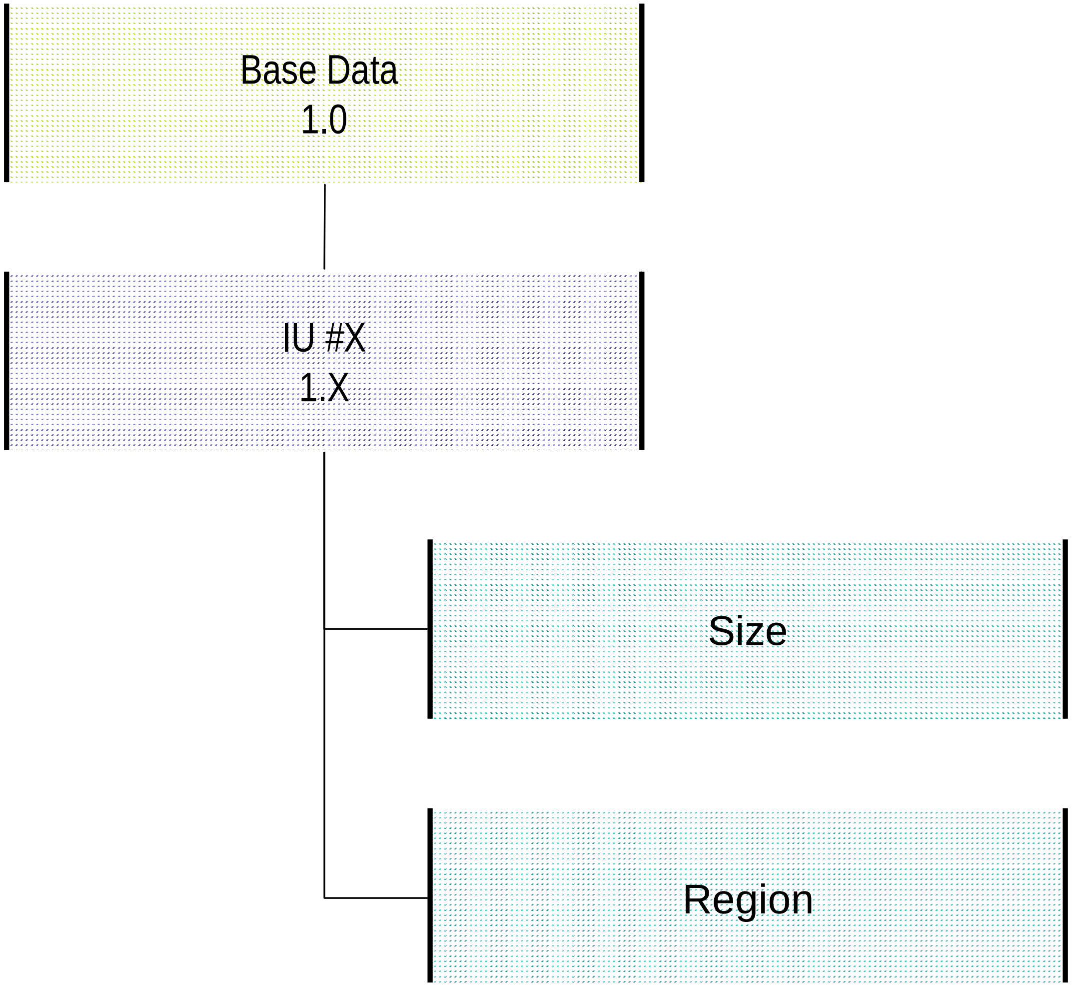
IU #28
1.31

IU #29
1.32

IU #26
1.33

Western
Wayne
Consortium
1.34

Node: Base Data



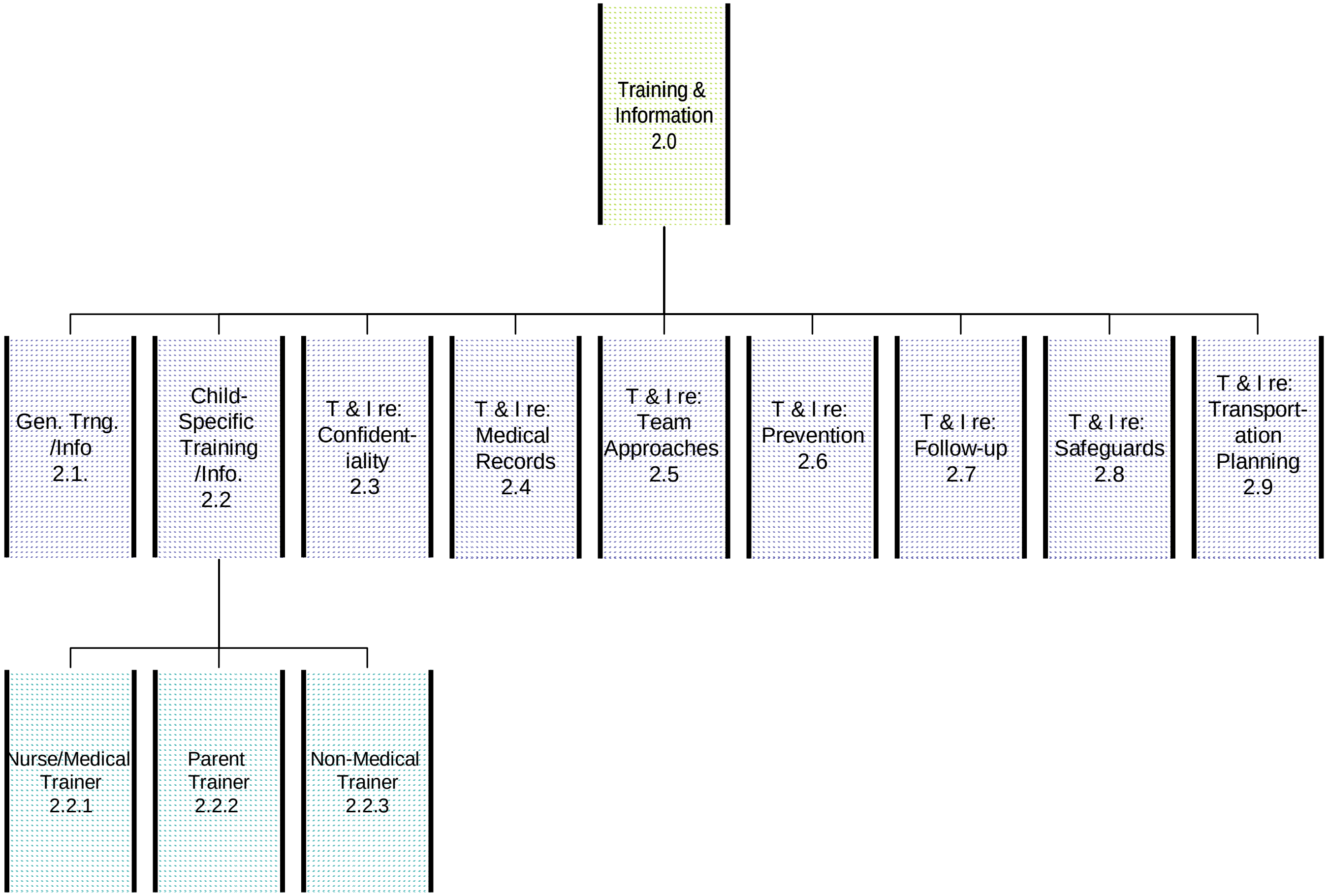
Base Data
1.0

IU #X
1.X

Size

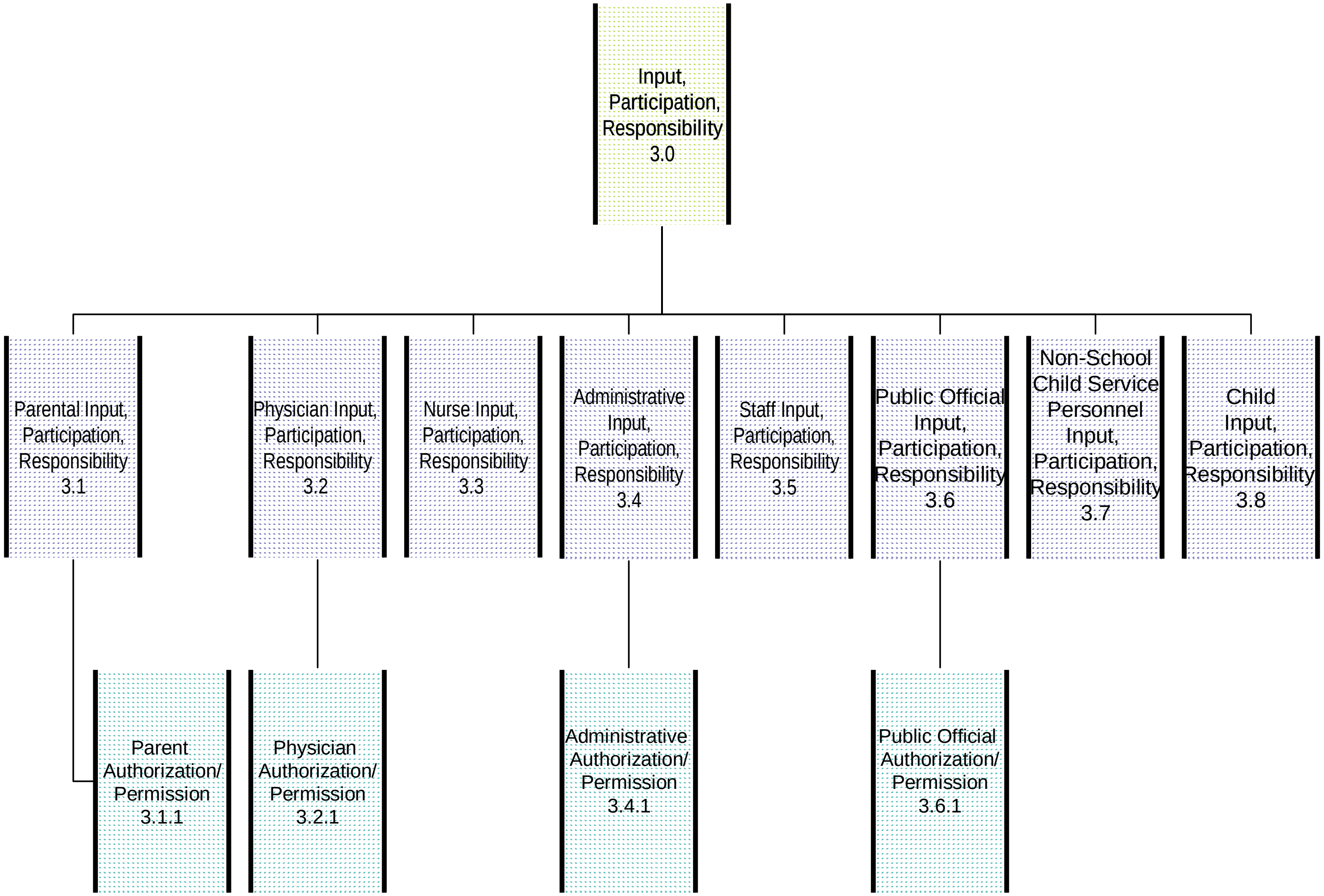
Region

Node: Training and Information



- Training & Information 2.0
  - Gen. Trng. /Info 2.1.
  - Child-Specific Training /Info. 2.2
    - Nurse/Medical Trainer 2.2.1
    - Parent Trainer 2.2.2
    - Non-Medical Trainer 2.2.3
  - T & I re: Confidentiality 2.3
  - T & I re: Medical Records 2.4
  - T & I re: Team Approaches 2.5
  - T & I re: Prevention 2.6
  - T & I re: Follow-up 2.7
  - T & I re: Safeguards 2.8
  - T & I re: Transportation Planning 2.9

Node: Input, Participation, Responsibility



Input, Participation, Responsibility 3.0

Parental Input, Participation, Responsibility 3.1

Physician Input, Participation, Responsibility 3.2

Nurse Input, Participation, Responsibility 3.3

Administrative Input, Participation, Responsibility 3.4

Staff Input, Participation, Responsibility 3.5

Public Official Input, Participation, Responsibility 3.6

Non-School Child Service Personnel Input, Participation, Responsibility 3.7

Child Input, Participation, Responsibility 3.8

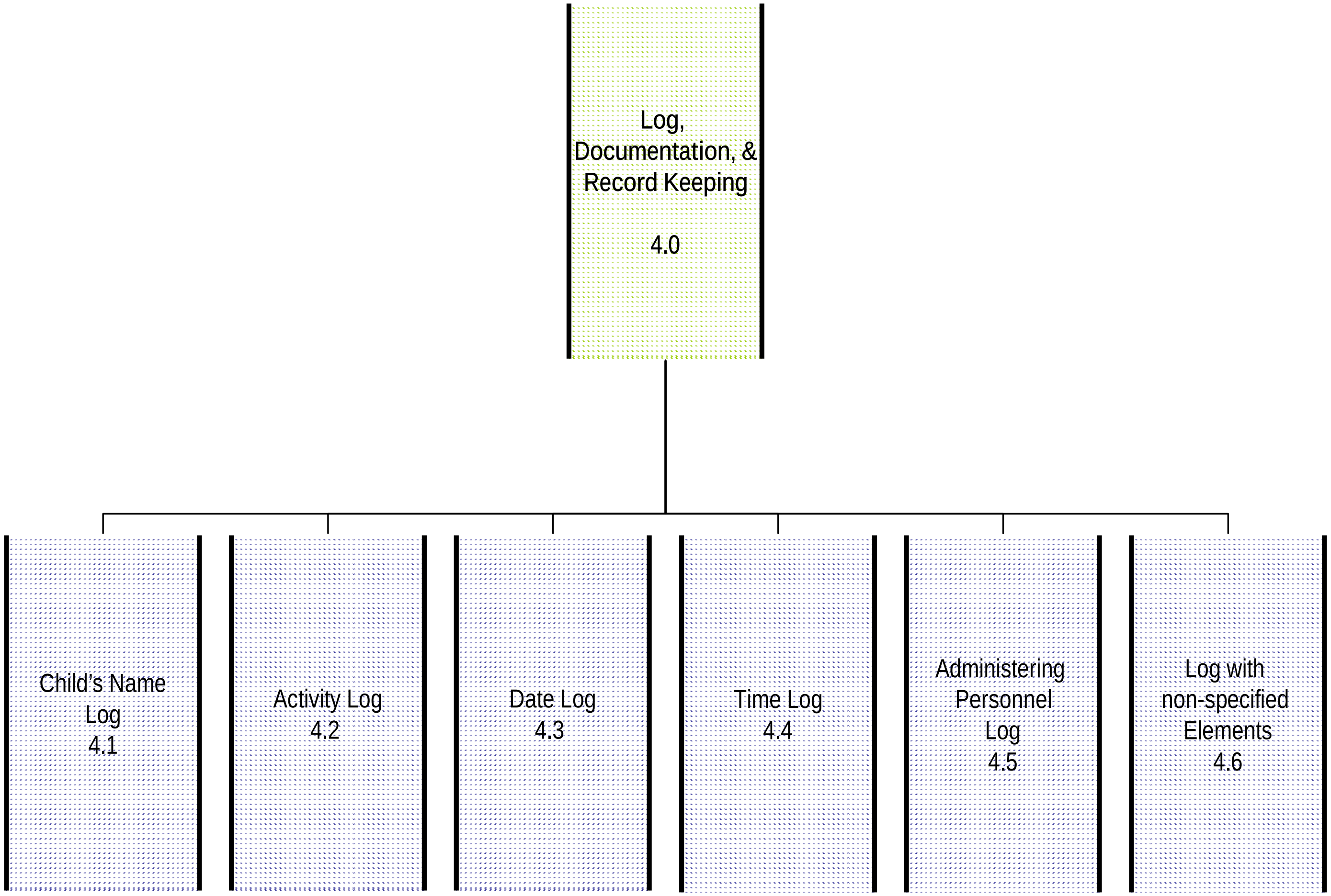
Parent Authorization/ Permission 3.1.1

Physician Authorization/ Permission 3.2.1

Administrative Authorization/ Permission 3.4.1

Public Official Authorization/ Permission 3.6.1

Node: Log



Log, Documentation, & Record Keeping

4.0

Child's Name Log
4.1

Activity Log
4.2

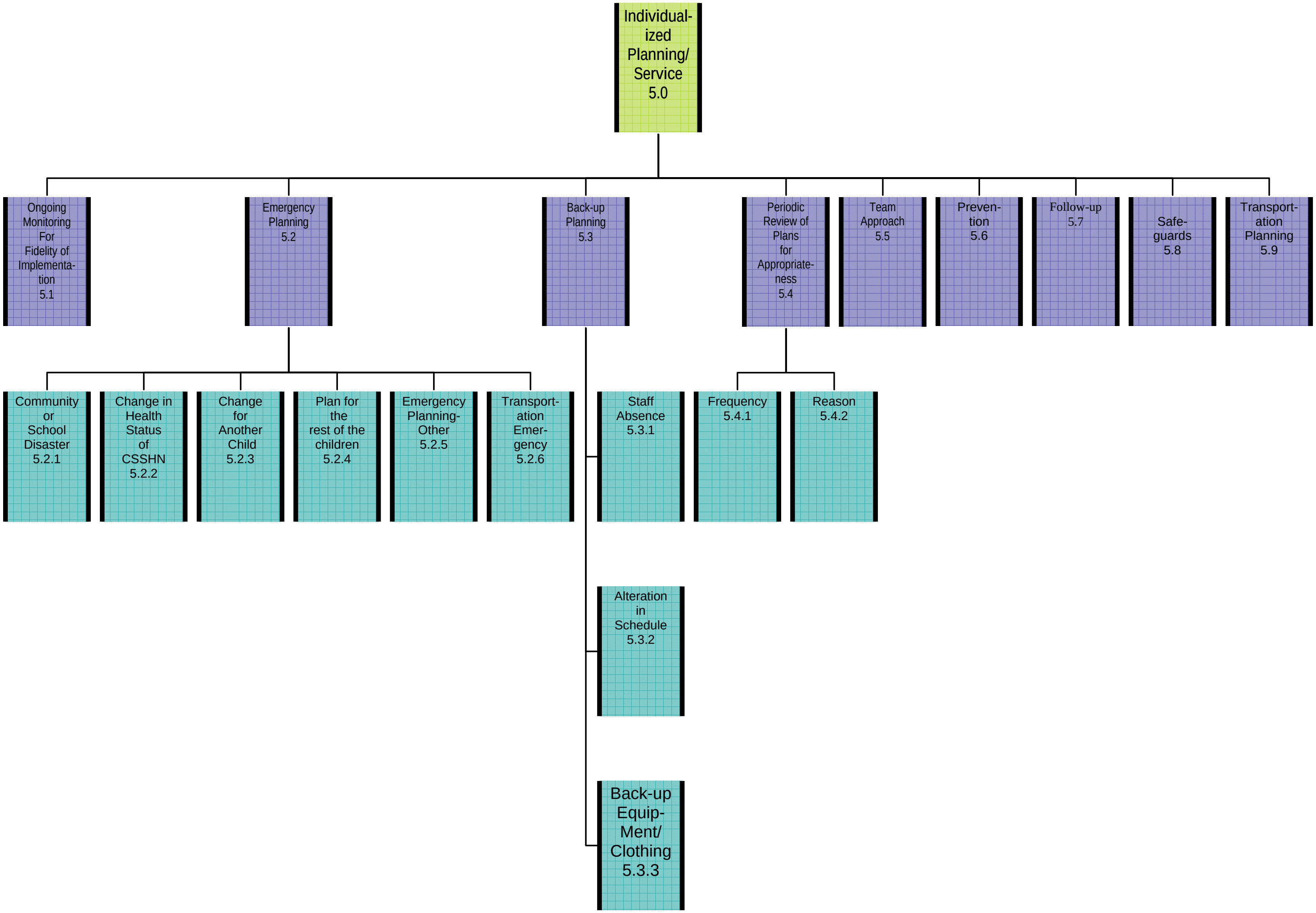
Date Log
4.3

Time Log
4.4

Administering Personnel Log
4.5

Log with non-specified Elements
4.6

Node: Individualized Planning

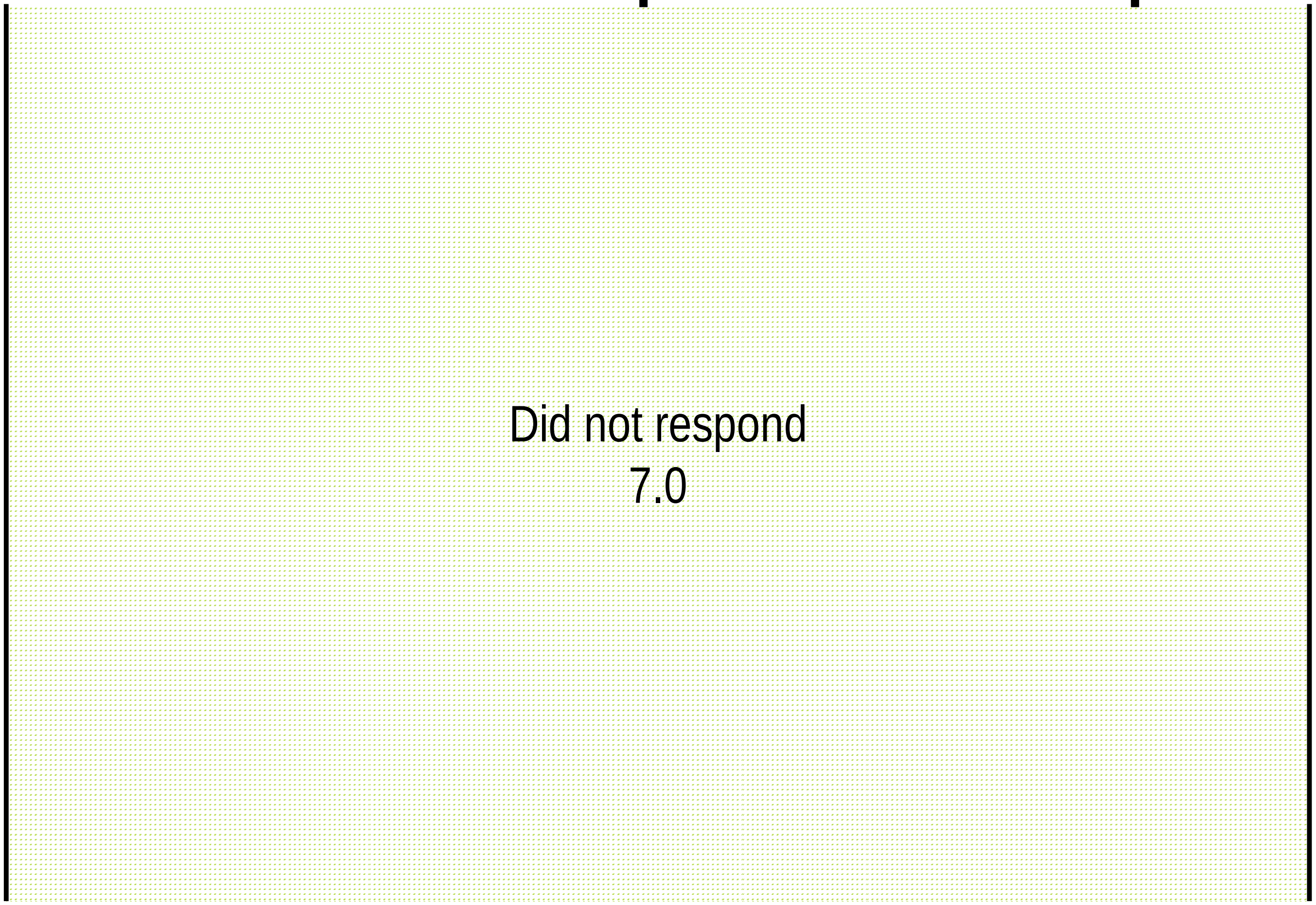


- Individual-ized Planning/ Service 5.0
  - Ongoing Monitoring For Fidelity of Implementa-tion 5.1
  - Emergency Planning 5.2
    - Community or School Disaster 5.2.1
    - Change in Health Status of CSSHN 5.2.2
    - Change for Another Child 5.2.3
    - Plan for the rest of the children 5.2.4
    - Emergency Planning-Other 5.2.5
    - Transport-ation Emer-gency 5.2.6
  - Back-up Planning 5.3
    - Staff Absence 5.3.1
    - Alteration in Schedule 5.3.2
    - Back-up Equip-Ment/ Clothing 5.3.3
  - Periodic Review of Plans for Appropriate-ness 5.4
    - Frequency 5.4.1
    - Reason 5.4.2
  - Team Approach 5.5
  - Preven-tion 5.6
  - Follow-up 5.7
  - Safe-guards 5.8
  - Transport-ation Planning 5.9

Node: No Policies or Procedures

Participants who indicated
“We have no policies or procedures for CSSHN”
6.0

Node: No Response Group



APPENDIX F

RANDOMLY SELECTED DOCUMENTS

Doc. #	Doc.Name	# Unt.
12	Chester Upland Use of Private Duty Nurses page 2 of 2	28
14	Erie 504 Accommodation Checklist page 2	62
27	Erie Protected Handicapped Students	28
28	Erie Section 504 and IDEA Flow Chart	35
39	IU #14 Bus Emergency Plan	40
41	IU #14 In School Medication Procedures	26
43	IU #14 Medication Record page 2	4
44	IU #14 Permission for Medication	34
45	IU #14 Physician Recommendation for In School Meds	39
47	IU #15 Health Examination & Screening page 1	47
48	IU #15 Health Examination & Screening page 2	52
50	IU #15 Policy on Use of Medication page 1	44
54	IU #15 School Health Protocol page 12	46
57	IU #15 School Health Protocol page 14	13
64	IU #15 School Health Protocol page 18	16
71	IU #15 School Health Protocol page 25	36
72	IU #15 School Health Protocol page 26	19
76	IU #15 School Health Protocol page 30	18
78	IU #15 School Health Protocol page 31A	36
82	IU #15 School Health Protocol page 36	24
83	IU #15 School Health Protocol page 37	27
89	IU #15 School Health Protocol page 4	25
97	IU #15 School Health Protocol page 6A	59
100	IU #15 School Health Protocol page 6D	21
102	IU #15 School Health Protocol page 6F	29
110	IU #15 School Health Protocol T of C page 2	11
112	IU #15 Student Referral for Health Services	40
118	IU #20 Authorization for Medication During School Hours	64
127	IU #20 IEP Review Summary for CSSHN	44
128	IU #20 Invitation to Participate in Meeting for CSSHN	60
130	IU #23 Parent's Request for Administration of Medication	31
137	IU #3 Decline of Services Form	48

141	IU #3 Health Care Plan with Nursing Summary	36
142	IU #3 Health Care Policy and Procedure	65
145	IU #3 Health Screening Questionnaire	156
153	IU #5 Hepatitus Fact Sheet page 2	25
155	IU #5 Policy & Procedure for Prevention & Transmission of Disease	33
162	IU #7 First Aid for Seizures	43
163	IU #7 Gastrostomy Button Feeding Bolus Method Possible Problems	34
178	IU #7 Health Care Plan	33
187	IU #7 Labeling Requirements	56
192	IU #7 OT or PT Referral Form	29
195	IU #7 Policy for Child Abuse and Neglect page 1	45
199	IU #7 Policy for Child Abuse and Neglect page 5	44
202	IU #7 Procedure for Catheterizing Female page 1	41
203	IU #7 Procedure for Catheterizing Female page 2	35
209	IU #7 Procedures for Gastrostomy Button Feeding Slow Drip or Continuous Pump page 2	23
213	IU #7 Procedures for Gastrostomy Feeding page 2	49
215	IU #7 Procedures for Nose & Mouth Suctioning w/ Bulb Syringe page 2	46
221	IU #7 Respiratory Care Form	46
225	IU #7 Traceostomy page 3	38
229	IU #7 Westmoreland IU Emergency Procedure	13
	TOTAL (21.29% of total lines of text)	1983

APPENDIX G

POLICY ON ADMISSIONS

Admissions Policy:

_____________Agency admits children from the ages of ____to ______ without regard to race, culture, sex, religion, national origin, ancestry, or disability. When the parent or legal guardian of a child identifies that a child has special needs, and the parent or legal guardian will meet to review the child's care requirements. _______does not discriminate on the basis of special needs. The program accepts children with special needs as long as a safe, supportive environment can be provided for the child. To help the program staff better understand the child's needs, the staff will ask the parent or legal guardian of a child with special needs to complete a "Special Care Plan" in conjunction with the child's health care provider(s). The program will attempt to accommodate children with special needs consistent with the requirements of the Americans with Disabilities Act. If the program is unable to accommodate the child's needs as defined by the child's health care provider(s) or the Individual Family Service Plan/Individual Education Plan without posing an undue burden as defined by federal law, will work with the parent or legal guardian to find a suitable environment for the child.

Source: Aronson, S., (2002). *Model Child Care Health Policies*. Elkgrove Village, IL:

Amercian Academy of Pediatrics.

APPENDIX H

POLICY ON FEEDING CHILDREN WITH NUTRITIONAL SPECIAL NEEDS

Sample Policy on Feeding of Children with Nutritional Special Needs:

Children with special needs related to their ability to eat or a nutritional need will have an individual management plan that includes a written description of each child's feeding history, including prohibited foods, and substitute foods where applicable, as supplied by the parent, legal guardian and the child's health care provider on admission to the program.

Source: Aronson, S., (2002). *Model Child Care Health Policies*. Elkgrove Village, IL:

Amercian Academy of Pediatrics

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