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Family-Centered Care: A School Nursing Model to Support Children with Special Health Care Needs and Their Families

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Family-Centered Care: A School Nursing Model to
Support Children with Special Health Care Needs and Their Families

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Abstract

Children and youth with special health care needs encompass a diverse group, yet many of their families face similar challenges in coordinating care and seeking support for their children. The licensed school nurse, having been trained as a public health nurse, is uniquely positioned to provide family-centered care that improves health outcomes, addresses health inequities, and empowers families to access resources. Intentional collaboration between the licensed school nurse and families will optimize children's health and ability to fully participate in school. School nurses have as part of their scope of practice the role of health teacher and health promoter (National School Nurses Association & American Nurses Association, 2011). By providing a more holistic, family-centered approach, the school nurse is able to see the child in the context of the family and better meet the needs of the child and the child's family.

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Children with special health care needs (CSHCN) are defined by the United States Department of Health and Human Services, Health Resources and Service Administration, Maternal and Child Health Bureau (2008) as children “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 in general” (para. 1). According to a survey conducted in 2009/2010 by the Data Resource Center for Child and Adolescent Health, 15.1% of children in the United States have special health care needs (National Survey of Children with Special Health Care Needs, n.d.). Licensed school nurses (LSN) are uniquely positioned to address the needs of CSHCN in the context of the family and community. This paper proposes a model for LSNs to provide family-centered care for children who have special health care needs that engages the community and informs public policy.

Background

Children with Special Health Care Needs and Their Families

Parenting a child with special needs, while challenging, also provides families an abundance of love and joy. The bonds of the family can be strengthened and family unity a source of comfort and resiliency. However, families who have a child with special health care needs also experience many challenges and struggles. Licensed school nurses working with families and CSHCN must consider the gifts the child brings to the family, while also being mindful of the struggles the family faces.

The goal of the LSN who provides care for CSHCN is to address inequities by providing comprehensive, family-centered care that focuses on the needs of the child in the context of the family. To achieve this, the LSN must consider the needs of the child, the needs of the family, and the ability of the child and family to participate in the community at large, including any

barriers to the child and family's participation. For many families, these barriers may be financial. For other families, disabilities may lead to social isolation. As a public health nurse, the LSN is uniquely qualified to view children and families holistically and address these barriers to improve the physical, social, spiritual, and emotional wellbeing of the CSHCN and their families.

Federal and State Health Initiatives

Healthy People 2020. Federal health initiatives are integral to the LSN's practice in caring for CSHCN and their families. Healthy People 2020, an initiative launched by the Department of Health and Human Services in 2010, has identified four overarching goals with specific objectives and interventions designed to achieve these goals:

- Attain high-quality, longer lives free of preventable disease, disability, injury, and premature death.
- Achieve health equity, eliminate disparities, and improve the health of all groups.
- Create social and physical environments that promote good health for all.
- Promote quality of life, healthy development, and healthy behaviors across all life stages.

In each of these four goals, the Federal government is committed to addressing the disparities in health seen in people with disabilities. As a nation, the US has a moral obligation to raise the standard of living for people who have been pushed to the margins of society for many years. The US government is taking a strong position to include people with disabilities as it looks ahead to shaping the health and wellbeing of our society. Health inequities seen in adulthood have their roots in early childhood. By bringing up the standard of living for children

and youth with special needs and their families, LSNs contribute to the advancement of the goals of Healthy People 2020.

Specifically looking at disability and health, Healthy People 2020 has a goal to “Maximize health, prevent chronic disease, improve social and environmental living conditions, and promote full community participation, choice, health equity, and quality of life among individuals with disabilities of all ages” (Disability and Health, para. 1). The LSN is in an advantageous position to maximize the health of children with disabilities. In the schools, much work is done on chronic disease management, from diabetes care and asthma management to tube feedings and catheterizations. LSNs work with children to improve their ability to manage their health conditions with increasing levels of independence, as well as working with families to connect with resources and providers when needs arise. By focusing on the needs of the child within the context of the family system, LSNs are able to provide better care to the child, the family, and the community.

Minnesota’s Olmstead Plan. Family-centered care supports the goals of Minnesota’s Olmstead Plan, created to align with the 1998 Supreme Court decision, *Olmstead v. L.C.* decision. Minnesota’s Olmstead plan (Minnesota Department of Human Services, 2015) was created to ensure that people with disabilities are allowed to participate fully in their communities, not in segregated settings populated primarily or exclusively by people with disabilities, but integrated into the community at large. People with disabilities should be given a voice in where they want to live and work, and the State has an obligation to provide them a path to greater independence and integration into society. This plan outlines four topics to achieve this goal; each of these topics have specific implications for LSNs who care for CSHCN and their families.

1. Ensure person-centered planning. The individual with the disability will have a say in what is important to them, what they want to do, and where they want to live. Their wants and needs will be at the heart of any plans made on their behalf.
2. People with disabilities will move out of segregated settings, and move into more integrated settings. This applies to schools, work places, and housing.
3. The State will increase its ability to support people with disabilities in the community by building up the resources available to meet these needs.
4. The State will increase community engagement of people with disabilities. Persons with disabilities will be involved in policy and decision making and welcomed into the community.

By advocating for CSHCN and their families, LSNs ensure that children are serviced in their least restrictive environment and support efforts to integrate children into regular education classrooms where they are taught alongside their typical peers. Lessons can be adapted to meet the child's learning needs, while keeping the child with his or her peer group.

Role of Licensed School Nurses

The LSN is tasked with many duties, including enforcing immunization law, medication management, participating in the special education process, creating safe plans of care for individual students, training staff on health conditions, and oftentimes assessing sick and injured children. The responsibilities of the school nurse may become very medically focused, as there are many competing needs. In addition, there may be a school social worker or counselor, and that individual is often in the building more than the LSN. Administrators and school staff often perceive the school nurse as being in the building for the purpose of seeing children who are sick or injured, not realizing the skills and depth of knowledge the LSN could contribute. Licensed

school nurses must be cognizant about educating their colleagues about the full scope of the LSN's roles and responsibilities, and how that role could be expanded to better meet the needs of students, including children and youth with special health care needs. Many students would benefit from a family-centered care approach that can address the barriers that their families face in participating in their child's education, facilitating a deeper connection between school and home, and strengthening involvement in the community at large.

The LSN has knowledge of the special education process as well as section 504 of the Rehabilitation Act and can speak to the family about what a child's needs are and how they might be addressed. The LSN also has skill in creating individual health plans and working with teachers and administrators to put accommodations in place and evaluate the effectiveness of those accommodations. The LSN is connected with local public health agencies, county programs, and has knowledge about insurance programs. Students and families would benefit greatly from a family-centered approach of nursing care from the LSN, in collaboration with other professionals from within and outside of the school setting, including the community.

Professional nursing standards. Professional nursing standards provide invaluable guidance for LSNs who care for CSHCN and their families, specifically the *Code of Ethics for Nurses with Interpretive Statements* (American Nurses Association [ANA], 2015) and the National Association of School Nurses (NASN) and ANA's (2011), *School Nursing: Scope and Standards of Practice* (2011).

Code of Ethics for Nurses. The guiding force of ethics in nursing practice, the *Code of Ethics for Nurses with Interpretive Statements* (ANA, 2015), has as its first provision that "the nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person" (p. 1). This provision includes five interpretive statements; each of these

statements is summarized below and related to the ethical responsibilities of the LSN who cares for CSHCN and their families.

- 1.1 **Respect for Human Dignity:** All individuals are afforded basic human rights, including the right to health care. Nurses provide care to patients that is respectful and considers the values of the individual. Nurses are called to be leaders in public policy development that supports the respect for human dignity.

School nurses care for children with a variety of health conditions, some of whom are medically fragile. The *Code of Ethics for Nurses* (ANA, 2015) makes clear that all children and families are to be treated with respect, regardless of circumstance. Nursing care reflects that every life has value and has inherent dignity.

- 1.2 **Relationships with Patients:** According to this interpretive statement, nurses are directed to provide care to individuals, families, and communities that takes into consideration the needs of the client served, including “culture, value systems, religious or spiritual beliefs, lifestyle, social support system, sexual orientation or gender expression, and primary language” (ANA, 2015, p. 1).

The LSN’s plan of care reflects the needs and values of the individual and family. Families are treated as part of the team. Resources align with the beliefs and culture of the client and are not forced upon families.

- 1.3 **The Nature of Health:** This component stresses that an individual’s worth is inherent to their being and is not dependent upon function, wealth, ability, age, or health. All human beings are accorded the same dignity and are to be treated with respect. Nurses aim to provide care that “enables the patient to live with as much physical, emotional, social,

and religious or spiritual well-being as possible and reflects the patient's own values” (ANA, 2015, p. 2).

Based on this statement, the LSN, in collaboration with the student and family, determines a plan of care that optimizes student wellbeing and ability to participate in their community. Ability to fully engage with the community will vary by individual, but the LSN will work to decrease barriers keeping the individual from accessing desired activities and supports.

- 1.4 The Right to Self Determination: Nurses work with individuals and families to create a plan of care that reflects the values of the individual. Nurses provide information regarding treatment option, including potential benefits and risks, to create plans that reflect the values of patients.

The LSN collaborates with families to create a plan that is consistent with the needs and values of the family. The voice of the child and family are heard and respected.

- 1.5 Relationships with Colleagues and Others: Nurses work across disciplines to provide care to patients. Communication with any member of the service team will be respectful. Nurses will collaborate with other service providers to provide optimal care for their patients.

The LSN may need to consult with other service providers, including the school social worker, county social worker, special education teacher, general education teacher, speech therapist, occupational therapist, physical therapist, or adapted physical education teacher. There may be providers within the school or the larger community who are providing the child with care or who could be of benefit to the family.

School Nursing: Scope and Standards of Practice. The NASN and ANA's (2011) *School Nursing: Scope and Standards of Practice* describe standards of practice and professional performance for school nursing expected of the school nurse. Duties and expectations can vary based on the setting, population, number of students, and years of experience, however, these standards provide a common language and describe what would typically be the responsibilities of the school nurse.

Standard 5: Implementation. This standard of practice details the steps needed in implementing the nursing plan of care. Competencies for this standard include creating a plan that is safe, realistic, and created in partnership with families. This plan should be a comprehensive plan that considers the needs of individuals from a variety of backgrounds and at different ages. This standard also speaks to the importance of individualized care that meets the needs of the client. Plans of care cannot be standardized, as each family and situation will be unique. The LSN must sit down with the family and discuss what is going well, what is causing strife, and resources are needed. This standard includes four components, as follows:

Standard 5A: Coordination of Care. The LSN coordinates with the healthcare provider, student and family to advocate for care that meets the needs of the child. The LSN works with staff to ensure that the plan is understood and implemented in the child's school day as well as extracurricular school activities.

Standard 5B: Health Teaching and Health Promotion. The LSN provides health education to individuals, groups of students, families, and staff. Health promotion activities are culturally appropriate and geared towards the needs of the learner.

Standard 5C: Consultation. Integral to the plan of care is the need for the LSN to collaborate with other health professionals and service providers to ensure the best plan of care.

The nurse cannot go it alone because there will likely be a need for team members beyond nursing care to meet the child and family's needs.

Standard 5D: Prescriptive Authority and Treatment. For advanced practice registered nurses, therapies and treatments are prescribed that are consistent with evidence based practice. Outcomes are monitored and treatments modified as needed to meet desired goals.

Standards 11, 12, and 13 speak to the need for the LSN to work effectively with families and service providers (NASN & ANA, 2011). As a member of the health care team serving the family, the LSN is often the link between the school and the medical community. Knowledge of educational terminology as well as medical terminology means that the nurse is often asked to be the bridge between families, schools, and medical providers. The LSN often knows the child well, and can communicate with the provider about the child's current health status and needs.

Standard 11: Communication. This standard states that the LSN needs to communicate with families and students clearly, using language that is understood by the recipient. Communication is encouraged between families, providers, and the LSN. Privacy and confidentiality are respected.

Standard 12: Leadership. This standard focuses on the leadership responsibilities of the LSN, and states that the LSN mentors colleagues, participates in wellness opportunities and administrative councils, and advances public health policy.

Standard 13: Collaboration. This standard states that the LSN collaborates with families to optimize health outcomes. The graduate-level prepared nurse draws upon knowledge of community health resources to target services at the populations served.

Role of Academic Nurse Educators

Nurse educators, as educators who are responsible for preparing the next generation of nurses, have a special obligation to be aware of the many issues facing children and youth with

special needs and their families, and how these needs can be addressed. The United States Department of Labor Bureau of Labor Statistics estimated that in 2014, 61% of registered nurses practiced in a hospital setting (Occupational Outlook Handbook, Registered Nurses, Work Environment, para. 1). With 39% of registered nurses working in community or public health settings, nursing students need to be well prepared in public health nursing to be competitive in today's job market.

Standards in nursing education. Standards used in nursing education also inform LSNs who care for CSHCN and their families, specifically *The Scope of Practice for Academic Nurse Educators* (National League for Nursing [NLN], 2012) and *The Essentials of Baccalaureate Education for Professional Nursing Practice* (American Association of Colleges of Nursing [AACN], 2008).

The Scope of Practice for Academic Nurse Educators. *The Scope of Practice for Academic Nurse Educators* (NLN, 2012) outlines the expectations and core competencies for the advanced practice nurse specializing in academic nursing education. Included in these competencies is Core Competency V: Function as a Change Agent and Leader (NLN, 2012), which states, “nurse educators function a change agents and leaders to create a preferred future for nursing education and nursing practice” (p. 19). As part of this expectation, academic nurse educators are expected to act as change agents within their work setting, to enhance nursing's visibility and contributions. Academic nurse educators working in a school nurse role would look for opportunities to incorporate innovative practices to advance the nursing profession. The skilled LSN would draw on leadership skills to promote culturally sensitive changes in meeting the needs of the students in the school. The LSN academic nurse educator participates in interdisciplinary work to meet the health and educational needs of students.

Based on the demands for nurses related to the changes in health care, nurse educators will need to tailor curricula to provide students with a deep knowledge of public health nursing in addition to nursing in the acute care setting. The nursing profession will be better served by nurse educators who can prepare students for a variety of nursing roles and provide students with opportunities to explore which roles may be best suited to their individual gifts. Nursing is an extraordinary profession; nurses can work with people throughout the lifespan, from prenatally, to advanced age, men and women, critically or chronically ill to promoting wellness in healthy individuals. Nurses provide hands-on care, do research, teach, and work on policy. Nurse educators must prepare nurses to have the knowledge, skills, and values to work in this expansive profession, but also to show them that these opportunities are available to them and needed by society.

School nursing is a very rewarding profession, allowing nurses to develop long-term relationships with children and families. Nurse educators, working as change agents and leaders, explore with their students the settings in which nurses serve, and equip them with the skills needed to be successful. They get to know their students talents and work with them to line up experiences which will allow them to develop their gifts and find their niche. For nursing students going into public health, nurse educators will need to be mindful of teaching students how to work collaboratively with other health care professionals, including doctors, occupational and physical therapists, speech therapists, social workers, and mental health providers. Culturally congruent care, effects of poverty on health, and the ability to assess health literacy will be important components of their education. In addition, nurses will need skills in working not just with individuals, but with families and their communities. Family-centered care practices will provide nurses with skills needed to be successful in all areas of public health.

The Essentials of Baccalaureate Education. As academic nurse educators plan, implement, and evaluate curricula for baccalaureate nursing programs, *The Essentials of Baccalaureate Education for Professional Nursing Practice* (AACN, 2008) guides the development of curriculum content and delivery of nursing instruction. These academic standards for nursing programs delineate the expected outcomes and competencies that a baccalaureate-prepared nurse must achieve to practice safely and independently, including specific competencies that prepare nursing students to assume nursing roles in community settings, including school nurses.

Essential II: Basic Organizational and Systems Leadership for Quality Care and Patient Safety, states that nurses must demonstrate leadership in health care systems. Care is provided as part of an interprofessional team, and nurses must have the necessary communication skills to work effectively as part of the team. Nurses are expected to work for quality improvement in care, and recognize the impact on individuals, families, and populations (AACN, 2008, pp. 13-15).

Essential VIII: Professionalism and Professional Values, focuses on the adoption of the ethical principles put forth by the nursing profession. Baccalaureate-prepared nurses combine evidence-based practice with an expert ability in working with diverse populations across the lifespan. Nurses recognize the innate dignity of every person, and respect the autonomy of each individual in determining their plan of care (AACN, 2008, pp. 26-29).

Essential IX: Baccalaureate Generalist Nursing Practice, describes the need for nurses to be able to provide care that is holistic in nature and culturally congruent with the individuals who are served. With rapid changes in the delivery of health care, nurses are often the link between health care services and individuals, families, and communities (AACN, 2008, pp. 29-33).

Family Centered Care

Principles of family-centered care. Licensed school nurses are uniquely positioned to provide family-centered care that is focused on both the child with special health care needs and their family. According to Lindeke, Leonard, Presler, and Garwick (2002), family-centered care is a philosophy that includes nine essential elements:

1. Recognize that the family is the constant in the child's life
2. Facilitate parent/professional collaboration in all aspects of care planning, delivery, evaluation, policy formation
3. Honor family racial, ethnic, cultural, and socio-economic diversity
4. Respect family strengths, individuality, and unique coping methods
5. Share complete, unbiased information with the family in a supportive and ongoing manner
6. Encourage and facilitate family-to-family support and networking
7. Incorporate the developmental needs of all children and families into the care process
8. Implement comprehensive policies and programs to provide emotional and financial support to families
9. Design accessible, flexible, culturally competent health care systems that are responsive to family-identified needs. (p. 294)

These elements provide a framework for working with CSHCN and their families. The values, needs, and strengths of the family are honored, and the child is recognized as part of a larger system, making interventions more relevant and effective. As noted by Looman, O'Conner-Von, and Lindeke (2008), having a child with a chronic health condition impacts every member of the family, from parental caregivers who may have physical pain, high blood

pressure, or anxiety, to siblings who may struggle with their feelings or the practical implications of having a sibling with a disability. The effects of the child's disability are often far-reaching, impacting the ability to access community resources and activities, attend social gatherings, attend area schools with siblings, participate in spiritual formation as desired, and plan for the future. The degree to which these activities are influenced by the disability will vary, but the potential is significant and may change over time. Therefore, strengths and areas of challenge will need to be assessed in an ongoing basis to monitor for changes in family functioning.

Settings for family-centered care. Children with special health care needs do not necessarily have special educational needs. Some children may need accommodations made for them to be successful in school, such as shortened assignments, additional time to complete work, access to frequent snacks, a place to rest when tired, movement breaks, or the use of assistive technology for written work. These types of needs can be met with a 504 accommodation plan. This plan is often written in consultation with the school nurse, particularly if the plan is written to meet health needs. When a child under three years of age has educational needs requiring special education services, an Individual Family Service Plan (IFSP) is written. Children age three and older receive special education services through an Individual Education Plan (IEP).

Family-centered care is the norm in birth to 3 years of age, but becomes less common when the child switches from IFSP to an IEP. A review of research found that as children got older, "the degree of family-centered practice was shown to decrease at each level from early intervention to preschool to elementary to secondary school programs" (Concepcion, Murphy, & Canham, 2007, p. 317). In the Birth to 3 program, services are most often provided in the home, as this is the natural setting for the child. School-based services typically begin at age 3. These

services focus on the needs of the individual learner, with the family emphasized less. Students who have special health care needs who are being evaluated for special education services will need a health assessment completed by the licensed school nurse, providing an opportunity for the LSN to provide a holistic assessment of the child and family, though this process could be used with any family. The child with special health care needs may have a health condition with a significant impact on the child and family, such as diabetes, with no educational needs.

Why Change?

School nursing practice can sometimes be compartmentalized as focusing on only the medical concerns of a student. In schools with a strong social work presence, many of the facets of emotional, spiritual, and social care are seen as falling under the jurisdiction of the school social worker. Licensed school nurses are able to assess many of these needs and concerns, and can play an integral role in working with families who have CSHCN to connect them to appropriate community resources.

Inclusion

The Federal government recognizes that children with special needs should be educated alongside their typical peers whenever possible. In planning for a school setting, special education staff aim to find the least restrictive environment (LRE) to educate a child, as directed under the Individuals with Disabilities Education Act of 2004, which states:

To the maximum extent appropriate, children with disabilities, including children in public or private institutions or other care facilities, are educated with children who are not disabled, and special education 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 the child is such that

education in regular classes with the use of supplementary aids and services cannot be achieved satisfactorily. (Section 300.114)

Though the Federal government does not use the term inclusion, the intent is clear that children with disabilities are expected to be included as part of the classroom and school community, and the use of segregated or self-contained classrooms is discouraged.

Children with special health needs must be welcomed into inclusive classrooms, and so too, should families be welcomed into the school environment. Burke and Hodapp (2014) found that when mothers of children with special health needs felt they had a strong, supportive relationship with the school, they had lower levels of stress. Lower parental stress enables parents to better support their children academically and socially, and enhances family wellbeing. Maternal stress levels decreased when “school personnel often or very often listened without judging the child or family, were people that mothers could depend on and trust, paid attention to what mothers had to say, were friendly, were honest even when they have bad news, and were available when mothers needed them” (Burke & Hodapp, p. 20, 2014).

Underutilization of the School Nurse

Licensed school nurses have expertise in child growth and development, nutrition, physiology and pathophysiology. They have been trained as public health nurses and have strong clinical skills. LSNs work in highly autonomous positions, often being the sole medical professional in the school. Despite this training, school staff often see the LSN as serving in a limited capacity. All too often, administrators assume the LSN’s primary function is to attend to the first aid needs of the student body, as this is often delegated to support staff in the absence of the nurse. In addition, the LSN is viewed as the person who administers medications, performs vision and hearing screenings, and conducts Early Childhood Screenings. Teachers and

administrators often overlook the necessary job functions of creating plans of care for children with special health care needs, training staff to care for children in the absence of the nurse, enforcing immunization laws, and participating in the special education process to identify children whose health conditions are impacting their academic success.

The responsibilities of the school nurse are many, and the time to complete them is often lacking. How do we then add more responsibilities? Increase the allocations for licensed school nurses. We do our students and families an immense disservice when we try to meet the needs of 500 students with a licensed school nurse available 2 days per week. The National Association of School Nurses (NASN) position statement on safe staffing advocates for 1 nurse for every 750 healthy students. Many factors can alter this recommendation, however, including health status, poverty, access to health care, and environmental stresses (NASN, 2015). This ratio is promoted as a minimum to meet basic safety for students, but does not imply that this is optimal for student and family wellbeing. NASN stresses that increasing LSN time in a building saves teachers and administrators time, decreases student absences, improves student health, and decreases time parents must take off from work, and saves money in health care costs for the community. When school districts increase nursing time, allowing LSNs to work at the top of their licensure, the schools and families reap many benefits.

Needs and Challenges for Families

Families with CSHCN face unique challenges. In a report from the Lucile Packard Foundation for Children's Health (Hughes, 2015), 52 families with CSHCN in the San Francisco area discussed their frustrations in working with service providers. Four themes emerged as commonalities in their experiences. These four themes included frustrations with (a) a complex and fragmented system; (b) a system that is not designed with families in mind; (c) failure of

service providers to recognize the burden on the family; and (d) barriers imposed by race, language, and income.

Current health care system. Parents are often responsible for coordinating care between multiple providers, as well as the school district and county workers. The multiple systems involved each have their own policies, forms, and procedures, and they often do not talk to each other. Parents must navigate through these systems and work with each provider separately, then report back to the other agencies. Parents expend a great deal of time and energy trying to coordinate their child's services and care providers. Many clinics have care coordinators, but the care coordinators may not communicate with each other. Other families must act as their own care coordinator, which is daunting for parents, many of whom have little health care experience, and may be trying to balance outside employment and other family responsibilities. One parent shared her experiences, saying, "I carry notes and records whenever we see the specialists because they-I don't believe-they don't talk to one another. One is only interested in [my son's] brain injury. The other only cares about orthopedic issues. They never come together [to share information]. That's my job" (Hughes, 2015, p. 14). For families with low health literacy or barriers to health care, this coordination can be overwhelming.

Hughes (2015) stated that parents often felt they were not aware of the services that were available, how to obtain them, or whom to contact. They saw other parents as their most reliable source of information. Said one parent, "Well I think that for us who have children with special needs, it's difficult. Because we always have to be looking. I mean, they never call us and say, 'Hey, we have this here for your son.' We always have to be looking and looking and looking and looking" (Hughes, p. 14, 2015).

Parents often expressed that systems were designed to accommodate the needs of the providers, rather than to be user friendly to families (Hughes, 2015). One parent recalled to Hughes an episode with a physical therapist, stating, “I didn’t have child care. I had a 2-year-old that I was bringing with me. Well, the PT was scolding our 2-year-old while we were trying to do [the exercises]- there just needs to be a family approach” (Hughes, 2015, p. 14).

Parents often do not feel that their providers really listened to what they have to say (Hughes, 2015). Parents of children with special health care needs are often keenly aware of their children’s health status. When something does not seem right, they perceive a change in their child’s health, they want providers to take their concerns seriously instead of being dismissive.

Hughes (2015) reported that families feel a heavy burden that largely goes unrecognized by others. There is time spent on case management and service coordination, financial stress, physical and emotional strain from caregiving, grief, feelings of isolation, and challenges with meeting the physical and emotional needs of other family members. These burdens are rarely discussed when meeting with providers, and families feel little support in meeting these challenges. Many families reported feelings of isolation, fear, and vulnerability. While this size of this study may be relatively small, this study indicates the importance of discussing these issues with families. Parents expressed concerns for their other children, their housing, access to adequate health insurance, and the toll of constantly struggling for services. One parent stated, “I think that people-even educated ones-don’t know. They might know how to interact with others but don’t know how families feel when there’s a child with special needs. It doesn’t just change the child’s life; the mother and the father need to learn how to fight” (Hughes, 2015, p. 18).

Health disparities. Families described in the Hughes (2015) report identified barriers to care due to language, race, and income. Families reported difficulty in obtaining information they could understand in their native language or at their education level, impacting their ability to make informed decisions regarding their child's care. Racial biases were felt by some parents to influence the care their children received. They reported that assumptions were made about their children based on their race, negatively influencing the relationship between the parent and provider. United States Census Bureau statistics from 2012 found that 37% of the population was white, non-Hispanic (United States Census Bureau [USCB], 2012). By 2060, that number is expected to be 57% of the United States population. Culturally appropriate care that respects the values and traditions of each family will be needed to assure that families' needs are heard and understood.

Disabilities are more prevalent in racial and ethnic minorities, due to higher levels of poverty. Despite this, African American families demonstrate an increased capacity for resilience due to strong kinship networks (Algood, Harris, & Hong, 2013). Extended family and community supports can provide caregiving, emotional, and physical supports to a family experiencing difficulties. This may take the form of grandparents, aunts, uncles, cousins, neighbors, friends, or church members. There is a strong sentiment of kinship in many minority communities, ensuring that children are provided for when parents are not able to care for a child on their own. While some African American families and other racially diverse families may feel support from their community, some may not have an extensive support system in place. The LSN should inquire about the availability of child care and social supports for each family. Public health nursing is invaluable in connecting with families who may be unaware of available services in the community or how to access them.

Economic disparities. According to research conducted by Looman, O’Conner-Von, and Lindeke (2008), 40% of families with children with special health needs in the United States reported having financial stress due to their child’s disability. Having a child with special needs limited their ability to be fully employed and often was associated with increased financial costs. Caregiving may consume a large portion of the day, impacting the ability for parents to work to the extent that they would like. Families may have financial concerns due to underemployment as well as additional costs associated with their child’s health condition. Families with limited incomes stated that the health insurance they were able to obtain restricted their ability to access providers (Hughes, 2015).

Faith and spirituality. Religious beliefs offer many families support in understanding their child’s disability. Research suggests that religiosity appears to be more important to family wellbeing than is participation in organized religious activities (O’Hanlon, 2013). Faith serves to bring meaning to the child’s disability, and in doing so, can bring comfort to families (Kamei, 2014). Parents and caregivers ability to attend religious services may be impacted by their child’s medical needs or behavior challenges. Part of a comprehensive nursing evaluation includes an assessment of spiritual wellbeing. If this is an area of importance for the family, the nurse should determine whether the child and family are able to participate in their faith community to the extent that they desire.

A study of nine families with children with special health care needs found that there were three key elements that were important in selecting a faith community (Richardson & Stoneman, 2016). First, families looked for an environment that physically met their child’s needs. For some families, this might mean a space that is wheelchair-accessible, has music, or lighting that is soft. Second, families were seeking faith leaders who were welcomed their

children and embraced the family. Third, families sought out faith communities where the other members welcomed their children with disabilities. In some cases, parents were reluctant to bring their children to services, not because they were not welcomed, but rather because they feared their child would display inappropriate behavior. The faith community can be an important source of support for families, decreasing social isolation and providing friendships and strengthening community connections for caregivers as well as children.

Isolation. Community involvement is an important component of healthy social life. It provides families with friendships, social supports, and recreational and spiritual opportunities. Children with intellectual disabilities and their families are at increased risk for social exclusion (Brown, Cobigo, & Taylor, 2015). Inclusive education places children with disabilities in a learning environment with their typical peers, but families may not perceive their child as being welcomed. For families with children in a more restrictive setting, the school may not be their community school, creating a disconnect between the family and the larger school community. Schools bear a responsibility in fostering community within their families, helping establish a sense of connectedness for all families, but in particular those who are at risk for marginalization.

Families with children with special health care needs may feel excluded from many of the social aspects of community life. Challenging behaviors can make outings more difficult. Sensory needs or physical impairments can limit access to social opportunities (Brown, Cobigo, & Taylor, 2015). In a study of children with spina bifida and urinary incontinence, affected children and their parents reflected on the child's desire to fit in with peers and the struggle with feeling different (Fischer, Church, Lyons, & McPherson, 2015). Many of the children expressed

feelings of isolation and embarrassment related to their incontinence. It limited their ability to go to sleepovers, attend camp, or establish friendships.

Societal attitudes towards people with disabilities is changing, but there is still much growth to be made in recognizing the value of every member of society, regardless of the degree of impairment. Intentional inclusion of children with special needs and their families creates a stronger, more vibrant community.

Resiliency. Parental stress is increased in families raising a child with an intellectual disability (Gerstein, Crnic, Blacher, & Baker, 2009). This may be due increased need for supervision or monitoring of behaviors. A positive, supportive relationship between parents is associated with more resiliency in mothers parenting a child with special needs. In a study looking at family resiliency ((Richardson & Stoneman, 2016), parents who demonstrated strong resiliency skills, such as flexibility and a willingness to get involved, were better able to establish their families in a faith community. These parents advocated for their children and family within the faith community by serving as leaders or members to advocate for their children's needs within the community. Clear, open communication about needs can be difficult for families, especially in coming into a new community when looking for acceptance. Encouraging families to have clear, open communication expressing needs and helpful accommodations can positively impact resiliency (Richardson & Stoneman, 2016).

How Will Family-Centered Care Work?

Licensed school nurses have an essential role in identifying the individual needs and challenges experienced by CSHCN and their families and assisting them in making connections with service providers and community resources. Specific components of the LSN role in family-centered care include (a) communicating the role of the LSN, (b) taking time to listen,

and (c) conducting a comprehensive health assessment. These components are visually depicted in a school nursing model of family-centered care presented in Appendix A.

Communicate the Role of the School Nurse

To meet the needs of the child, the needs of the family must be identified. A thorough nursing assessment by the LSN could address many of these challenges. For many families, as reported by Hughes (2015), what is needed is someone who will take the time to truly hear to what they need to say. A parent may be looking for resources, or may be looking for a compassionate person who will listen without judgment. School nursing is well suited to this type of care, since the LSN is able to give families the time needed to discuss the challenges as well as the successes. The LSN is able to go on a home visit or meet with the family at school. The relationship is not bound by insurance reimbursement formulas or provider schedules. In addition, the LSN often develops relationships with families and children that span several years, often having contact with a child from once per week to multiple times per day.

Licensed school nurses are uniquely positioned to provide family-centered care that is focused on both the child with special health care needs and their family.

Take Time to Listen

Children's Hospital of Philadelphia began a training program with doctors, nurses, and other health care professionals to educate them about the basics of family-centered care (Heller & McKlindon, 1996). The idea was to recruit parents of children with special needs to speak about their experiences raising their children with health care providers. Parents circulated pictures of their children and told providers about their families, including the reasons that family-centered care was important to them. The medical model tends to focus on the disease process; however, parents emphasized how their child's condition impacted their family. Parents

wanted providers to understand that “the children who are patients have an entire world beyond the hospital’s walls, a world that professionals must understand and support” (Heller & McKlindon, 1996).

Children are more than their disability. They are sons, daughters, cousins, friends, athletes, artists, and students. They have interests and abilities. Parents want their children to be known beyond their health condition. Health care providers need to be comfortable talking less and listening more. Given the opportunity, families will tell health care providers what they need to know about their child’s needs and what is most important. Health care providers who are overly focused and ask closed-ended questions do a disservice to children with special health care needs and their families, and compromise their own ability to provide care that promotes the health and wellbeing of CSHCN and their families.

Conduct a Comprehensive Health Assessment

A parent interview is one of the most important components of a comprehensive health assessment. This may be done over the telephone, though it can be done as part of a home visit or with the parents coming to school. Meeting face to face can facilitate more open communication and strengthen the relationship between LSN and family. A home visit gives insight into the child’s environment and family strategies in managing their child’s health condition at home. The parent interview gives the family an opportunity to discuss their concerns for their child, while providing the nurse with the information to address the concerns and create a plan of care. In addition to a review of systems and health history, an assessment of general health and family health can also be included in the interview.

General health. Questions to assess the general health of the child may include: Does your child have a primary care provider? Who are all the providers your child sees? How often

do you see each one? Has your child ever been seen in the emergency room? Has your child ever been hospitalized? Has your child had any surgeries? Does your child have any diagnoses? Does he/she take any medications (including over the counter medication, traditional medicines, or herbal/homeopathic)? Who is your child's dentist? Does your child have a county social worker? How is your child doing physically? Do you have any social or emotional concerns for your child?

Family health. Questions focused on the health of the family may also be addressed as part of comprehensive assessment, for example: What is your main concern for your child? Are you able to access community activities, such as playgrounds, sports, friendship/play groups, or religious services to the extent that you would like? What is going well? What is hard? What does your child need? What does your family need? How are you coping with the demands of caregiving? Who are your supports? Who are the people you can call to help you?

Ecomap. Ecomaps provide a visual representation of families' social supports. The nurse works with the family to name the relationships, supports, and social networks (Ray, 2005). The family is at the center of the ecomap, with satellites branching off representing the people, communities, and resources supporting the family. Lines can be made thicker to indicate stronger bonds, or wavy to indicate a strained relationship. Arrows indicate the directional flow of support. This tool allows the family to better visualize where they are able to draw support, as well as provide a means for the nurse to see how well supported a family feels. Families who can name few social supports, or who expend many resources supporting others, may need assistance in locating supports for themselves.

Communication with service providers. Licensed school nurses working closely with children with special health care needs often accumulate data that would be helpful for service

providers, such as primary care doctors, pulmonologists, endocrinologists, and neurologists. A signed release of information could facilitate a collaboration that would benefit the child and family to ensure that care meets the child's needs and providers have an accurate picture of the child's health. The LSN can send the family written documentation to take to the provider describing physical functioning, such as peak flows, albuterol usage, breath sounds, and health teaching. When needed, the school nurse could communicate directly with the provider. Coordination of care would assist families by taking some of the burden off of them for relaying health information.

What Will Change as a Result of Family-Centered Care?

Family-centered care puts the focus where it belongs: on children with special health care needs and their families. By listening to families and addressing their unique needs and concerns, the actual and potential benefits of family-centered care are significant for CSHCN, their families, and their communities.

Increased Parental Ability to Work

Parents of children with special health care needs may have difficulty obtaining or maintaining employment that provides the flexibility needed to care for their child. Parents may need time off work for medical appointments, therapies, and frequent or prolonged illnesses. With better care coordination and access to needed resources, parental ability to maintain employment increases. Maximizing employment opportunities will decrease parental stress by increasing family income (Knestrict, 2009). Families who are able to make more money have more options in choosing housing and school districts. They are able to modify their homes as needed to meet their children's needs. With a higher income and adequate employment, families are able to afford better insurance coverage, increasing opportunities for health care providers

and therapies. Increasing income is associated with increased resiliency and emotional wellbeing (Knestrict, 2009).

Racial and Ethnic Minorities Respected as Partners

Culturally appropriate, family-centered care has a positive impact on families feeling that they have a voice in their child's care, a concept referred to as shared decision making (Smalley, Kenney, Denboba, & Strickland, 2014). A family's ability to feel connected to the plan of care is influenced by the provider's ability to communicate effectively and respect cultural norms. As noted by Hughes (2015), assumptions about a family's beliefs, values, socioeconomic situation, or health literacy can degrade the relationship between provider and family. The LSN must work with families in a culturally appropriate, family-centered manner that respects the experiences and beliefs of the caregivers. Open ended questions allow the nurse to determine strengths and areas of need and provide the family an opportunity to describe their situation without making assumptions about what is needed. Drawing in families and partnering with parents creates partnerships and gives parents a voice in their child's care.

Better Utilization of the School Nurse

The LSN has multiple demands on limited hours. Providing family-centered care is an endeavor that will take a great deal of time. However, this type of care is invaluable to the families lacking care coordination, disconnected from care providers, or lacking social supports. Many families may be well connected to resources and have adequate social supports. However, in communities where economic and geographic disparities are more prevalent, the need will likely be greater. Basic first aid services is a component of school nursing that would be more cost-effective to have performed by a health assistant, allowing the LSN to devote more time to the functions best suited to their licensure.

Better Care Coordination

The LSN, in working with a family over several years, is able to see the child during times of illness as well as good health. The LSN develops a relationship with the family and can meet with parents to discuss care coordination concerns. The LSN is a valuable resource in determining when a child needs medical attention, and directing families to appropriate providers. Care coordination can be complex for children with special health care needs. The LSN can assist families in setting up appointments, arranging transportation to appointments, and facilitating communication between school, family and providers.

Families Feel Heard and Supported

For many families, the daily struggles of parenting can be challenging. Families with children with special needs may be feeling increased pressure, perhaps overwhelmed by the demands on their resources. Nurses can offer families the gift of therapeutic use of self. The act of listening without judgement, or just sitting with someone in their time of pain, can be a kindness that families may not get from other members of their extended family or health care team. Families want to know that you genuinely know and care about their child, not just the medical condition and the evidence-based treatment options. Families want to feel heard and understood.

Community Involvement

Connecting families to opportunities for play and participation in community activities, encouraging community building within the school, and empowering families to develop social support systems, increases the connectedness of families to communities. School nurses work with families to find summer camps, adaptive recreation, and school organizations. With health conditions addressed, children may be better able to participate in social activities.

Family-Centered Care and Public Policy

The State of Minnesota's Minnesota Children & Youth with Special Health Needs Strategic Plan 2013-2018 has as its vision, "to improve health through building the capacity of all systems that serve families of children and youth with special health needs" (Minnesota Department of Health, 2013). Five overarching themes were identified to support this vision, the first being family-centered care. The family is recognized as central to the health of the child. The policy is the result of a work group which included parents of children with special health needs. Care must be culturally congruent and explained in plain language. Parents should be respected as partners, and families viewed holistically.

The Goal: A Better Life

By breaking down the barriers preventing children and families from participating in the larger community, feelings of isolation diminish. Children are placed in less restrictive environments and are able to develop friendships with their typically developing peers. Families venture out to find spiritual homes, and have the tools to openly ask for the accommodations their children need. The community is enriched by having all families present, all abilities represented, and all voices heard. When children with disabilities and their families are excluded from the community, we are all diminished.

Family-centered care results in improvements in children's health, allowing them to attend more school days. Research by Knapp, Madden, and Marcu (2010) found that a strong provider-patient partnership was associated with a decrease in emergency department visits by 20% and fewer missed school days. These results are positive for children as well as providers in terms of better patient outcomes and cost savings.

The LSN is uniquely positioned to provide family-centered care to the child with special health care needs and their families. The long-term relationships established with children and families fosters the nurse's ability to establish rapport and build trust. The LSN has the public health background to work with families from diverse backgrounds and connect them to resources that will be beneficial and culturally appropriate. They are able to track how a child is doing and how a family is coping over months to years, and can connect with providers when needs arise. Over 90% of school nurses have daily contact with families (Concepcion, Murphy, & Canham, 2007), such as telephone calls, letters, emails, or home visits. The role of the LSN is ideally structured, professionally and ethically, to provide family-centered care that optimally serves children with special health care needs and their families.

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Appendix A

School Nursing Model of Family-Centered Care

for Children with Special Health Care Needs and Their Families

