

ARE THE HEALTH SERVICES FOR CHILDREN WITH SPECIAL HEALTH CARE  
NEEDS MET THROUGH SCHOOL SERVICES?

by

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Through School Services?

The Maternal and Child Health Bureau recognizes children with special health care needs (CSHCN) as “those with chronic physical, developmental, behavioral, or emotional conditions that require health and related services of a type or amount beyond that required of children generally” (Kuhlthau et al., p.136). These children may need medication, medical care, mental or educational services, or special therapy in order to maintain functionality (Houtrow, Okumura, Hilton, & Rehm, 2011). Nationally, 98% of children attend school daily and 16% of those students have additional healthcare needs (DurRant, Gibbons, Poole, Suessmann, & Wyckoff, 2010). In North Carolina, 195,416 students with one or more disabilities are enrolled in the 2013-2014 school year (“Exceptional children”, 2013).

Federal law requires schools to adapt their services to accommodate children with special needs, but many schools struggle to adapt programs because of costs associated with personnel and resources (Murphy & Carbone, 2008). Seventy-five percent of elementary, middle, and high schools nationwide exempted students with disabilities from activities primarily due to their cognitive or physical disabilities (Murphy & Carbone, 2008). Therefore, CSHCN are more likely to have unfavorable outcomes in school such as repeating grade, lack of engagement, and increased absences when school services are not fully available to them (Reuben & Pastor, 2013). It is important to understand how schools provide comprehensive programs for CSHCN in order to improve both their academic and health outcomes.

## **Review of Literature**

### **Barriers of Children with Special Health Care Needs**

Children with special health care needs is an umbrella term that includes a wide range of mental, emotional, and functional limitations (Aruda et al., 2011). Children can be identified as having a special health care need if he or she had a chronic condition for one year in addition to either the need for prescribed medications, a need for medical care greater than the average person his or her age, limited in own ability, in need of special therapy, or participating in counseling for emotional, behavioral, or mental issues (Houtrow et al., 2011). Children with birth defects, asthma, autism, attention deficit disorder, developmental limitations, and chronic conditions are recognized as having special health care needs (Meyer & Cassell, 2009). About 20% of children meet the standards based on their decreased ability to function on the same aptitude as children without disabilities of the same age (Houtrow et al., 2011). Each classification of CSHCN has different needs that require specific services and resources in order to have their health care needs met adequately (Strickland et al., 2011).

Numerous studies used the National Survey of Children with Special Health Care Needs to identify the prevalence of different aspects of CSHCN on a national and state level (Fulda, Johnson, Hahn, & Lykens, 2012; Houtrow, Jones, Ghandour, Strickland, & Newacheck, 2012; Skinner & Slifkin, 2007). The survey reported factors such as health insurance, geographic location, severity of impairment, and racial and ethnic backgrounds to be associated with meeting the needs of CSHCN (Fulda et al., 2012). Children with complex chronic conditions require medical attention or further technology, which requires additional needs, costs, and access to health services (Murphy, Kobayahi, Golden, & Nageswaran, 2012; Houtrow et al., 2011).

Fulda and colleagues (2012) conducted a study that identified the extent of unmet health care needs in a sample of over 40,000 children with special health needs in all fifty states (Fulda, et al., 2012). The degree of met needs were based on factors such as routine preventive care, specialist care, dental check-ups, prescription medication, physical/occupational/or speech therapy, mental health care, short term care, vision care, and genetic counseling (Fulda et al., 2012). The Midwest and Northeast had the lowest unmet needs and the West and South had the highest unmet needs of children with disabilities (Fulda et al., 2012). Approximately half of every region did not provide short term care, with the highest incidence in the South with 55.10% (Fulda et al., 2012). In comparison, a study based in six rural counties in North Carolina reported that rural areas do not have the resources or personnel available to meet the needs of children with disabilities and clients has to travel approximately forty miles to receive adequate care (Murphy et al., 2012).

### **The Role of Family Centered Care Program**

Kulthau et al. (2011) conducted a systematic review on FCC programs set in the United States included various study designs. The FCC objective is based on the principle that “families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services that they receive” (Kuhlthau et al., p.136). Many of the studies that focused on FCC in schools resulted in different findings. One study reported no change in missed days of school after FCC was implemented while other studies showed a reduction in school absences and improved overall health satisfaction (Kuhlthau et al., 2011). All of the studies concluded that FCC improved communication among care providers and families and no reports found negative outcomes related with FCC (Kuhlthau et al., 2011).

Trust must be established between professionals to facilitate mutual goal setting and decision making (Kuhlthau et al., 2011). Several studies identified that FCC is meant to promote communication, satisfaction, and access to health care for the child and his or her family (Bellin, Osteen, Heffernan, Levy, & Snyder-Vogel, 2011; Law, McCann, & O'May, 2011; Murphy et al., 2012; Shaw & McCabe, 2008.). Caregivers have an important role in communication between healthcare professionals and the educational setting concerning their child's needs, but many caregivers feel inadequate as the mediator between the two parties (Aruda et al., 2011). Aruda et al. (2011) indicated that parents do not feel involved in making health decisions for their child and think that health professionals have the only opinion.

### **School Participation**

The level of participation in the academic setting directly affects how students develop socially, intellectually, and personally (Reuben & Pastor, 2013). A correlation exists between participation and the level of mental and physical health that is achieved (Murphy & Carbone, 2008). Two studies stated that factors such as time, family environment, misconception, school and community support, and functional limitations are barriers that deter participation (Houtrow et al., 2012; Murphy & Carbone, 2008). Cost of specialized equipment was indicated as a significant barrier that prevents participation of children with health limitations (Murphy & Carbone, 2008).

Numerous articles support the finding that all classifications of CSHCN have a higher incidence of school absences and grade repetition, lack of engagement in the classroom, and disciplinary problems (Bethell et al., 2012; Houtrow et al., 2012; Meyer & Cassell, 2009; Reuben & Pastor, 2013; Shaw & McCabe, 2008). The degree of the child's illness is related to the increased number of school absences and decreased motivation (Shaw & McCabe, 2008).

Children with chronic health care needs were two to ten times more likely to have unfavorable school outcomes compared to those in optimal health (Reuben & Pastor, 2013).

### **School Services for Children with Special Health Care Needs**

As a result of several laws, all public schools are required to accommodate CSHCN. Three federal laws that relate to children with special health care needs are the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA) (“Services in school”, 2011). IDEA mandates that public education must be provided to the general population in the least restrictive environment (Murphy & Carbone, 2008). The Other Health Impaired is a subcategory of the IDEA that requires individualized educational plans for students with medical impairments that affect their functioning (Shaw & McCabe, 2008).

Section 504 mandates equal opportunities to be provided to those with a functional limitation and restricts them from being excluded from any activities (Murphy & Carbone, 2008). Schools are required to modify their services to adapt activities to include students with disabilities (Murphy & Carbone, 2008). Modified assignments, access to specialized equipment, and additional time for tests are services that promote inclusion of students with disabilities (“Services in school”, 2011). The American Academy of Orthopedic Surgeons developed a “participation possibility chart” that depicts the best activities for different types of medical conditions that promote inclusion of children with special health needs in activities (Murphy & Carbone, 2008). The ADA prohibits discrimination of children with psychiatric or physical disabilities in the educational system (“Services in school”, 2011).

Limited resources in the school systems directly affect the extent to which these laws are enforced (Murphy & Carbone, 2008). The National Association of School Nurses recommend

1:750 nurse to student ratio for students without disabilities and 1:125 in student populations with additional health care needs (DurRant, Gibbons, Poole, Suessmann, & Wyckoff, 2010). The number of school nurses decreased due to inadequate school funding (DurRant et al., 2010). Three studies reported that when nurses are not available, medical interventions like finger-sticks and tube feedings are delegated to staff members (DurRant et al., 2010; Kruger, Radjenovic, Toker, & Comeaux, 2013; Kruger, Toker, Radjenovic, Comeaux, & Macha, 2009). Two studies revealed that most schools have first aid kits, but not all have oxygen tanks, pulse oximeters, blood pressure equipment, or disposable gloves, which can be detrimental to the health of a child with a chronic illness (Kruger et al., 2013; Kruger et al., 2009). Nursing care would improve if the student to nurse ratio decreased at schools and the staff were more educated on the needs of the students (Kruger et al., 2009).

New programs have been implemented to benefit the needs of the student body, but have directly enhanced the academic performance of CSHCN directly. For instance, the Wayne Initiative for School Health was established in six schools to provide health services such as health assessments, immunizations, and dental screenings to students with or without insurance (Williams, 2013). Although this program is not specific to children with special health care needs, schools with this program have decreased absentee rates, increased academic success, and better managed health needs, which relate to school participation barriers associated with students with disabilities (Williams, 2013).

The majority of this literature evaluated the National Survey of Children with Special Health Care Needs and few studies involved the school setting. Other literature supported Family Centered Care for CSHCN, but little information is known about the integration of these services in public schools. The purpose of this senior honors project is to examine the programs

and services that support the health and well being of CSHCN with regard to the public school setting.

This project was one part of a 7-week community health clinical practicum and was conducted in partnership with a school nurse preceptor. The clinical practicum involved working one to two days each week in a school-based health clinic and collaboration with the school nurse preceptor to learn about the role of the school nurse with CSHCN. The school-based health center served a middle school population of 537 students, in grades 5 through 8.

### **Methodology**

The methodology used for this senior honors project involved several components. First, an environmental study was conducted to understand the context of the community that the school is located. Second, mandated health programs and services for CSHCN were identified and observed in the school based health center, physical education program, and special education classroom. Third, interview questions were developed to understand the health services and programs in this public school. Fourth, key informants relevant to this project were interviewed. The key informants included a district school nurse, nurse practitioner, special education teacher, and physical education teacher.

A distinction must be made between the district school nurse and the school nurse preceptor, the RN located daily at the school-based health center. This nurse was responsible for the health needs of approximately 80% of the students at this middle school, those who were enrolled in the school health based clinic. She worked closely with the district school nurse who rotated between three county public schools and was responsible for collecting all of the health information, which included immunization records, allergies, medications, and other medical concerns, of every student at all three schools.

The school nurse preceptor was a continuous resource to me throughout this study though was not considered a key informant and not interviewed. I worked weekly with the school nurse preceptor and used the observations from my personal interactions with her to inform findings from this project. All key informants were given the same description of my project and were asked the same four questions.

The interview questions were:

- 1) What are the health services/accommodations provided for CSHCN at this school?
- 2) How would you define CSHCN?
- 3) What is your role in the care of these students?
- 4) What health needs of CSHCN present as barriers in delivering services?

Materials and responses from interviews were reviewed to identify barriers and facilitators in health services pertaining to CSHCN. Materials were collected from both the physical education teacher and special education teacher. The materials included step-by-step instructions on how to adapt lesson plans based on both physical and intellectual disabilities of students. Lastly, the data collected from the project were compared to the literature to evaluate health services for CSHCN.

### **Results**

There were three major findings in this project. First, no CSCHN who needed any assistive devices such as wheelchairs or walkers were enrolled at this school. Second, the majority of CSHCN were integrated in regular classrooms. Third, numerous barriers exist for parental involvement with the school in the on-going planning and evaluation of their special needs children.

There were a total of 81 CSHCN at this public school. The major health concerns of CSHCN include learning disabilities (38), mild or moderate intellectual disability (16), autism (6), emotional disabilities (3), speech impairments (1), and other (1) (“Exceptional children”, 2013). The 18 out of 81 CSHCN with moderate limitations are in one of two Exceptional Children (EC) classes at this middle school. CSHCN with moderate limitations have a lower absence rate in their classes compared to all other students. According to the key informants, the majority of absences of CSHCN are not related to scheduled health services outside of school. The majority of the CSHCN in the EC classes look forward to coming to school and become upset when they are not able to attend.

The EC classrooms have technological adaptations to accommodate to their needs. They are integrated 1.5 hours per day with the general population during elective classes. During the physical education class, their peers do not accept them because they are identified as “different from them”. The EC students have assigned seats together in the back of the classroom, which decreases the integration with the other students. The physical education teacher used to pair a student with a CSHCN with moderate limitations. This was implemented in order to promote interaction by having the student help the CSHCN with assignments. However, she had to stop this program because of the lack of interest from the general population to want to be paired with a CSHCN with moderate limitations during class. Teachers have modified lesson plans that adapt to the type of limitation of the CSHCN. For example, the physical education has a breakdown of various physical limitations and a flow chart describing how to modify the activity to make appropriate accommodations.

The main barriers were low socioeconomic status and minimal family centered care at this middle school. All key informants identified minimal communication between the school

staff, health professionals, and family contribute to the health barriers of CSHCN in the school setting. The school based health center was established to provide health services for children in this low socioeconomic area. All key informants reported that the school based health center was essential to providing health services. A nurse, nurse practitioner, and mental health counselor are available for physical examinations, health concerns, and medication administration every day at this school. However, this clinic is not authorized to provide services to students that are not enrolled. Approximately 80% of the student body is enrolled in the clinic for the 2013-2014 school year. It is unknown how many of the students enrolled are of the 81 CHSCN, which is a gap in the health programs needed by CSHCN at this middle school.

Before the establishment of the school based health center, the district school nurse was the only health professional for CSHCN and non-CHSCN at three schools. The addition of the school-based health clinic reduced the number of students to nurse ratio. The district school nurse is in charge of the health of students that are not enrolled in the clinic at this middle school and all of the general health information, including immunizations. With a full-time nurse at the school based health center, there is a registered nurse to provide medications for CSHCN. Still an incident occurred during the clinical rotation where, a CHSCN had a seizure in a classroom, and the teacher brought him to the school based health center to seek medical attention. It was determined that seizure management protocol was not clear to all teachers.

All key informants identified family involvement as a barrier. Both the EC teacher and school health nurse send home forms to obtain health information about the CSHCN, but parents do not have the knowledge about their children's health needs to fill out the form adequately. Therefore, the school has multiple barriers that impact the health care of CSHCN, families and school staff.

### **Discussion**

Findings from my senior's honors project suggest multiple propositions to improve health services provided for CSHCN. Safety needs to be a priority with the parents, health professionals, and school staff when providing health services for CSHCN. The health professionals at the school based health center need to determine an accurate number of CSHCN enrolled in the clinic. Pamphlets describing the health services provided by the school based health center needs to be sent home to parents of CSHCN to increase awareness of the benefits of the school based health center.

The school needs to find better ways to integrate parent involvement in the on-going planning and evaluation of their special needs child. Simplified health enrollment documents make the renewal process simpler for the parents of CSHCN to fill out pertinent health information about their child. The school nurse needs to be in communication with the parents in order to be informed of any new health needs for the particular student. In addition to increasing the participation of parents in health services for CSHCN, nurses need to clarify and provide necessary training for school staff on seizure management protocol. Teachers need to be equipped with the basic steps on how to handle a health emergency to avoid unnecessary health related problems.

Limitations pertaining to this project included the number of key informants interviewed. Only one out of two Exceptional Children teachers at this middle school were interviewed. Scheduling conflicts with key informants posed as a barrier due to time restraints. Increasing the number of key informants will provide variety and more information about health services provided for CSHCN in the school setting. Future projects should focus on a larger population of CSHCN, which will provide a more accurate conclusion on the major barriers contributed to

receiving adequate health services in rural areas of Wayne County. The middle school in this project had limitations on the types of physical limitations of CSHCN. Ultimately, health services at this middle school were successful in meeting the health needs of CSHCN.

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