

INVOLVEMENT OF TRANSITION-AGE STUDENTS WITH SEVERE DISABILITIES IN  
THEIR HEALTH CARE AT SCHOOL

BY

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DISSERTATION

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## **Abstract**

The purpose of this qualitative study was to examine student involvement in specialized health care procedures at school for transition-age students with complex health care needs and severe disabilities. To investigate how students were involved, and beliefs about their involvement, a basic qualitative methodology that incorporated ethnographic and multiple-case study methods was utilized. Nine cases were selected through purposeful sampling. A case included a student and the student's respective special education teacher, school nurse, classroom nurse or paraprofessional, and parents. Data were collected from demographic questionnaires, documents, observations, and interviews, and were analyzed case-by-case using an inductive coding approach. A cross-case synthesis was then conducted to identify themes. Although a majority of students were found to partially participate in their specialized health care procedures at school, individualized educational planning and systematic instruction were notably absent. Additionally, school personnel did not afford students with profound disabilities and significant behavior challenges opportunities to be involved in their health care. Overall, there was limited evidence of educational planning, goals, and systematic instruction to support student involvement in specialized health care procedures at school. Participants identified numerous obstacles based on students' disability related deficits, but overwhelmingly reported valuing student involvement in specialized health care procedures as beneficial to students' well-being. School personnel may have limited awareness of and/or knowledge in teaching self-care skills within the context of health procedures to students with complex health care needs and severe disabilities. Implications for research and practice are discussed based on this study's findings and recommended practices.

*For My Beautiful Son Xuanlin  
Forever in Our Hearts*

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## **Chapter 1**

### **Introduction**

Transition-age students with complex health care needs (CHCN) and severe disabilities (SD) are a low-incidence population in schools. Health care is an essential component in their daily life activities. Students with CHCN and SD therefore have unique curriculum needs in the area of self-care. Involvement in specialized health care procedures (SHCP), and other health management skills, is distinctly relevant in the lives of this population.

Numerous sources advocate teaching adolescents and young adults with disabilities to be involved in their health care. These include: (a) policy statements from the United States Maternal and Child Health Bureau (MCHB; 2013), the American Academy of Pediatrics (AAP; Eichner et al., 2012), and the Council for Exceptional Children Division for Physical, Health and Multiple Disabilities (CEC, DPHMD, 2008); (b) special education legislation (Individuals with Education Disabilities Act, 2004); and (c) recommended practices in the field of SD (Browder & Spooner, 2011; Collins, 2007; Heller, 2017; Heller, Forney, Alberto, Best, & Schwartzman, 2009; Porter, Branowicki, & Palfrey, 2014; Brown, McDonnell, & Snell, 2016; Westling, Fox, & Carter, 2015).

When students with CHCN and SD are not provided opportunities, support, and instruction to be involved in their health care they are at risk for wholly dependent care, loss of dignity and self-efficacy, and poor adult outcomes (Lehr, 2014; Lehr & Harayama, 2015). Despite strong backing across policy, law, and recommended best practices for student involvement in health care, very little research exists on this priority. A review of the literature yielded only nine studies that addressed student involvement in SHCP (Bosner, & Belfiore,

2001; Clarkson, 1982; Derrickson, Neef, & Parrish, 1991; Hannigan, 1979; Neef, Parrish, & Hannigan, 1989; Tarnowski & Drabman, 1987) and other health management behaviors (Babbitt, Parrish, Brierley, & Kohr, 1991; Beck, Cataldo, Slifer, Pulbrook, & Ghuman, 2005; Ghuman, Cataldo, Beck, & Slifer, 2005). None of these studies were conducted in secondary school settings. Research on transition planning for students with CHCN and SD further indicates nominal planning around promoting independence and self-determination in health care for this population (Bargeron, Contri, Gibbons, Ruch-Ross, & Sanabria, 2014; Morningstar et al., 2001). Consequently, there is little information available on how transition-age students are participating in their health care at school.

The purpose of this investigation was to understand how transition-age students are involved in their health care at school, and the beliefs of school personnel and families about their involvement. To meet the goals of this investigation, an exploratory qualitative study design was developed. The design drew upon basic qualitative research principles and incorporated ethnographic and multiple-case study data collection and analysis strategies. Purposeful sampling was used to select nine cases. Each case included a student with CHCN and SD (hereafter called “focus student”), and the focus student’s special education teacher, school nurse, parent(s), and personnel delegated by the school nurse to implement the focus student’s SHCP. Data collected were (a) a demographic questionnaire; (b) a document review of the focus student’s Individualized Education Program (IEP), transition plan, and individualized health care plan; (c) an initial interview; (d) observations; (e) a post-observation interview; and (f) a follow-up interview.

Data analysis was comprised of data management, analysis procedures, and measures to promote trustworthiness. Qualitative data analysis software, MAXQDA, was utilized to

manage data, and to facilitate data analysis. An inductive analysis, which included initial and focused coding approaches, was used to analyze individual cases on a case-by-case basis. Categories, focused codes (after initial coding was completed), and themes were determined for each case and then summarized in a matrix display (Miles, Huberman, & Saldaña, 2014; Saldaña, 2013). Analyses of all individual cases were completed prior to cross-case synthesis (Patton, 2015). Using the matrix displays created for individual case analyses, a cross-case synthesis was conducted to examine patterns and themes across cases (Yin, 2009). Rigorous peer debriefing with the second researcher (Thesis Committee Chair) occurred during each stage of analysis, for both individual case analyses and cross-case synthesis, to ensure assertions were dependable and grounded in the data (Saldaña, 2013). Measures to promote trustworthiness were data triangulation (data sources and investigators), disconfirming evidence, member checks, researcher reflexivity, and transferability (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005; Patton, 2015). Given the exploratory nature of this investigation, the author anticipated that findings might inform future research needed on student involvement in health care at school for transition-age students with CHCN and SD.

### **Definition of Terms**

Several health-related terms are used in this manuscript that warrant definition. The following definitions are based on the work of Porter et al. (2014), except where otherwise noted.

**Adherence.** Adherence is a health management behavior necessary for following a requirement in a health care regime, such as taking a prescribed medication.

**Care coordination.** Care coordination is the organization of health care supports across contexts and providers to ensure the delivery of appropriate and necessary health care services.

Communication between families, physicians, and appropriate school personnel is critical to care coordination.

**Classroom nurse.** A classroom nurse is a nurse assigned to two or more individual students located in the same classroom when continuous direct nursing services are needed to ensure the students' safety and health at school.

**Clean intermittent catheterization (CIC).** CIC is a procedure wherein a catheter is inserted into the urethra (the tube urine passes through) to eliminate urine.

**Colostomy/Ileostomy.** A colostomy or ileostomy is the surgical placement of the colon or ileum intestine outside the abdominal wall via a stoma. Fecal matter is expelled into an ostomy pouch—a medical appliance that adheres to the outside of the abdomen.

**Complex health care needs (CHCN).** CHCN is a type of special health care needs (SHCN) (see definition of SHCN) that are low-incidence and generally more complicated to manage compared to higher-incidence SHCN (e.g., allergies, asthma). Conditions associated with CHCN vary considerably, but may include serious heart and/or lung problems, significant gastrointestinal impairments, and severe neurological disorders. CHCN typically require medical technology and nursing supports to prevent further disability or death.

**Delegation.** Delegation is a health care practice that involves a registered nurse assigning components of an individual's care (e.g., implementation of SHCP) to non-medical personnel. A nurse may delegate only when it is (a) the right task, (b) under the right circumstances, (c) with the right directions and communication, and (d) under the right supervision and evaluation (American Nurses Association, & National Council of State Boards of Nurses, 2006). Personnel who implement a SHCP without delegation, training, and

supervision by a school nurse can be held civilly or criminally liable for practicing nursing without a license (Engel, Favini, & Sindelar, 2014).

**Health management.** Health management refers to a wide array of health promotion behaviors and skills, including adherence to one's health care routine (e.g., taking medications at the prescribed time and dosage), and other behaviors that promote safety and wellness (e.g., following dietary and exercise guidelines). Health management also encompasses self-care skills in health care procedures (e.g., self-catheterization).

**Individualized health care plan (IHCP).** An IHCP is a school nursing plan that outlines required health care supports and interventions (e.g., SHCP) for a student to safely attend school. The IHCP is based on standards of care regulated by each state's Nurse Practice Act, and is developed and written by the school nurse in collaboration with the student's physicians and individualized education program (IEP) team. The IHCP is considered part of the IEP when referenced in, and attached to the IEP document.

**Mechanical ventilator.** A mechanical ventilator is a machine that is used to assist or supplant spontaneous respiration.

**Medical technology.** Medical technology is a device that compensates for the loss of a basic bodily function, such as a mechanical ventilator for respiratory support, a feeding tube for intake of nutrition, a catheter to eliminate urine, and an intravenous pump to deliver medication for blood glucose regulation.

**Post-secondary students.** Post-secondary students are adult students ages 18-21-years-old, who are receiving special education services in secondary transition programs under the Individuals with Disabilities Education Act (IDEA, 2004).

**School nurse.** A school nurse is the health care professional who develops and oversees the IHCP for students with health care needs in school. The role of the school nurse includes care coordination within the school setting.

**Self-care.** Self-care skills fall under the broad category of functional skills, and the sub-category of personal daily living skills. Self-care is the act of maintaining and caring for one's own body to promote health. Example self-care skills include hygiene, self-dressing, self-feeding, and toileting skills. Within this manuscript, the term *self-care* is commonly used to reference self-care in specialized health care procedures.

**Severe disabilities (SD).** Persons with SD have moderate to severe intellectual disabilities and may also have autism, developmental disabilities, or multiple disabilities, including communication, physical, sensory, health, and behavioral disabilities.

**Special health care needs (SHCN).** SHCN are health care needs that are greater than what is commonly experienced by a child or adolescent, and include one or more chronic physical, developmental, behavioral, or emotional conditions (Maternal and Child Health Bureau, MCHB, 2013).

**Specialized health care procedures (SHCP).** SHCP are a nursing practice in schools involving the systematic implementation of a specific health care task, such as CIC, colostomy care, tube feeding, and tracheostomy care. SHCP also require a physician's medical authorization.

**Tracheotomy.** A tracheotomy is a surgically created opening in the windpipe to allow for the insertion of a breathing tube to support respiration.

**Transition-age.** The term transition-age in this paper is used to encompass students at the secondary level (middle and high school), as well as, post-secondary students. In the state of

Illinois, transition planning is mandated in the individualized education program (IEP) by age 14.5. In this study, middle school students younger than 14.5-years-old (i.e., 12-years-old) were identified as transition-age based on health literature advocating for early transition planning (see MCHB, 2013).

**Tube feeding.** A tube feeding is the provision of liquid nutrients through a tube into the stomach or directly into the intestines. Common types of feeding tubes are nasal feedings tubes, gastrostomy feeding tubes (G-tube), and jejunostomy tubes (J-tube).

### **Overview of the Manuscript**

This manuscript includes four additional chapters as well as references, figures, tables, and appendices. Chapter two describes an overview of the relevant literature. The conceptual framework and the statement of the problem are also described in Chapter two. Chapter three details the methodology used in this investigation, including the conceptual framework, sampling, recruitment, data collection and analysis procedures, as well as, measures taken to promote trustworthiness. Chapter four describes a cross-case synthesis of findings based on this investigation's two research questions. Chapter five provides a reflection of the findings in comparison to this investigation's conceptual framework, a discussion of finding across major issues identified, as well as, limitations and implications for research and practice.

## **Chapter 2**

### **Literature Review**

Children with special health care needs (SHCN) are broadly defined as individuals 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” (MCHB, 2013, p. 5). There are approximately 11.2 million children (15.1% of all children) in the United States with SHCN, with the highest prevalence in children ages 12-17 (18.4%) (MCHB, 2013). SHCN types range considerably in complexity. A subset of children with SHCN has complex health care needs (CHCN) that often necessitate medical technology (e.g., feeding-tubes, ostomy bags, mechanical ventilators, urinary catheters) (Elias, Murphy, & Council on Children with Disabilities, 2012). The former U.S. Congress Office of Technology Assessment (OTA, 1987) defined this group as requiring "a medical device to compensate for the loss of a vital bodily function and substantial and ongoing nursing care to avert death or further disability" (p. 3). The most recent data available, estimates that 100,000 children with SHCN nationwide require assistance from medical technology (OTA, 1987; Palfrey et al., 1994). Children who have CHCN commonly have co-occurring intellectual, developmental, and/or physical disabilities that may be considered severe in nature (Elias et al., 2012; Houtrow, Okumura, Hilton, & Rehm, 2012; Mastropieri & Scruggs, 2010).

Students with severe disabilities (SD) have moderate to severe intellectual disabilities (ID) and one or more communication, behavior, physical, sensory, or health disabilities (Bruce, 2011; Mastropieri & Scruggs, 2010; National Dissemination Center for Children with Disabilities [NICHCY], 2011). Students who have SD are typically eligible for special education services under the categories of autism, intellectual disability, and multiple disabilities

(Kearns, Kleinert, Kleinert, & Thomas, 2009). There is no formal tracking system in place for students with CHCN and SD because they are eligible for special education under different categories. As a result, their exact prevalence in schools is unknown. However, it is reasonable to assume that there are significantly less than 100,000 students nationwide based on existing data for children who require medical technology.

Students with CHCN and SD typically require specialized health care procedures (SHCP) in order to attend school (Heller & Tumlin, 2004). SHCP are unique to individual students and non-generalizable, as components in care may vary considerably from student to student even when the same type of procedure is required (e.g., tube feedings; Heller & Avant, 2011). Common SHCP implemented in schools for students with CHCN include ostomy care, clean intermittent catheterization (CIC), tracheostomy care, ventilator management, oxygen management, and medication administration (Heller & Avant, 2011). Only a registered nurse (i.e., school nurse), and personnel who are delegated, trained, and supervised by a school nurse, can implement SHCP in school settings (Engel et al., 2014).

SHCP are procedurally described in the individualized health care plan (IHCP). An IHCP is a comprehensive and collaborative document that addresses individualized student health care and nursing needs at school that includes (a) a health overview (health history, health status, medications, nutritional needs, and equipment list); (b) nursing plan of care (assessment, diagnosis, goals, interventions, implementation, evaluation, and outcomes); and (c) action plan for school personnel (health monitoring procedures, common problems and actions, emergency plan) (Heller & Avant, 2011; Obusek et al., 2014). The IHCP is developed and written by the school nurse in collaboration with the student's physicians and individualized education program (IEP) team.

## **Historical and Legal Background**

Prior to 1975 an estimated 1 million children with disabilities were wholly excluded from public schooling (U.S. Department of Education, 2010). Parents and professionals argued based on *Brown v. Board of Education* (1954) that children with disabilities were being denied equal educational opportunity on the basis of disability (Yell, Rogers, & Rogers, 1998). In 1972, advocates succeeded in litigating (see *Pennsylvania Association for Retarded Citizens v. Commonwealth of Pennsylvania* and *Mills v. Board of Education*) for the rights of children with disabilities to a free and appropriate public education (FAPE).

Although federal law (the Education for All Children Handicapped Act [EACHA], 1975) guaranteeing educational rights soon followed, students with CHCN were slower to gain access to public education. Limited portability of medical technologies and restrictive health care funding policies consigned many of these young individuals to institutions and hospital-based settings (Burke & Alverson, 2010). Medical advancements and the Katie Beckett waiver, enacted in 1982 under the Tax Equity and Fiscal Responsibility Act (P.L. 97-248), helped to improve this circumstance. The Katie Beckett waiver provides Medicaid funding for home-based care for children with medical disabilities irrespective of family income. Since its enactment, the Katie Beckett waiver has afforded a half million children with medical disabilities the right to live at home instead of in institutions and hospitals (U.S. Department of Health and Human Services, 2014). Living at home, in turn, enabled children with CHCN to begin attending public schools.

EACHA was amended in 1986 and then reauthorized as the Individuals with Disabilities Education Act in 1990, 1997, and 2004. Students with CHCN and SD, who require SHCP at school, are entitled to special education under FAPE. FAPE is a foundational component in

IDEA, and its historical renditions, and is defined in IDEA (2004) as “special education and related services that are provided at public expense” (34 C.F.R. § 300.17(a)) that “are provided in conformity with an individualized education program (IEP)” (34 C.F.R. § 300.17(d)). Schools initially questioned and challenged their responsibility to provide school health and nursing services for students requiring SHCP, which were perceived as cost-prohibitive and outside the purview of education (Katsiyannis & Yell, 2000).

Two U.S. Supreme Court rulings have helped to clarify the responsibility of schools to meet FAPE requirements for students who require SHCP—*Irving Independent School District v. Tatro* (hereafter *Tatro*, 1984) and *Cedar Rapids Community School District v. Garret F.* (hereafter *Garret F.*, 1999). In *Tatro* the Supreme Court ruled that CIC was a related service under IDEA and therefore necessary for the student to receive FAPE. The Supreme Court also established a three-prong test to aide lower courts in determining when a health care service constitutes a related service under IDEA, which is as follows: (a) the student’s disability requires special education services; (b) the health care service is necessary for the student to receive educational benefit; and (c) the health care service can be provided by a school nurse or otherwise qualified person. Health care services that require a physician are considered *medical services*, and are excluded.

This ruling was later upheld in *Garret F.* in a case involving a student with multiple SHCP. *Garret F.* required ventilator management, tracheostomy suctioning, urinary catheterization, and blood pressure monitoring (*Garret F.*, 1999). The ruling helped to clarify the rights of students with CHCN, who necessitate multiple health services that require skilled nursing supports. Subsequently, IDEA (2004) added school nurse services to the definition of related services accordingly: “school nurse services designed to enable a child with a disability to

receive a free appropriate public education as described in the individualized education program of the child” (34 C.F.R. § 300.34(c)(13)).

### **Recommended Best Practices**

The CEC, DPHMD (2008) “Position Statement on Specialized Health Care Procedures” states that SHCP (e.g., tube feeding, CIC) and other health management skills (e.g., behaviors that promote health) are self-care skills. SHCP should be considered for IEP goals to foster student participation and independence in their health care and day-to-day lives. It is also the position of the American Academy of Pediatrics (AAP) that children with disabilities should participate in the management and direction of their own care whenever possible (Eichner et al., 2012). Further, recommended best practices in curriculum and instruction for students with CHCN and SD also posit that SHCP and other health management skills are important to promoting independence in this population (Browder & Spooner, 2011; Collins, 2007; Heller, 2017; Heller et al., 2009; Porter et al., 2014; Brown et al., 2016; Westling et al., 2015).

A prerequisite to teaching involvement in SHCP and other health management skills is a safe and healthy environment for students (CEC, DPHMD, 2008; Lehr, 2014). This requires a collaborative IEP team approach focused on (a) care coordination (communication between families, physicians and appropriate school personnel); (b) general knowledge, including basic safety skills (e.g., universal precautions, first aid, and cardio pulmonary resuscitation [CPR]); (c) the IHCP and emergency plan; and (d) personnel training (Heller et al., 2009; Heller, 2017; Lehr, 2014; Obusek et al., 2014). A safe and healthy school environment for students with CHCN and SD includes the basic assumption that students are at school to learn (i.e., they are not patients). Care coordination, general knowledge, and personnel training should optimize environmental

conditions to promote student engagement and learning. This goal reflects an important development in educating students with CHCN and SD.

In the past, the medical model (a deficit-based approach) informed educational service delivery for students with CHCN and SD. Students were viewed as patients to be medically treated and cared for in schools, rather than as competent learners (Reger, 1972). The term “medically fragile,” formerly used to describe this population, characterized students with CHCN and SD as exceedingly vulnerable. This deficit-based orientation resulted in the over-medicalization of these students and wholly dependent caretaking practices (doing care to students without their involvement), thereby grossly limiting expectations for learning independence. Unfortunately, this problem may continue to persist (Lehr, 2014; Lehr & Harayama, 2015). When care is *done to them* (students) without their involvement, this can result in loss of dignity and learned helplessness. Additionally, the perceived social competence of these students by peers and school personnel may be harmed. Students with CHCN and SD may also miss important learning opportunities (e.g., acquiring self-care skills; Lehr, 2014; Lehr & Harayama, 2015; Heller, 2017).

Viewing students with CHCN and SD from a strengths-based model, having high expectations, and recognizing SHCP as self-care skills can transform passive caregiving during SHCP into functional learning opportunities (Ward & Ward, 2014). Self-care skills are necessary for day-to-day functioning (e.g., feeding, toileting). If students do not learn these skills, they will be entirely dependent on a care provider for their care, which may potentially harm an individual’s self-concept and sense of self-efficacy (Ward & Ward, 2014). In contrast, teaching students with SD self-care skills in SHCP can enhance their independence and self-determination (Cannella-Malone et al., 2011). For individuals with CHCN and SD, full

independence may not always be possible; however, students should be given opportunities to be involved in their SHCP in other ways. The IEP team decides how students with CHCN and SD will be involved in their SHCP.

### **Types of Involvement**

The CEC, DPHMD (2008) identifies four types of student involvement in SHCP to target for IEP goals and objectives. These are (a) independent performance, (b) partial participation, (c) directing someone else in performance, and (d) knowledge of the task. Across pediatric medicine, school nursing, and special education there are strong policy statements and recommended best practices that advocate for teaching children of all ages and disabilities self-care and health management skills in SHCP; however, there is little research available on this practice. Existing research is predominately dated, disparate in its coverage of adolescents with SD, and has been largely conducted in inpatient pediatric hospitals or outpatient clinics.

A review of the literature was conducted in ERIC, PsychoInfo, PsychArticles, and PubMed using systematic combinations of the following search terms (a) “child” or “adolescent or young adult,” (b) “disability,” (c) “self-care” or “health management,” and (d) “health care” or specific SHCP (i.e., “clean intermittent catheterization,” “insulin injections,” “nebulizer administration,” “ostomy care,” “oxygen delivery,” “tube feeding,” “suctioning,” “tracheostomy care”). Nine studies were identified that addressed teaching at least one child or adolescent involvement in their SHCP or other health management skills. Table 1 describes the type of involvement in SHCP or health management skill addressed, method, participants, setting, intervention, and results for each study identified.

Six studies were conducted prior to 2000 and three studies were conducted between the years 2001 and 2005. Studies investigated the effectiveness of behavioral interventions to teach

independent performance of SHCP ( $n = 4$ ), partial participation in SHCP ( $n = 2$ ), and health management skills ( $n = 3$ ). The primary method used across studies was single case research with a multiple baseline design ( $n = 6$ ). Four studies included participants with disabilities including ID and autism. The majority of studies took place in a pediatric hospital or outpatient clinic ( $n = 6$ ). No studies were conducted in K-12 school settings or secondary transition programs. Subsequently, a potential impact of location in these studies may be poor generalization to school settings. However, the interventions examined in these studies are commonly applied in school settings with students have SD. Interventions included (a) chaining ( $n = 4$ ), (b) modeling ( $n = 1$ ), (c) prompting ( $n = 5$ ), (d) reinforcement ( $n = 7$ ), (e) simulation ( $n = 3$ ), and (f) shaping procedures ( $n = 3$ ). Results varied across interventions and subjects. These studies are discussed in greater depth in the following sections.

**Independent performance.** Independent performance is when a student learns how to complete a SHCP on his or her own with adaptations as needed. Three studies addressed independent self-catheterization (Hannigan, 1979; Neef, Parrish, & Hannigan, 1989; Tarnowski & Drabman, 1987) and one study addressed independent self-suctioning (Derrickson, Neef, & Parrish, 1991). Except for Hannigan (1979), these studies utilized a single case A-B multiple baseline design across subjects and/or behaviors. Independent self-catheterization and self-suctioning were taught using total task forward chaining, a system of least-to-most prompts, and systematic reinforcement. Caution-steps were taken during intervention when students were self-catheterizing. This involved interrupting a child if they began to make a mistake and providing physical assistance to prevent potential injury. The use of a doll for simulation training was also employed in three of the studies (Derrickson, et al. 1991; Hannigan, 1989; Neef et al., 1989). Twelve children ages 4-8 years old, including 2 children with mild ID,

received the treatment intervention. All children were completely dependent on an adult caregiver for catheterization or suctioning pre-intervention.

All four interventions were highly effective in teaching independent performance in SHCP. In follow up data, four children were independent, four children were 91.7-100% accurate, and four children were steadily progressing towards independence. Assistive technology (AT), a mirror for female students to locate the urethra opening, also supported skill acquisition. Across studies incorporating doll training, use of a doll was shown to minimize potential embarrassment, motivated children to learn, and allowed for repeated trials without risk of injury before learning in vivo (Derrickson, et al. 1991; Hannigan, 1989; Neef et al., 1989). Only Neef et al. (1989) formally collected data on social validity. The children's teachers, nurses, and parents all reported satisfaction with the intervention and the self-esteem of children improved after learning how to self-catheterize.

**Partial participation.** The second type of involvement in SHCP recommended for IEP goals and objectives is partial participation. The principle of partial participation states that students with SD should be supported to be active participants in activities relevant to their daily life and school experience, with adaptations as needed, even when full independence may not be possible (Baumgart et al., 1982; Ferguson & Baumgart, 1991). Partial participation promotes independence and decreases dependence by actively involving students in their SHCP (Heller & Avant, 2011). Partial participation may also lead to increased independence over time (Ferguson & Baumgart, 1991; Bosner & Belfiore, 2001; Erwin-Toth, 1988).

Two studies were identified that addressed teaching partial participation to adolescents in their SHCP. In a longitudinal case study, Clarkson (1982) followed a female in occupational therapy from age 8 until age 13. Occupational therapy was provided in the child's home to both

teach steps in the catheterization procedure and how to motor through these steps. The child was initially taught to participate in discrete steps (e.g., pull the catheter out) and then taught to perform all steps in sequence. After one year, she was able to self-catheterize with assistance for undressing/dressing. Following two years of occupational therapy, she was completely independent across settings.

In a later study, Bosner and Belfiore (2001) addressed partial participation in administration of insulin for a 16-year old female with moderate ID and Down syndrome in the home setting. A single case A-B multiple baseline design was used across two behaviors: (a) preparation, and (b) administration and cleanup. The intervention consisted of total task forward chaining, a least-to-most prompting system, and systematic reinforcement. Caution-steps were taken to prevent potential harmful errors (i.e. full physical assistance). Independent performance was addressed for all steps required for preparation (e.g., washing hands, gathering supplies); and partial participation was addressed for steps in administration and cleanup. The adolescent partially participated by saying “ready” for both injecting and removing the syringe. The intervention was effective with the adolescent achieving 100% accuracy in behavior one (preparation) and 88% accuracy for behavior two (administration and cleanup). Additionally, 3 weeks post-intervention she progressed from partially participating in removing the syringe (i.e., saying “ready”), to independent removal.

**Directing care.** The third type of involvement in SHCP recommended for students with CHCN and SD is directing someone else in the performance of one’s care. Directing care allows for involvement of students who would otherwise be dependent in all facets of care. Students who have physical disabilities that affect fine motor and gross motor skills needed to perform steps in a SHCP may instead direct their care by communicating directions and steps to the

individual implementing the SHCP. A review of the literature resulted in no studies on children or adolescents directing their care. A search of peripheral literature (e.g., directing hygiene care, oral feeding) also resulted in no relevant studies.

**Knowledge of the task.** The fourth type of involvement in SHCP is knowledge of the task, which includes learning and following a schedule to identify when a SHCP should occur, and identifying and problem solving issues that may occur in a SHCP (Heller & Avant, 2011). No studies that discretely addressed knowledge of the task were identified, however it stands to reason that this type of involvement overlaps considerably with the other three types (independent, partial-participating, directing).

**Health management.** In addition to considering the four types of involvement in SHCP, the CEC, DPMHD (2008) also recommends IEP goals and objectives for other health management skills. Health management skills include a wide range of behaviors related to coping with, adhering to, and self-administering care needs associated with complex and chronic conditions (Koller, Khan, & Barrett, 2015; Modi et al., 2013). Given that behavior challenges are a common characteristic in individuals with SD, health management skills are critical. Non-adherence to medical treatment in persons with CHCN and SD can lead to dire health consequences. Problems related to medication adherence (i.e., swallowing medication) were prevalent in the literature. Swallowing medication is an important health management skill as hiding medication in food can result in inconsistent administration, food aversions, and mistrust of adults. Additionally, caregivers may unfortunately result to using restraint and force to ensure that children take needed medications (Babbitt, Parrish, Brierley, & Kohr, 1991; Ghuman, Cataldo, Beck, & Slifer, 2005).

Three studies were identified that addressed swallowing medication in children and adolescents who had Autism and/or attention hyperactivity deficit disorder (Beck, Cataldo, Slifer, Pulbrook, & Ghuman, 2005; Ghuman et al., 2005) and moderate to severe ID (Babbitt et al., 1991). Across all four studies, a shaping procedure (gradual increase of pill size) and systematic reinforcement were used to teach pill swallowing. In the Babbitt et al. (1991) study, three out of four children and adolescents learned to swallow the practice pills and generalized to independently swallowing their medication in the home setting. The fourth child withdrew prematurely from the study and no follow up data were available for this child. Beck et al. (2005) found that a shaping procedure was effective for teaching seven out of eight children to first swallow practice pills, and then also swallow their actual medication with a therapist. Six out of eight children generalized to independently swallowing their medication with a parent across settings. In the third study, Ghuman et al. (2005), the researchers did not teach generalization from swallowing practice pills to real medication. However, two out of four children learned to swallow practice pills with a therapist 81-100% of the time and then generalized to a parent. One child learned to swallow practice pills 54% of the time but did not generalize to a parent. The remaining fourth child withdrew participation from the study. No data on this child were available. Overall, these intervention studies, with the exception of Ghuman et al., demonstrated the effectiveness of a shaping procedure and systematic reinforcement to teach pill swallowing and therefore improve adherence to taking prescribed medication in children and adolescents with SD.

### **Teaching Involvement**

Students with CHCN and SD have unique learner characteristics in the areas of cognition, communication, mobility, physical endurance, and often experience (e.g., lack of previous

exposure and instruction due to low expectations; Heller, 2017). Therefore, assessment is a critical first step to identifying appropriate IEP goals, objectives, and individualized instructional strategies to teach student involvement in SHCP and other health management skills.

Assessment data should also identify any needed adaptations and AT. Criteria for IEP goals and objectives should be high, given the importance of accuracy in health care for safety reasons (Heller, 2017). IEP goals and objectives may also require regular review for changing medical needs (Ward & Ward, 2014). The determination of IEP goals and objectives should be family and person centered, as well as culturally responsive. Finally, IEP goals and objectives should also be reflected in the student's IHCP (Obusek et al., 2014).

Teaching student involvement in SHCP and other health management skills is coordinated by core IEP team members directly involved in the student's health care at school, such as the school nurse, the special education teacher, and personnel delegated to implement the students' SHCP (Heller et al., 2009). The special education teacher is responsible for designing instruction; however, he or she must work closely with the school nurse to understand steps in the SHCP. Given the sequential and procedural nature of SHCP, task analysis instructional strategies are commonly used to teach self-performance of SHCP (see Bosner & Belfiore, 2001; Derrickson et al., 1991; Tarnowski & Drabman, 1987), therefore the special education teacher must clearly understand the task (Heller & Avant, 2011). It is the position of the CEC, DPMHD (2009) that "even when health care personnel are responsible for performing these procedures, teachers must work closely with them, providing appropriate instructional strategies, error analysis, and correction procedures."

A variety of instructional strategies may be appropriate, but will depend on the type of involvement and the learning characteristics of the student (Heller & Avant, 2011). Instructional

strategies include task analysis, prompting procedures, doll simulations (Derrickson et al., 1991; Hannigan, 1979; Neef et al., 1989), demonstration (Ghuman et al., 2005), video modeling, and visual aides (Bray & Sanders, 2007; Brown, 1990). Caution steps or time-limited steps also need to be identified in order to prevent potential risk to the student during instruction. Caution or time-limited steps are associated with discrete steps in the procedure, and involve using more intrusive prompts to prevent errors or a delay in the performance of a time sensitive step (e.g., inserting or removing a suctioning tube). The teacher, nurse, or personnel overseeing the procedure must shadow students during identified caution or time-limited steps to prevent potentially harmful errors from occurring (Heller & Avant, 2011).

### **Beliefs About Involvement**

Students with CHCN and SD are an extraordinarily heterogeneous and low-incidence population. Beliefs about teaching this population self-care in their SHCP is likely a moving target as many school professionals have limited experience educating this population because of their low-incidence. Additionally, even “experienced” personnel may feel unprepared to educate and support individual students based on the unique characteristics of their CHCN (Lehr, 2014). Only one study was located that addressed beliefs about teaching student involvement in SHCP.

Heller and Tumlin (2004) examined the receptivity of primarily special education teachers and school nurses on writing IEP objectives targeting student performance of SHCP pre-and post-in-service training. Individuals participated in a 1-day training provided by the researchers on IHCP development, types of student involvement in SHCP, IEP goals and objectives development, and strategies for teaching student involvement through demonstration, practice, videos, and discussion. A total of 323 participants completed the pre-in-service survey

(125 special education teachers, 136 nurses, and 62 other), and 309 completed the post in-service survey (127 special education teachers, 123 nurses, and 50 other).

Pre-in-service training findings indicated that (a) 58.9% of school nurses and 24.6% of special education teachers had students who were learning how to perform their SHCP, and (b) 47.2% of school nurses and 24.6% of special education teachers had students with IEP goals and objectives that addressed performance of SHCP. Post in-service training indicated that (a) 93.4% of school nurses and 93.7% of special education teachers would consider teaching students to independently or partially perform their SHCP, and (b) 85.1% of school nurses and 94.5% of special education teachers would consider developing IEP goals and objectives that addressed student performance of SHCP as appropriate. During the in-service training, a majority of participants also informally disclosed that they had received no previous formal training on how to safely teach self-performance of SHCP (e.g., caution and time-limited steps) to students, including students with SD and multiple disabilities.

### **Health and Transition**

Advances in medicine and health-care delivery systems have enabled children with SHCN, particularly individuals with CHCN, to live longer than previously possible (Turchi & Mann, 2012). Older children, ages 12-17, have the highest prevalence of SHCN. Approximately 500,000 of these children will turn 18 each year; however, only 40% will receive appropriate services for transition to adult health care, employment, and independence (MCHB, 2013). Overall, young adults with SHCN have poorer adult outcomes than their counterparts without SHCN, and young adults with CHCN are the most likely to live with parents and to have never experienced employment (Maslow, Haydon, Ford, & Hapern 2011). Quality transition services are critical to improving adult outcomes for young adults with CHCN and SD. The MCHB

(2008) has established a national goal that *all* children with SHCN will “receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence” (Core Outcome 6). This goal is also reflected in “Healthy People 2020,” a national agenda for improving the health of all Americans (U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion, 2010).

Although IDEA (2004) does not address transition to adult health care, it does state that the purposes of IDEA includes “ensuring that all children with disabilities have available to them a free appropriate public education (FAPE) that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living” (34 C.F.R. § 300.1(a)). IDEA also states that transition services be made available to students beginning age 16. IDEA defines transition services as:

A coordinated set of activities for a student with a disability that: a) is designed to be within a results oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post school activities, including: postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living or community participation; and b) is based upon the individual child’s needs, taking into account the child’s strengths, preferences, and interests and includes instruction, related services, community experiences, the development of employment and other post school adult living objectives, and if appropriate, acquisition of daily living skills and functional vocational evaluation (34 C.F.R. § 300.43(a)).

Under IDEA, transition services are defined broadly and may encompass instruction in health related skills to promote independent living (e.g., self-care) and community participation (e.g., accessing health in the community, safety skills; Agran, 2012; Hackett-Hunter & White, 2014; Targett, Wehman, West, Dillard, & Cifu, 2013). Individual states vary, and may mandate transition services to begin earlier than 16-years-old. The state of Illinois requires that transition services and planning are included in the IEP by the age of 14.5.

Health transition planning for students with CHCN and SD, however, requires in depth knowledge of students' specific health care needs. The National Association of School Nurses (NASN, 2014) position statement on "Transition Planning for Students with Chronic Health Conditions" states that

the school nurse has the perspective and skills to provide care coordination and lead the planning team to address transitions for students with special health care needs that includes the development of health management and decision-making skills to foster active participation in maintaining his/her own health (Summary).

Although IDEA (2004) does not formally require transition services until the age of 16, it is recommended that transition planning for youth with SHCN begins in middle school (White & Hackett, 2009). Early transition planning is necessary for youth to have adequate time to learn and practice skills that will lead to independence and self-determination in their health care. Transition services for students with CHCN and SD should address health across functional domains: (a) independence and self-determination (e.g., self-care in SHCP and health self-advocacy); (b) job training (e.g., understand health needs at work); (c) home living (e.g., manage health care supplies); (d) community (e.g., refill prescription); and (e) leisure and recreation (e.g., follow health restrictions; Hackett-Hunger & White, 2014). Transition services should also be coordinated across health care, educational, vocational, and other relevant systems to ensure a successful transition to adulthood that includes accessible health care and care coordination across environments (e.g., home, community, work; White & Hackett, 2009).

Only two studies were identified that addressed health transition planning in schools (i.e., transition planning under IDEA) (Barger et al., 2014; Morningstar et al., 2001). This research indicates several barriers to health transition planning. In a survey of 240 schools in Illinois, Barger et al. (2014) found that (a) only 26% of schools consistently addressed health related issues in IEPs and transition plans, and (b) 63% of schools identified lack of

knowledge/information (on health transition) among the IEP team as a moderate to significant barrier to including health related goals in secondary IEP and transition plans. Morningstar et al. (2001) used longitudinal interviews to investigate the transition experiences of students supported with medical technology. Findings indicated (a) low expectations for adult outcomes for students with feeding tubes and ID (e.g., no expectations for future employment); (b) age 17, and even age 18, was viewed as too young to begin the transition planning process; and (c) limited to no involvement of health care providers and students in transition planning. Findings from these two studies exemplify low-expectations, inadequate professional knowledge, and limited involvement of health care providers as significant barriers to health transition planning for students with SHCN, particularly for students with CHCN and SD (see Morningstar et al., 2001). Findings from this research are also consistent with the MCHB (2013) determination that the majority of students with SHCN do not receive appropriate transition services to prepare them for adult life.

### **Conceptual Framework**

Based on the review of the literature, a conceptual framework was developed as a resource that was utilized to broaden understanding of relationships between key constructs specific to this investigation's research questions. This conceptual framework was also used as a tool to focus data collection and analysis (Maxwell, 2013; see Figure 1). The framework may be applicable to conceptualizing processes and beliefs that support involvement in SHCP for individual students, or the population of transition-age students, with CHCN and SD in schools. Since this study does not seek to build or confirm theory, it is important to emphasize that the conceptual framework was intended to serve as a practical explanation of observed relationships

between constructs identified in the literature to potentially provide deeper insight into the phenomena under investigation.

The framework is represented by three concentric circles that potentially interact and inform the constructs and processes identified in each circle. It may be helpful to begin by describing the core circle in the framework, which is a description of target learning outcomes for student involvement in SHCP at school. These outcomes are (a) independent care, (b) partial participation in care, (c) directing care, and (d) knowledge of care (CEC, DPMHD, 2008). Students who have SD are unlikely to learn any of these complex self-care skills without systematic supports. Thus, moving outwards to the second circle the special education process is illustrated as a systematic mechanism for identifying, progressing in, and achieving target learning outcomes in SHCP based on students' individualized learning needs. There is likely an interaction between the special education process and target learning outcomes. For example, either deficits or progress in one or more area may prompt assessment, instruction, and goals to promote specific target outcomes. Additionally, the beliefs of school personnel and parents may influence what target outcomes are valued, perceived as meaningful, and to what extent they might be addressed through the special education process. For the purposes of providing additional clarity to this issue, two theories were incorporated into the conceptual framework, represented in the outer circle—self-care theory (Orem, 2001) and causal agency theory (Shogren et al., 2015).

These theories help to explain the human motivation behind, significance of, and pathways supportive of student involvement in SHCP at school. Although these theories extend from mutually exclusive fields, they are complementary when considering students with CHCN and SD. Self-care theory is a well-established theory in the field of nursing, first published in

“Nursing: Concepts of Practice” in 1971 by Dorothy Orem (Orem, 2001). Causal-agency theory (Shogren et al., 2015) is the most recent iteration of the functional model of self-determination (see Wehmeyer, 1999), a well-established concept in the field of special education.

Self-care theory postulates that self-care is a basic human motivation to maintain one’s personal life, health, and well-being, and is promoted through self-care agency. Self-care agency is intentional behavior that includes involvement in the planning and delivery of one’s health care through activities initiated, performed, or guided by the individual (Orem, 2001). Nursing in school should focus on self-care agency for students who require SHCP through instruction in and support for self-care even when substantial health deviations exist. Orem (2001) defines health deviations as significant differences in typical health functioning necessitating nursing services. In the presence of a need for dependent-care, which can deepen feeling of illness and abnormality in the individual, nursing services that include support for self-care agency can enhance overall wellness and competence. Self-care theory, however, is unique to the field of nursing, can be interpreted as deficit-based, and does not adequately address causal mechanisms in the development of agency in one’s health care.

Therefore, causal-agency theory in special education was also incorporated into the conceptual framework. Causal agency is purposeful and intentional behavior to effect a change or achieve a goal, which in turn enables the individual to become more self-determined. It does not mean control over specific events and outcomes; instead, causal agency is characterized by *volitional action* (self-initiated and autonomous behavior), *agentic action* (response to opportunities and obstacles), and *action controlled beliefs* (personal empowerment) (Shogren et al., 2015). Students can become more self-determined in their health when causal agency is promoted by involving students in their health care planning, providing instruction and

support in self-care, and through supports that augment capacity (e.g., assistive technology). The important iteration that causal agency does not mean *control* is useful when considering the life circumstances of students with CHCN and SD. Whilst the health conditions and required medical interventions are frequently beyond the control of an individual, how one manages these conditions in his or her daily and future adult life can be enhanced through causal-agency.

### **Statement of the Problem**

Transition-age students with SHCN whose “daily activities are consistently affected” by their health conditions are particularly at risk for poor adult outcomes in the areas of adult health care, employment, and independence (MCHB, 2013, p. 45). The low-incidence sub-population of students with CHCN and SD are most likely to encounter low-expectations, resulting in a reduced quality of life (Lehr, 2014). SHCP and other health management skills present opportunities for students with CHCN and SD to learn self-care skills. These self-care skills should be addressed in the IHCP, IEP, and through transition planning in the IEP. Multiple sources, including national policy (Health People 2020; IDEA, 2004), position statements from key organizations (AAP [Eichner et al, 2012]; CEC, DPMHD, 2008; MCHB, 2008; NASN, 2014), and recommended best practices in school nursing (Heller et al., 2009; et al., 2014) and special education (Browder & Spooner, 2011; Collins, 2007; Brown et al., 2016; Westling et al., 2015) strongly advocate for teaching individuals with disabilities self-care in SHCP and other health management skills (e.g., adherence to health routines). This priority is even more urgent for transition-age students with CHCN and SD who are nearing or entering early adulthood.

School is the most influential environment in an adolescent’s or young adult’s life, second to home (AAP, 2016). Yet, none of the existing research on teaching involvement in SHCP and other health management skills has been conducted in schools. Further, what research

is available is limited and dated. Research on addressing transition planning for students with CHCN and SD suggests that schools are not adequately addressing health during transition planning (Barger et al., 2014), and expectations for adult outcomes for this population are low (Morningstar et al., 2001).

In order to adequately ensure that transition-age students with CHCN and SD are progressing towards the recommended practice of self-care in health care, research is needed to understand how students are currently involved in their SHCP. Understanding the beliefs of school personnel and families about student involvement in their health care is also key, as the IEP team is influential in determining IEP goals and objectives and transition plans. Since relatively limited data are currently available on these issues, an exploratory qualitative study design was used to address these gaps in the literature and deepen understanding of this phenomenon. It is anticipated that findings may inform a framework for future research on student involvement in health care for transition-age students within the context of health transition planning.

## **Chapter 3**

### **Methodology**

The purpose of this qualitative study was to understand how transition-age students (middle school, high school, and post-secondary students) with severe disabilities (SD) and complex health care needs (CHCN) are involved in their specialized health care procedures (SHCP) at school. Two research questions guided this investigation. These were as follows:

1. How are transition-age students with CHCN and SD involved in their SHCP at school?
2. What are school personnel's and families' beliefs about involving transition-age students with CHCN and SD in their SHCP at school?

Currently, the phenomenon of involvement in SHCP for transition-age students with CHCN and SD has not been well explored. Given the exploratory nature of this investigation, qualitative inquiry was best suited to answer the research questions (Cresswell, 2014). A basic qualitative approach was applied to this study's overarching design because it was a good fit for the practical and straightforward goals of this investigation (Merriam, 2009; Patton, 2015). Merriam (2009) describes a basic qualitative design as a widely used inquiry framework in social science research that is rooted in the philosophy of constructivism and is particularly well suited to examine practical topics in education research. The utilization of a basic (also termed "generic") qualitative research design is utilitarian, allowing for flexibility in the research procedures. More so than other distinct qualitative inquiry traditions (e.g., hermeneutical phenomenology), this approach requires a transparent explanation of the interpretive paradigm and strategic inquiry framework used as little can be inferred by the names "basic" or "generic" (Caelli, Ray, & Mill, 2003).

The interpretive paradigm utilized in this investigation's basic qualitative research design was social constructivism based on four philosophical assumptions (Cresswell, 2014): (a) ontological— multiple realities (interpretations) of any single phenomena exist and are formed by lived experiences and social interactions; (b) epistemological— understandings of these multiple realities are co-constructed between the researchers and participants; (c) axiological— individual realities are valued and represented; and (d) methodological—multiple sources of data are examined and knowledge construction actively resists preconceived notions, allowing for findings to emerge from the data through consensus among participants and researchers.

Patton's (2015) 12 core strategies for qualitative inquiry were used in the design framework. These were strategic (a) design principles: "naturalistic, flexible, and purposeful sampling"; (b) data collection and fieldwork principles: "qualitative data, personal experience and engagement, empathic neutrality and mindfulness, and dynamic systems perspective"; and (c) reporting principles: "unique case orientation, inductive analysis and creative synthesis, holistic perspective, context sensitivity, and reflexivity" (pp. 46-47; see Table 2 for a description of how Patton's 12 core strategies were applied in this investigation's design framework). Procedures described in the Data Collection and Data Analysis sections further elaborate on the application of these qualitative research design principles in this investigation.

### **Researcher Identity**

My researcher identity is influenced by my personal perspectives as a parent, educator, and researcher in the field of SD. As a parent of a child with CHCN and autism, my son learned self-care and independence in his SHCP at home and later generalized these skills to school. In fact, this skill-set became a critical demonstration of his capacity to be compliant with treatment, and self-manage his care when he was later evaluated for heart/double lung transplant. Although

my son did not live long enough to receive a transplant, I learned from this experience how critical self-care skills could be for personal independence, autonomy, and even, self-advocacy for a life-saving treatment.

As an educator, I had to be creative around promoting self-care and independence during SHCP for my students. For example, I developed a picture-based self-assessment for a high school student to give professionals feedback on her tube feeding procedure and communicate her physical comfort/discomfort. This student frequently tried to initiate different steps in her SHCP, but the school nurse did not permit her involvement beyond gathering needed supplies. At the time, my understanding of school nursing considerations when planning for student involvement during a SHCP was rudimentary. I found the limitations on my student's involvement in her care confusing, as did she.

My experiences as a parent and educator prompted a deep interest in, as well as many questions about, the school experiences of transition-age students with CHCN and SD. In particular, I am concerned with how this population is supported to be as independent as possible given their extensive health care needs in school. It is not uncommon to encounter individuals with CHCN and SD having their care done *to* them, without direction or input from the individual receiving care, by school staff wearing medical scrubs. These scenarios raise several concerns for individuals with CHCN and SD, including the likely consequence of learned helplessness and loss of dignity. Student passivity in health care is not necessary to ensure the safety of this population at school. In fact, passivity may harm or hinder students with CHCN and SD. Instead, when students are supported to assume an active role, to learn the functional skills necessary for their day-to-day self-care, they may experience better health, personal, and educational outcomes such as, health advocacy, self-determination, and independent living.

While my personal experiences and perspectives likely bear some usefulness (e.g., may have facilitated understanding of the phenomenon under investigation) (Maxwell, 2013; Patton, 2015), as a qualitative researcher my goal in the investigation at hand was to understand individual participant's meanings and experiences about the involvement of transition-age students with CHCN and SD in their SHCP at school. By engaging in disclosure and reflexivity about my predilections and researcher stance, I worked in each step of this investigation to re-construct the meanings and experiences of my participants and remain open to different possible interpretations of the data (see Data Analysis section, subheading Trustworthiness).

### **Participants**

The participants in this study were (a) 9 transition-age students with CHCN and SD, who had SHCP at school (hereafter called "focus students"); (b) 10 special education teachers of focus students; (c) 7 school nurses of focus students; (d) 2 classroom nurses; (e) 3 paraprofessionals; and (f) 10 parents of focus students. An individual focus student and their special education teacher, school nurse, parent, and paraprofessional or classroom nurse constituted one case. There were a total of 41 participants across nine cases, which met inclusion criteria (see Sampling subsection), and participated in the study.

Participating focus students were equally distributed across middle schools ( $n = 3$ ), high schools ( $n = 3$ ), and secondary transition programs ( $n = 3$ ) school placements, and ranged from 12 to 21-years-old with a mean age of 16.6-years-old. There was a disproportionately higher number of female ( $n = 6$ ) compared to male focus students ( $n = 3$ ). The ethnicity of focus students was majority white ( $n = 7$ ), with the exception of 1 Asian American and 1 African American student. Students were eligible for special education under the primary eligibility

categories of intellectual disability (ID,  $n = 4$ ), multiple disabilities ( $n = 4$ ), and traumatic brain injury (TBI;  $n = 1$ ).

The most common secondary eligibility category was other health impairment (OHI;  $n = 4$ ). The most common types of SHCP required by students were g-tube feedings ( $n = 7$ ), followed by clean intermittent catheterization ( $n = 2$ ), insulin injections ( $n = 1$ ), and nebulizer treatments ( $n = 1$ ). Students' overarching health conditions varied and included seizure disorders, Trisomy 12, Spastic Quadriplegic Cerebral Palsy, Microcephaly, Coffin-Siris Syndrome, Spina Bifida, Lennox-Gastaut Syndrome, and Type 1 Diabetes (see Student Demographics, Table 3). Students' disability characteristics related to communication, mobility, vision, hearing, and behavior were roughly equally distributed across grade levels (see Student Disability Characteristics, Table 4). For example, in middle school, high school, and secondary transition programs there was one student each characterized as having profound disabilities (co-existing sensory impairments [i.e., functional blindness], physical, and communication impairments). All students were documented to have severe ID.

Across the twenty-two school personnel that participated in the study, the gender and ethnicity was predominantly female and white. There was one male (Case 6 Classroom Nurse) and one non-white school personnel (i.e., African American; Case 1 School Nurse; see Personnel Demographics, Table 5). School personnel ranged with respect to the number of students on their caseload who had CHCN and SD, from 1 to 8 with a mean of 2.7 students. One school personnel (Case 6 School Nurse) had an exceptionally large caseload made up of 40 students that was excluded from the previous calculation. Case 6 School Nurse worked for a large special education cooperative that primarily served students with CHCN and SD. School personnel also

varied in years of experience with students with CHCN and SD that ranged from 1 to 26 with a mean of 7.1 years.

Ten parents participated in the study. Parents were all mothers, except for one father who participated in the interview with the mother (Case 4B). The ethnicity of parents was primarily white ( $n = 8$ ), with the exception of 1 Asian Indian mother and 1 African American mother. The majority of parents reported having assistance from a partner (e.g., spouse) in the home to share in providing health care for their children ( $n = 7$ ). Three parents reported that they were the sole care provider for their child. No parents reported having additional children with disabilities and/or health care needs in the home. The majority of parents reported receiving Supplemental Security Income (SSI) and Medicaid to support their child in the home setting ( $n = 7$ ). Three parents reported having to rely on their private income and health insurance to care for their child (see Parent Demographics, Table 6).

**Settings.** Seven cases were located at unique school sites, and two cases were located at shared school sites. School sites were geographically located in central and southern Illinois, approximately two hours from the researcher. Schools were based in rural ( $n = 4$ ) and small urban ( $n = 3$ ) communities. School sizes varied significantly from a population of 442 to 1,494 students with a mean of 830.7 students. Differences in school populations did not appear to be attributed to location (i.e., rural or small urban). However, the ethnicity of students in schools located in rural communities was primarily White, ranging from 50% to 92% for a mean of 80.3%. In contrast in small urban schools, the percentage of students identified as White ranged from 15% to 45% with a mean of 32.6%. In small urban schools, students identified as Black and Hispanic, respectively, ranged from 34% to 56% with a mean of 42%, and 7% to 13% with a

mean of 11%. Schools ranged in percentage of students with disabilities from 6% to 15% for a mean of 11.6% (see School Demographics, Table 7).

All focus students' SHCP were observed in the natural location where they occurred in their respective school sites. The most common setting in which SHCP were performed was a self-contained special education classroom ( $n = 7$ ). In these settings, typically other students with disabilities and school personnel were present during observations (e.g., related service personnel, paraprofessionals). The next most common setting in which SHCP were observed was the nurse's office ( $n = 3$ ). In one case, all SHCP occurred in a private therapy room designated by the school for the individual student (see Context and Duration of SHCP Settings, Table 8).

**Sampling.** Participants were purposefully selected using homogeneous sampling in order to answer this investigation's research questions (Patton, 2015). Although transition-age students with CHCN and SD who require SHCP at school are a highly heterogeneous group, here *homogenous* refers to a set of shared core characteristics unique to this sub-population of students. Inclusion criteria for each type of participant were as follows:

- focus students were transition-age, had SHCP provided at school, and had SD;
- special education teachers held a current special education teaching license in Illinois and were the case manager for a focus student in a public school located in a 2-hour driving distance from the researcher;
- school nurses were a licensed school nurse or registered nurse (RN) and were the school nurse of record for a focus student;
- a parent was the legal guardian of a focus student;

- one-to-one nurses were identified by the school nurse as responsible for implementing the focus student's SHCP;
- paraprofessionals were identified by the school nurse as delegated to implement the focus student's SHCP.

Definitions of inclusion criteria and exclusion criteria are described in Table 9.

In qualitative research, there are no definitive parameters for establishing sample size, however an inverse relationship exists between depth of knowledge possible for smaller sample sizes and breadth of knowledge as sample size increases (Patton, 2015). When determining sample size, the low incidence of transition-age students with CHCN and SD who have SHCP at school (significantly less than 1% of all students) was considered. Therefore, all eligible cases with shared interest in participation across participants were included for a total of 9 cases across 7 unique school sites. This number was considered to be appropriate to answer this investigation's research questions with substantive depth and breadth. In total, 32 potential cases were screened. Twenty-one potential cases did not meet student eligibility requirements, and in 2 cases there was not a shared interest in participation across potential participants, resulting in the 9 cases selected.

**Recruitment.** A flowchart illustrating recruitment procedures is located in Figure 2. Recruitment of participants for each case began with sending a recruitment email to special education teachers in the state of Illinois. Recruitment of special education teachers was limited to a 2-hour driving radius to ensure potential research sites were physically accessible to the researcher for data collection. Contact information for licensed special education teachers was obtained from the Illinois State Board of Education (ISBE) under the Freedom of Information Act. The initial recruitment email was sent in early March 2016. A reminder recruitment email

was sent one-week later to increase the likelihood that recipients had the opportunity to view the email (see Appendix A). The recruitment timeline is described in Table 10. All recruitment materials informed recipients that individuals who completed the study (except for focus students) would receive a \$40 Visa gift card as an incentive for participation.

Special education teachers who voluntarily contacted the researcher to express an interest in the study were contacted via email to schedule a telephone-screening interview. Teachers who maintained interest were then screened to determine their eligibility for participation (see Appendix B). During the telephone-screening interview, the researcher explained that the study involved additional participants (i.e., a focus student, the school nurse, the focus student's parents, and personnel who implement the focus student's SHCP). The screening-interview procedures included questions about the special education teacher's current caseload that facilitated the identification of eligible student participants (e.g., "How many of your students with SD have at least one scheduled, or regularly occurring, SHCP every school day?"). Additionally, special education teachers were asked to nominate school nurses who were the nurse case manager of eligible students.

A recruitment email was then sent to school nurses. A reminder email was sent if no response was received within one week (see Appendix A). If the school nurse did not respond or declined to participate, recruitment stopped and the special education teacher was sent an email notification of his/her non-selection to participate (See Appendix C). A telephone conversation was scheduled with school nurses who expressed interest in participating in the study. School nurses, as the health professional responsible for overseeing SHCP in the school setting, were recognized as gatekeepers in this study. Therefore, if a school nurse maintained interest in participating in the study a telephone conversation was held in order to personally address

questions or concerns regarding the details of the study and what participation entailed (see Appendix B).

After eligibility of the special education teacher and interest from the school nurse were confirmed, the special education teacher was asked to contact the school principal to express her/his interest and (with permission) the school nurse's interest in participation in the study. The researcher then contacted the school principal to obtain permission for on-site research (see Appendix D). The researcher then contacted the superintendent for written approval (see Appendix D). This process was repeated for each school site. All principals and superintendents provided approval. Three cases were affiliated with an Illinois special education cooperative. Permission was also obtained from the director of each special education cooperative.

Following confirmation of administrative approval, the researcher proceeded to obtain informed consent from eligible and interested potential participants. The special education teacher and school nurse at each school site were notified of their acceptance into the study (see Appendix E) and provided a consent form (see Appendix F). The special education teacher was asked to send a recruitment flyer and the parent consent form home to eligible students' parents (see Appendix F). The school nurse was asked to forward a consent form to any personnel delegated by the school nurse to implement the focus students' SHCP (see Appendix F), or to provide the personnel's email contact information so that the researcher could contact them directly (see Appendix E). If no response was received from a given potential participant within one week a reminder email was sent (See Appendix E). Special education teachers assisted the researcher in reminding parents to return consent forms.

All potential participants were reminded that the researcher was readily available via telephone to explain the consent form and to answer any questions. Special education teachers,

school nurses, and additional personnel returned the consent forms to the researcher via email. Parents returned signed consent forms to their child's special education teacher. Parent consent forms were collected during the initial site visit. If a potential participant declined to participate, the remaining invited participants for that case were notified that there was not a shared interest in participation and therefore, they were not selected to participate (see Appendix C).

Focus student assent was obtained immediately prior to each scheduled observation. The researcher used a simple picture-based assent form (see Appendix F) to explain the purpose of the observation. Focus students gave assent using alternative forms of communication that included vocalizations, affect, and gestures. The special education teacher or school nurse was present during assent procedures to help interpret focus student responses to the researcher. All focus students assented to be observed in every scheduled opportunity during data collection.

### **Data Collection**

Multiple sources of data were used to answer this investigation's research questions. Sources of data included questionnaires, document reviews, interviews, and observations. Data were collected case-by-case. A case centered on the focus student with CHCN and SD and corresponding participants (the focus student's special education teacher, school nurse, and parents; and if applicable, personnel delegated by the school nurse to implement the focus student's SHCP, such as a paraprofessional or classroom nurse). The data collection timeline is described in Table 11. Data for individual cases were collected in the order in which informed consent was obtained. In order to avoid confusing the particulars of each unique case, data on no more than two cases were collected simultaneously (Stake, 2006). Within each case, data were collected in the following order: (a) demographic questionnaires, (b) document review, (c) observations, (d) post-observation interviews, (e) interviews, and (f) member checking.

In qualitative inquiry, the researcher is the primary instrument of data collection. The interaction of the researcher with participants and the setting bears a natural influence on data collected (Merriam, 2009). Therefore, the researcher documented her interactions, and behavior in the field through analytic memos. Analytic memos were additionally recorded on the researcher's personal reactions, thoughts, feelings, and insights during data collection and analysis (Emerson, Fretz, Shaw, 2011; Saldaña, 2013). Analytic memos were documented in digital journal entries stored on the researcher's computer. These memos were used to focus data collection and analysis (e.g., pursue and test leads; Emerson, Fretz, Shaw, 2011; Saldaña, 2013).

### **Instruments**

Data collection instruments were a demographic questionnaire (see Appendix G), document review guide (see Appendix H), field notes recording sheet (see Appendix I), post-observation interview guide (see Appendix J), and interview guide (see Appendix K). Instruments were developed based on recommendations for qualitative data collection guides (Emerson et al, 2011; Patton, 2015), a review of the literature on SHCN and students with SD, and this investigation's conceptual framework (see Chapter 2 and Figure 1). One expert in qualitative methods and three experts in curriculum for students with SD (i.e., Thesis Committee members) reviewed the demographic questionnaire and interview guides to determine that questions were "clearly worded, not leading, appropriate and sufficient for exploring domains of interest" (Brantlinger et al., 2005, p. 202). The expert reviewers also examined the document review guide and field notes recording sheet to ensure the researcher was gathering relevant information. The instruments were revised based on feedback received from the expert reviewers.

A former student of the researcher, her parents, special education teacher, school nurse, and home caregiver agreed to participate in a pilot of the instruments. These individuals were located out-of-state; therefore, pilot interviews and observations were conducted via Skype. Skype observations of the student during her tube feeding occurred in the student's home setting with a home caregiver. Although these conditions did not replicate the exact conditions of the study, it allowed for a close approximation among individuals who were comfortable participating in the pilot procedures. Relevant documents were shared with the researcher via mail. Interview pilots included cognitive interview techniques to evaluate how respondents were interpreting specific questions (Marsden & Wright, 2010; see Appendix L). During piloting, the researcher recorded reflections on limitations and strengths for each respective guide. Based on these reflections and the feedback collected during cognitive interviews, minor revisions were made to the interview guides to improve understandability of specific questions.

### **Demographic Questionnaires**

The school personnel demographic questionnaire was distributed through email, after all participants in an individual case returned consent. The school personnel demographic questionnaire was filled out by the special education teachers, school nurses, and delegated personnel. Participants returned completed demographic questionnaires to the researcher via email. The questionnaire was comprised of 10-items (see Appendix G). The parent questionnaire was provided to parents at the end of the interview with a pre-paid self-addressed envelope (see Appendix G), however all parents requested (for reasons of convenience) to fill out the questionnaire in private while the researcher waited. Demographic information (e.g., gender, age, race, ethnicity) was collected and reported to provide the researcher and readers additional context on participants and individual cases.

## **Initial Site Visit**

Initial field entry began with early conversations with key gatekeepers, special education teachers and school nurses, during which the researcher explained the nature of the study. The initial site visit, however, marked the researcher's first opportunity to physically enter the field to further develop trust and rapport with participants and an understanding of cultural expectations for the researcher's behavior within each respective setting (Patton, 2015). For example, if participants engaged the researcher in small talk this was readily reciprocated. Conversely, the researcher also negotiated expectations for participants by explaining in a friendly manner that during the formal observation time (i.e. set-up, implementation, and cleanup of the specialized health care procedure) no conversation should occur with the researcher. According to Patton (2015), reciprocity is a key goal in fieldwork wherein the relationship between the researcher and participants develops into one of mutual exchange. Keeping reciprocity in mind, the researcher endeavored to demonstrate to participants that their cooperation in the study was worthwhile by striving to make interactions pleasant and communicating the importance of their involvement.

During the initial site visit the researcher collected the parent consent form from the special education teacher. Following verification of parent consent, the researcher spoke briefly with participants present during the visit. Conversations varied per the availability of participants, but focused on introductions, thanking participants for agreeing to participate, and answering any questions posed to the researcher regarding the investigation. Scheduling and locations for future observations were also discussed and confirmed. These conversations lasted 15-20 minutes across cases.

## **Documents**

Documents were viewed as an important source of data, potentially offering access to information that may otherwise be difficult to glean through interviews and observations (Patton, 2014). Therefore, a careful review of student documents (individualized education program [IEP], transition plan, and individualized health care plan [IHCP]) was completed. Documents were reviewed the same day as the initial site visit in a private location. The time and location were specified by the special education teacher or administration at each school site. Most commonly, documents were reviewed after school in a classroom with only the special education teacher present.

All students had an IEP on file. Only one student had an IHCP on file. Transition plans were only on file for the six students who were in high school and secondary transition programs. None of the middle school students had a transition plan due to their younger ages (e.g., 13-years-old). A document review guide (see Appendix H) was used to focus data collection, as IEPs, transition plans, and health care plans contain a wide range of information. The document review guide included fields to collect data on (a) student demographics (e.g., gender, age, race, ethnicity, eligibility category, health condition); (b) nursing health assessments, goals, interventions, and outcomes; and (c) IEP goals and objectives and transition goals specific to involvement in health care. Demographic data and goals (health, IEP, and transition) were copied verbatim. Assessment data were summarized. Following completion of the review, all documents were returned to the special education teacher. Student documents varied with respect to length and detail. The time to review documents ranged from 30 to 60 minutes. Public documents (i.e., online school report card) were also reviewed for school demographic data (e.g., school size, location, student make-up).

## **Observations**

Observations took place in the natural setting where the student's SHCP routinely occurred in the school. Individual focus students' SHCP were observed three times on three different data collection days. In two cases, students had two distinct SHCP (e.g., g-tube feeding and CIC). Multiple SHCP were observed on the same day for up to three times across different data collection days. In Case 1, two adults regularly implemented the student's SHCP. In this case the SHCP was observed three times for each adult who implemented the procedure, also across different data collection days. An exception to observing each SHCP three times was made in Case 5A. In this case, two observations were conducted on a given data collection day for a total of six observations. This focus student had g-tube feedings that were divided into small amounts across hourly intervals to prevent emesis (vomiting), resulting in multiple brief SHCP. Additional observations were completed to collect an adequate amount of data for analysis.

The length of observations depended on the type of SHCP and students' individualized needs. For example, although most students had g-tube feedings, some students could tolerate a faster feeding time (e.g., two cans of food in 20 minutes versus 30 minutes). The length of the observation also included any needed preparation or clean-up time related to the SHCP. Observations ranged from 10 minutes to 2 hours with a mean observation of 39 minutes. In one case, two observations had to be rescheduled due to student illness. Otherwise all scheduled observations took place accordingly.

Ethnographic field notes were taken during observations to create a detailed picture of the scene observed (Emerson et al., 2011). This approach allowed for holistic and rich data collection during observations that was not limited by pre-conceived notions regarding how students might be involved in their SHCP. Field notes were taken on (a) concrete and sensory

details (i.e., specific details so the scene can be visualized); (b) action (i.e., actions of the student and adult participants); (d) dialogue (i.e. dialogue between adult participants and the student); and (e) characterization (i.e., observable qualifiers that describe the demeanor of participants during the observation). Congruent with ethnographic field note recording practices, observation data were recorded in a continuous running format that described the scene observed based on concrete and sensory details, action, dialogue, and characterization. Reflections were also recorded on the researcher's personal questions, reactions, and ideas specific to observations (Emerson et al., 2011). See Appendix J for the field notes recording sheet. Field notes were recorded by hand in a plain journal. Following each observation (immediately after exiting the field or at the end of the same day), field notes were reviewed, typed into a word processing document, and expanded. Specifically, any fragmented text or abbreviations were expanded into long form and additional researcher' reflections were added (Emerson et al., 2011; Yin, 2016).

## **Interviews**

Two types of interviews were conducted. These were informal post-observation interviews and formal interviews. Post-observation interviews were conducted immediately following each observation with the adult participant who implemented the student's SHCP. Post-observation interviews were brief, ranging from 2-10 minutes, and occurred in semi-private locations (i.e., the classroom or school nurse's office where no one could overhear the conversation) or private locations (i.e., a therapy room or the school nurse's office with no other individual's present). Although the researcher had prepared a semi-structured interview guide, consisting of four semi-structured open-ended questions (see Appendix J), post-observation interviews tended to occur naturally and were very informal. After the completion of the SHCP, participants would frequently automatically address the researcher. For example, "He was very

excited today, but otherwise he participated as usual.” (Case 7, School Nurse). In some instances, the personnel tended to focus on sharing technical aspects of the health care procedure with the researcher. During these occurrences, the researchers more closely relied on the post-observation interview guide to prompt participants to talk about the student’s involvement specific to that particular day and type of procedure.

A major purpose of the post-observation interview was to obtain respondent validation on whether or not the observation data were considered typical. This was important given that unanticipated events can occur during a SHCP and students with CHCN and SD may experience fluctuations in endurance and alertness. Another goal of the post-observation interview was to ask participants what they thought about the student’s involvement immediately following a SHCP. Post-observation interviews were not audio-recorded because they typically occurred during the school day in mostly semi-private conditions where audio recording might have drawn undue attention or resulted in capturing audio from non-participants. Instead, verbatim hand-written notes were taken (Patton, 2015).

The second type of interview conducted was a formal semi-structured interview (see Appendix I) held in-person with individual participants (special education teacher, school nurse, parent, and delegated personnel) at a time and location chosen by the individual. Interviews were audio-recorded and ranged from 25 to 74 minutes in length with a mean duration of 41.2 minutes. The researcher was careful to maintain empathic neutrality and mindfulness during the interviews by staying actively engaged and focused on what participants were sharing, not judging, and by demonstrating interest and responsiveness.

An interview guide approach with semi-structured open-ended questions was used to ensure that data collection across participants was fairly systematic (Patton, 2015). The initial

interview guide was comprised of 18-items following a schema made up of three parts: (a) background (e.g., general beliefs about involvement); (b) type of involvement (e.g., perceptions on how the student is currently involved); and (c) involvement and transition planning for adult life (e.g., beliefs about involvement in relation to adult life). Question types included experience, opinion, feeling, and knowledge questions (Patton, 2015).

Immediately following an interview (1-3 days), individual participants were provided a bullet formatted list through email or mail that included 3-5 salient quotes (e.g., quotations that may be used in the write up of findings) and 8-10 summarizing statements from their personal interview transcripts. Summarizing statements were both summative and interpretive, representing the researcher's preliminary interpretations of interviewees' reported experiences and beliefs across all interview questions. The researcher listened to the audio recording of the interview 1-2 times to identify salient quotes and to develop summarizing statements. The relative immediacy of developing these member checking summaries helped the researcher to reflect in depth on the personal meanings shared by individual participants in relation to this investigation's research questions. This was important given the relatively large number of interviews conducted ( $N = 31$ ). It was the hope of the researcher that participants would also benefit from receiving member checking materials soon after the interview and be more likely to provide critical feedback while the interview was "fresh in their mind." Participants were invited to affirm, correct, and/or annotate the list. The majority of participants responded with statements such as "Looks good" or "I agree." Three respondents responded with corrections to their quotes that were related to grammar only. Two parents and one teacher replied with clarifying statements. This member checking information was then incorporated into data

analysis. All participants returned member checking materials, which helped to triangulate and verify the accuracy of findings.

### **Data Analysis**

Data analysis was comprised of three major phases. These were data management, implementation of analysis procedures, and steps to promote trustworthiness.

#### **Data Management**

The first step in data analysis was preparing and organizing the data (Cresswell, 2013). This step naturally overlapped with data collection. Qualitative data analysis software (QDAS), MAXQDA, was utilized to facilitate organization and analysis of the data. MAXQDA was selected over other software packages (e.g., NVIVO) due to its enhanced flexibility to attach an analytic memo to a segment or body of data and to view analytic memos and related data simultaneously (see Figure 3; Saillard, 2011). All analytic memos created during data collection and analysis were linked to the associated data by case (e.g., analytic memo for the parent interview in Case 1 was linked to the parent interview transcript for Case 1). As data were collected it was prepared and imported into MAXQDA. Data preparation varied depending on the type of data. All data were stored securely on the researcher's personal password protected computer and were backed up on a secure server (Box). Data shared for transcription and analysis purposes occurred via the secure server, Box. A key linking identifying participant information to raw data was stored separate from the data in a locked personal file cabinet in the lead researcher's personal home office. All investigators (i.e., the researchers and a graduate student) were trained on Institutional Review Board (IRB) guidelines for protecting the confidentiality of the data.

**Demographic data.** Demographic information for participants and schools were inputted into MAXQDA from the questionnaires, document review forms, and the web-based school report card. Demographic data were then linked to all associated data (document, observation, interview) by case.

**Document data.** The researcher typed document review forms filled out by hand verbatim. All document data were retained in the document review form in order to identify document sources. Typed up document review forms were then inputted into MAXQDA by case.

**Observation data.** Observation field notes were typed in expanded form immediately after each observation. Data from the double column-recording sheet were separated into two documents. Data from the left column, a detailed picture of the scene observed, were saved by case number and observation (Obs.) number (e.g., Case 1, Obs. 1). Data from the right column, the researcher's reflections (personal questions, reactions, ideas, and commentaries), were saved as an associated analytic memo (e.g., Memo 1, Case 1, Obs. 1). Files were uploaded into MAXQDA by case and analytic memos were then linked to the appropriate observations.

**Interview data.** Three trained graduate students transcribed interview audio files for all formal interviews. Transcripts were formatted to facilitate data analysis using recommendations from Merriam (2009). For example, each line of text was assigned a number. Measures were also taken to capture unconventional language, utterances (e.g., oh), and prosodic elements (emphasis, loudness, long pauses) that if omitted would potentially affect interpretation (see Appendix J for transcription protocol). The researcher checked transcriptions for accuracy against the audio-recorded interview. Any correction made was added to the transcript in the

color red. The researcher transcribed handwritten interview notes from post-observation interviews. Files were uploaded into MAXQDA by case.

### **Data Analysis Procedures**

Data analysis was completed on a case-by-case basis. Cross-case synthesis occurred after all individual case analyses were completed. The understanding that knowledge constructed from this investigation was particular to individual cases examined was an important design principle in the data analysis procedures (Patton, 2015; see Table 2). The goal of data analysis was not to generate replicable results, but rather to produce dependable findings consistent with the data collected (Merriam, 2009). Therefore, quantitative data analysis procedures (i.e., inter-coder agreement) were not used. Instead, data were analyzed using solo coding, and rigorous peer debriefing during each step in the data analysis procedures (Saldaña, 2013). Rigorous peer debriefing occurred with the second researcher (Thesis Committee Chair), for individual case analysis and cross-case synthesis.

Analysis procedures for individual case analysis followed an inductive approach and occurred in the following order (a) identification of categories; (b) initial coding; (c) focused coding, (d) development of themes; and (e) testing and confirming themes through visual analysis using matrix displays (Miles et al., 2014; Saldaña, 2013). Cross-case synthesis then ensued and involved (a) visual analysis (using a matrix display compiled from individual case analyses) to compare/contrast findings across cases, and (b) a synthesis of themes across cases (Yin, 2009). Peer debriefing for individual case analysis and cross-case synthesis involved (a) sharing raw data and analytic memos, (b) sharing analysis (e.g., codes), (c) critical feedback from the second researcher (e.g., alternative interpretations of the data); and (d) face-to-face intensive discussion and verbal consensus (e.g., reaching verbal consensus on interpretations).

Peer debriefing occurred 1-2 times per case, and 3 times for cross-case synthesis. Additionally, external auditors (i.e., Thesis Committee members) critically examined the data collection and analysis procedures, and findings (i.e., final themes) (Brantlinger et al., 2005; Saldaña, 2013).

**Case analysis.** Case analysis focused on developing an in depth understanding of individual cases through content analysis, using data reduction strategies to discern core meanings inherent in the data (Patton, 2015). The goal of this exploratory study was to develop a preliminary understanding of the phenomena under investigation, therefore preconfigured categories and codes common in hypothesis testing were not used (Maxwell, 2009; Patton, 2014). Data were analyzed case-by-case in the order each case was completed. In order to limit potential confusion of cases, no more than two cases were analyzed simultaneously (Stake, 2006). A master codebook was developed by the researcher to catalog and define categories and codes (see Appendix O). The codebook was used to ensure consistent application of categories and codes across the data, and was continuously updated as categories and codes were created, revised, or deleted (Saldaña, 2013). Throughout analysis the researcher reflected on meaning inherent in the data, relationships between the data, and personal reactions and thoughts, documenting these in analytic memos. Demographic data were previously assigned attribute codes in the data preparation stage, and were not further analyzed until cross-case analysis.

***Categories and initial codes.*** Iterative back and forth readings of the data were conducted to identify categories and initial codes (i.e., sub-categories) based on patterns discernable in the data (Miles et al., 2014; Saldaña, 2013). This process included multiple edits to categories and initial codes (i.e., creation, revision, deletion) to ensure they fit the data. Categories and codes were limited to no more than 10 categories and 8 to 14 initial codes per

category to avoid over abstraction of the data, which can potentially hinder analysis and interpretations (Cresswell, 2013).

Categories were identified using a holistic coding approach. This involved coding large segments of data (e.g., whole pages) to identify broad patterns in the data. Next, a more detailed analysis followed. Smaller segments of data were coded (i.e., phrase, sentence, or paragraph) for units of meaningful data or a complete thought or topic using a descriptive initial coding approach (Miles et al., 2014; Saldaña, 2013). Categories and initial codes were then evaluated, challenged, and discussed through peer debriefing with the second researcher. Discussion focused on whether the categories and initial codes were a good fit for the data. Categories and initial codes were then revised based on back and forth discussion and verbal consensus with the second researcher. Following revision of categories and initial codes the data were re-read again. Additional analytic memos were recorded on questions, new insights, and reflections on patterns discernable in the data. Categories and initial codes were refined and resubmitted for peer debriefing, and again revised.

***Focused codes and themes.*** The next stage of analysis (focused coding) involved identifying initial codes that accounted for the data in relation to the research questions. Focused codes provided clear insight into the phenomena (i.e., how things work) within the data corpus (Miles et al., 2014; Saldaña, 2013). Procedures for focused coding were (a) reviewing all initial codes across data sources (in an individual case), (b) identifying the initial codes which reoccurred frequently in the data or were otherwise illuminative (e.g., answered this investigation's research questions), and (c) raising selected initial codes to focused codes (i.e., coded in a different color in MAXQDA). Analytic memos were written to confirm or disconfirm the saliency of a focused code.

Focused codes remained grouped in the same categories previously associated with the data. Since focused coding further reduced the data, it was necessary to reexamine and revise these categories. For example, if focused coding resulted in only one code being identified in a category, then this category was collapsed. Categories and focused codes were then examined to identify themes. A theme described how the data worked together in a category. Categories, focused codes, and themes were submitted to peer debriefing procedures and subsequently refined. In order to test, challenge, and confirm themes with the second researcher, a visual matrix was created that facilitated critical examination of all corresponding data at a glance. Following discussion and verbal consensus themes were finalized. The visual matrix for individual cases was updated and then compiled as a preparatory stage for cross-case analysis (Miles et al., 2014; Saldaña, 2013).

**Cross-case synthesis.** A unique case orientation approach was used in the cross-case synthesis (Patton, 2015). Patterns of meanings discerned from individual cases were treated as unique examples of the phenomenon under investigation (Miles et al., 2014). This approach was consistent with the interpretive framework (i.e., social constructivism) and research design principles (i.e., unique case orientation and context sensitivity) that guided this investigation (Patton, 2015). Cross-case synthesis focused on (a) visual analysis (using a matrix display compiled from individual case analyses) to compare/contrast findings across cases, and (b) a synthesis of themes across cases (Yin, 2009). At this stage, analytic memoing helped to further focus analysis by documenting the researcher's notes to herself about similarities and dissimilarities across cases, as well as phenomena unique to a given case (i.e., not shared across other cases; Miles et al., 2014). A total of 416 analytic memos were recorded (throughout the duration of this investigation), including definitions of categories and codes.

A cross-case matrix was developed and progressively refined as part of this process. Initial development of the matrix involved compiling all visual matrices from individual cases into a single matrix. This matrix was then synthesized through visual analysis to show cases with similar and dissimilar themes as well as their associated focused codes. If a theme appeared unique to a given case this was incorporated into the matrix as a stand-alone theme. A deeper level of analysis was then performed to identify observable differences in focused codes for cases sharing similar themes. This process aided in identifying discrepant evidence to determine where cases were perhaps more dissimilar than alike. Finally, demographic data were analyzed to look for patterns specific to participant and school characteristics across cases. Given the small sample size, no assertions were made regarding demographic characteristic unless these data triangulated with another data source (e.g., interview data).

The cross-case matrix, analytic memos, and preliminary cross-case themes were submitted to peer debriefing procedures. During peer debriefing, existing assertions were challenged and alternative explanations for patterns across cases were proposed resulting in the researcher conducting further comparative analysis and cross-case synthesis. Following multiple iterations, cross-case themes were again submitted for peer debriefing. Based on verbal consensus with the second researcher themes for cross-case synthesis were finalized. The cross-case synthesis matrices were then further refined to identify themes across cases by research question (see Tables 12-19 for research questions 1-2, respectively). Eight themes were finalized in the cross-case synthesis. Four themes answered research question 1 (5 categories, 38 focused codes) and four themes answered research question two (5 categories, 39 focused codes). The auditors (i.e., Thesis Committee members) provided additional input on themes for individual cross-case synthesis, which were subsequently incorporated into this investigation's findings.

## **Trustworthiness**

Multiple measures were taken to promote the credibility and trustworthiness of findings. These were data triangulation (data sources and investigators), disconfirming evidence, member checks, researcher reflexivity, and transferability (Brantlinger et al., 2005; Patton, 2015). Triangulation was used to verify that assertions based on the data were consistent across different sources (e.g., participants), types of data (e.g., observations and interviews), and investigators (i.e., different investigators discerned the same patterns inherent in the data) (Patton, 2015). Disagreement among researchers and discrepant evidence were actively pursued as opportunities to challenge initial assertions and deepen understanding of inconsistency within the data. When disagreement and discrepant evidence were present, triangulation was used to confirm or disconfirm alternate interpretations of the data and subsequent claims (Stake, 2006).

Member checking (respondent validation) was used to confirm the credibility of observation and interview data collected, and to elicit participant feedback on the researcher's preliminary interpretations of the data (Brantlinger et al., 2005). Researcher reflexivity and using rich and detailed description to promote transferability also promoted the trustworthiness of findings. The researcher engaged in reflexivity in each stage of the research process, working to construct authentic descriptions and understandings grounded in the data (Brantlinger, et al., 2005; Patton, 2015). In order to facilitate reflexivity, every effort was made to limit data collection to two cases at a time, to avoid potentially confusing reflections on the particularities of unique cases (Stake, 2006). The researcher documented her reflections in field notes and analytic memos. Analytic memos included copious descriptions of the researcher's personal reactions, thoughts, feelings, and insights during data collection and analysis (Saldaña, 2013). The researcher also engaged in self-disclosure by (a) describing her personal experiences

relevant to the phenomenon under study in the researcher identity statement, and (b) clearly delineating in the write-up of findings how her personal experiences informed her interpretations (Patton, 2015). Finally, to promote transferability (naturalistic generalization) of findings, the write-up included sufficient detail and depth for readers to decide for themselves the application of findings to their unique circumstances (Brantlinger, et al., 2005; Patton, 2015).

## **Chapter 4**

### **Findings**

The results presented in this chapter are a cross-case synthesis of findings, across nine cases, organized around this investigation's two research questions. Where relevant, findings unique to individual cases are highlighted.

#### **Student Involvement in Their SHCP at School**

Four themes emerged regarding how students with complex health care needs (CHCN) and severe disabilities (SD) are involved in their specialized health care procedures (SHCP) at school. Themes were (a) taking part in one's own health care; (b) a time to socialize; (c) posing a potential health risk to oneself; and (d) care received without opportunities to participate. High school and post-secondary students tended to be more involved in their SHCP than middle school students. Additionally, students with profound disabilities (co-existing sensory impairments [i.e., functional blindness], physical, and communication impairments) and behavior challenges were the least likely to participate in their SHCP at school. How or if students were involved in their SHCP also depended on the actions taken, or not taken, by school personnel to provide students opportunities and supports (e.g., instruction, adaptations, modifications) to take part in their care.

#### **Taking Part in One's Own Health Care**

Partial participation was the primary way in which students were found to be involved in their SHCP at school. In five of the nine cases, students partially participated in one or more of the following ways: (a) carrying out steps in their SHCP ( $n = 5$ ); (b) making choices in their SHCP ( $n = 2$ ); and (c) reporting relevant health concerns during the SHCP ( $n = 2$ ). Some students partially participated in more than one way and/or at higher levels (i.e., carrying out

multiple sequenced steps in their SHCP). Across the five cases where students partially participated in their SHCP at school, levels of involvement varied with respect to how students acquired, or were in the process of acquiring, the skills to take part in their care. These differences were associated with prior skill acquisition at home, formal or informal goals, and instruction addressing student involvement in SHCP.

Students who carried out steps in their SHCP had different types of procedures. These were gastrostomy tube (g-tube) feedings (Cases 1, 3, and 4A), clean intermittent catheterization (CIC, Case 4B), and insulin injections (Case 7). Four students partially participated in preparatory and clean-up steps in their SHCP by gathering the required supplies (e.g., feeding tube, catheter, syringe), disposing of used supplies, and returning reusable or extra supplies to a designated area in the classroom, nurses office, or the student's backpack (Cases 1, 4A, 4B, and 7). All five students partially participated in core steps in their SHCP (e.g., use of medical technology, delivery of food or medication). In two cases, students lifted their own shirts to be either connected or disconnected to their feeding extension tube by school personnel (Cases 1 and 3) or to receive an insulin injection (Case 7). Other ways in which students partially participated in core steps in their SHCP included giving oneself a bolus feed (Case 4A), attempting to insert a catheter for a CIC (Case 4B), and testing and reporting blood glucose levels (Case 7).

To a lesser extent, students also partially participated in their SHCP by making choices and reporting relevant health issues. Case 1 Student chose the group of peers (with disabilities) with whom she wanted to sit to receive her g-tube feeding and Case 7 Student chose his insulin injection site (e.g., left/right arm, tummy). Choice making was likely a less common form of partial participation observed due to the systematic nature of students' SHCP, which may have

resulted in fewer natural opportunities to make choices compared to non-health care activities. Both Case 3 and Case 7 Students reported relevant health concerns during their SHCP. In these cases, students had the verbal skills to communicate discomfort without prompting (e.g., “hurts”), and the ability to specify by pointing to the source of discomfort (or to confirm discomfort) when verbally prompted by school nurses.

Students who exhibited the highest levels of partial participation in their SHCP at school learned these self-care skills at home and then generalized them to the school setting ( $n = 2$ ). In Case 4A, the parent indicated her daughter was independent in her g-tube feeding (i.e., no assistance or supervision was needed), having spontaneously started to self-administer her procedure at home two years prior. The parent believed her daughter acquired these skills from years of partial participation (e.g., holding the syringe) and observation of her SHCP at home. In Case 7, the parent shared that she worked at home to teach her son how to independently test his blood glucose levels and manage his supplies (e.g., restock his diabetes management kit). It is also relevant to note that neither student had fine or gross motor difficulties that required physical adaptations or specialized instruction in motor skills. In both cases, the parents trained school personnel by having their child demonstrate how and what they did in their own care. These cases tentatively suggest that skill acquisition at home coupled with the absence of fine or gross motor difficulties may be associated with higher levels of student involvement in SHCP at school.

Goals addressing student involvement in SHCP appeared to support the likelihood of students partially participating in their SHCP at school. Goals were written as either a formal IEP objective (Case 1; e.g., gather supplies) or identified in the Present Level of Academic Achievement and Functional Performance section of the IEP (PLAAFP; Case 4B; i.e., “working

with the school nurse to learn how to self-catheterize”). In three out of the five cases where students partially participated in their SHCP, goals were informal (i.e., not documented in the IEP). Informal goals were identified by school nurses (Cases 3 and 7), or the special education teacher and paraprofessional (Case 4A) in their respective individual interviews, and were framed as desired student learning outcomes. Examples of informal goals were to understand the importance of, and demonstrate the use of, clean technique to self-administer a g-tube feeding (Case 4A), and to make low-carbohydrate food choices (Case 7). Observation data generally supported that both formal and informal goals were addressed through instruction; however, substantial variation existed with respect to school personnel’s consistency in providing students instructional opportunities supportive of students’ partial participation in their SHCP at school.

Types of instruction provided to students were visual prompting (Case 4A), verbal prompting (Cases 1, 3, 4A, 4B, and 7), verbal prompting paired with gestural prompting (Case 1), and verbal prompting paired with physical assistance (Cases 1, and 4B). Students with fine motor difficulties received the latter, more intrusive prompts. Steps in students’ SHCP targeted by instruction did not appear to follow a forward or backwards task analysis (except in Case 4A). Instead, instruction generally focused on discrete steps in the SHCP reported as safe and feasible by school personnel to teach students. Adaptations to the environment were also provided in Cases 1, 4A, and 4B. Examples of environmental adaptations included an adapted container used by the student to gather supplies (Case 1) and a bathroom with a bar to assist the student in independent transfer to the toilet (Case 4B). All students received verbal praise when they completed a step in their SHCP, such as “good job,” “awesome,” and “you are a rock star.”

Instruction received by students was inconsistent in Cases 1 and 3. In Case 1, the student was not afforded instructional opportunities to participate in her SHCP as specified in her IEP

objective in half of the trials observed. The school nurse and the paraprofessional were observed in these instances to automatically do steps in the SHCP for the student. This commonly occurred when they were engaged in personal conversation with other school personnel. Compared to the school nurse, the paraprofessional was considerably more likely to implement the SHCP without providing the student instructional opportunities to take part in her care. The propensity to focus on personal conversation and not student instruction during the SHCP suggests that the paraprofessional may not have valued the student's partial participation in her care. In Case 3, the school nurse also automatically did steps (identified in an informal goal) for the student in more than half of the trials observed. The school nurse cited concerns over the student's reported behavior challenges (i.e., screaming, hitting, kicking) and not wanting to "trigger" the student as reasons for her inconsistent follow-through. The informal nature of the goal, identified only by the school nurse, appeared to leave out the IEP team's input and potential educational supports (e.g., behavioral) that may have mitigated the school nurse's concerns.

### **A Time to Socialize**

Across six cases, SHCP were observed to be a time for socialization between students and school personnel who oversaw and implemented students' procedures. Some students socially interacted with school personnel in a step related to their SHCP and in conversation with school personnel focused on topics unrelated to their SHCP (e.g., school activities, student interests;  $n = 4$ ). Other students were only engaged in conversation with school personnel unrelated to SHCP ( $n = 2$ ). No social interactions between focus students and peers with or without disabilities were observed during students' SHCP. Social interactions appeared to normalize SHCP as everyday school activities for focus students; however, conversation unrelated to the SHCP (initiated by school personnel) sometimes was the primary focus during

the SHCP ( $n = 2$ ). In these cases, school personnel may have valued social involvement over other forms of partial participation, and/or were unsure how to otherwise support student involvement in SHCP at school.

The majority of social interactions related to steps in the SHCP appeared to occur naturally between students and school personnel (Cases 1, 4A, and 7). Naturally occurring social interactions appeared unprompted by school personnel. For example, Student 1 mimicked the school nurse shaking the cans of liquid food for her g-tube feeding by shaking her head and body while smiling at the school nurse, who would respond: “Are you shaking too! Come on shake, shake, shake.” Both the student and school nurse would then laugh. Interestingly, however, the school nurse did not try to give the student a can of food to shake herself despite the student showing awareness of, and the physical ability to partially participate in, this step. In Case 4A, the student would sometimes make an error. On one occasion, Student 4A accidentally tried to connect the feeding tube at the wrong end. Both the student and the special education teacher then spontaneously burst into laughter upon realizing the mistake; still smiling and giggling, Student 4A self-corrected her error without assistance.

Although most social interactions emerged naturally, school personnel did initiate social interactions that appeared to encourage student involvement in their SHCP (Cases 4B and 7). These interactions appeared very informal in nature. School nurses in Cases 4B and 7 consistently initiated social interactions with students specific to steps in their SHCP. In Case 4B, the student was reported by school personnel and parents to be uncomfortable with her body and reluctant to learn how to self-catheterize. The school nurse was observed to make jokes with the student that appeared to lessen her anxiety. Specifically, the student laughed and then appeared more comfortable repeating attempts to self-insert the catheter with physical assistance

from the school nurse. Social interactions of this nature were apparently an informal instructional support. Across cases where social interactions between students and school personnel occurred naturally, or were initiated by school personnel, socializing during the SHCP appeared to promote students' engagement and understanding of their SHCP.

Another form of socialization was conversation between focus students and school personnel unrelated to SHCP. Conversation varied in frequency and duration across cases. Students' conversation with school personnel included verbal responses (Cases 3, 4B, and 7) and non-verbal responses such as gestures, affect, and vocalizations (Cases 1, 4A, and 5A). Students with more verbal language skills chatted with school personnel on a range of topics centered on student interests (e.g., school, pets, shopping, siblings, sports games; Cases 3, 4B, and 7) intermittently across the duration of the SHCP. Students 4B and 7 were more likely to engage in conversation with school personnel unrelated to their SHCP, while simultaneously partially participating in their care. In contrast, social conversation appeared to be the primary focus during Student 3's SHCP. The special education teacher for Student 3 reported, "When I have observed it's been more just chit chat about her day. And the feeding is just something that's being done to her, and there is not a whole lot of explanation why." Although the school nurse did provide the student some limited opportunities for partial participation in her care, the school nurse primarily engaged the student in social conversation unrelated to her SHCP. The school nurse explained her reasoning: "The other nurse didn't talk to her at all and just went on with things. I didn't like that. So, we talk about dogs and kittens. She really likes talking about dresses and pretty, glittery stuff." Case 3 School Nurse also consistently reported concerns regarding the student's reported behavioral challenges. Social conversation was possibly

construed by the school nurse as a more feasible and/or safe means of involving the student in her SHCP.

In Cases 1, 4A, and 5A, students communicated non-verbally and were not observed to have access to augmentative and alternative communication (AAC), although individualized AAC systems were documented in students' respective IEPs. Social conversations between students and school personnel in these cases tended to be less frequent, occurring at the beginning and the end of the SHCP. Additionally, conversations were shorter in duration. In Case 5A, the classroom nurse approached the student to begin her g-tube feeding. The student was attending to a movie, and the classroom nurse exclaimed: "The Minions!" The student orientated her head away from the movie and towards the classroom nurse and smiled. The classroom nurse asked: "Do you like the Minions?" The student turned her head closer to the classroom nurse and smiled bigger. The classroom nurse responded by saying, "Yes, you do like the Minions" and then started her g-tube feeding. Overall, social interactions between students and school personnel, related and unrelated to SHCP, appeared to normalize students' medical procedures as an everyday typical school activity.

### **Posing a Potential Health Risk to Oneself**

Students were observed and reported to potentially pose a health risk to themselves during their SHCP ( $n = 4$ ). This was essentially a form of counterproductive student involvement in SHCP. Concerns observed and/or reported included students inconsistently adhering to a clean technique (Case 4A), misreporting blood glucose levels and/or distracting the school nurse (Case 7), and potentially removing their g-tube (Case 3 and 5B). In two of these cases (4A and 7) the students had achieved a somewhat higher level of independent self-care within their overall SHCP in comparison to the other cases in this study. As student involvement

increases, it is plausible to assume a greater potential for risk; however, safety concerns observed and reported across all four cases appeared related to unique student issues as opposed to their respective level of involvement in their SHCP. Unrelated but compounding health issues (Case 4A), as well as behavior challenges (Cases 3 and 5B), or stereotypic behaviors (i.e., a preoccupation with numbers; Case 7) appeared to increase the likelihood of students presenting a health risk to themselves during their SHCP at school.

In Case 4A, all school personnel conveyed serious concerns about the student's understanding of hygiene and ability to adhere to a clean technique in her SHCP. Observations of the student confirmed these concerns. Although school personnel reported and were observed to consistently provide instructional supports in this area (i.e., verbal and photo prompts for hand washing), the student was also considered nearing independence in her SHCP, therefore supervision was intermittent (i.e., periodically walking up to check on the student). On one occasion the special education teacher was not in the classroom. The student was observed to drop her feeding syringe on the classroom floor and attempt to use it without washing it. The researcher waited, but had to intervene and prompt the student to wash the syringe before continuing her SHCP. A second major concern reported and observed for this student, was physical discomfort resulting from dental abscesses and the student's tendency to touch her mouth and then touch her feeding supplies and g-tube. Interestingly, although instructional supports were in place to prompt hand washing at the start of the procedure (i.e., visual cue) there was no photo prompt to remind the student not to touch her mouth and then touch her feeding supplies during her SHCP. Instead, school personnel were observed and reported to do this verbally, but sometimes did not catch the student in the behavior in time due to the use of a

privacy screen, and other student behaviors in the classroom that drew their attention away from Student 4A.

Student 7 presented with a very different safety concern in his SHCP due to his personal fascination with numbers. Although he independently tested his blood glucose levels, and then presented the reading on the meter to the school nurse, the school nurse reported that she had to carefully verify the date and time because “He wants praise for a lower reading, and will sometimes show me a lower blood sugar number from the day before.” Although this behavior occurred infrequently, it presented a serious safety concern that could potentially lead to a miscalculation in the student’s insulin dosage. Additionally, when the nurse shared information about his carbohydrate count while calculating his insulin dosage, the student would begin calling out different numbers. For example, when told a lunch item had 16 carbs, he responded: “Sixteen. Sixteen is my favorite number! Do you know what comes after sixteen? Seventeen, 18, 19....” This behavior was observed across all three observations. The nurse reported having to double-check her calculations and dosing carefully to avoid potential errors in calculations due to the random numbers the student called out. Aside from the nurse indicating that she had to double-check his meter reading and her calculations, school personnel and the parent did not appear especially concerned about the student’s behavior and related potential risk for the school nurse making an error in his SHCP. The school nurse’s office was always busy, and despite her apparent attention to detail, the student’s behaviors appeared to create a challenging situation at times, as evidenced by the nurse exasperatedly stating: “There you go again Buddy with the numbers. You are just trying to throw me off.”

Lastly, in Cases 3 and 5B school personnel expressed concerns regarding students’ behavior challenges and the potential for students to pull out their g-tube button from their

abdomen during a behavioral episode. In Case 5B, the parent also reported a similar concern as her son had pulled out his g-tube button in the home setting four times prior, necessitating a hospital visit each time. Student 5B was observed to frequently sway suddenly and quickly during his SHCP in the opposite direction of the classroom nurse, who would have to follow his movements to avoid tension on the extension feeding tubing and g-tube button. This student was observed and reported to not be involved in his SHCP except around some limited social interactions that were unrelated to the SHCP. School personnel reported using “distraction techniques,” specifically giving the student something to keep his hand busy (i.e., a squishy ball) to prevent him from pulling on his feeding tubing. However, the student was only observed to have something to hold in his hands in 1 out of 3 observations.

Across all cases where students were observed and reported to exhibit a health risk to themselves during their SHCP no IEP goal or behavioral interventions (i.e., behavior support plan) were documented. It should be noted, however, in Case 4A school personnel reported taking multiple measures to address the student’s dental hygiene with the parent. The presence of dental abscesses was reported to cause the student ongoing pain, and hinder her ability to adhere to a clean technique during her SHCP as she would frequently touch her mouth while self-administering her procedure. Additionally, the student’s eyeglass prescription was reportedly outdated and she subsequently had difficulty seeing. The student was observed to squint and press her face close to her feeding materials to see them. The parent reported that she was in the process of making a dental and vision appointment, but was struggling financially and had no transportation to take her daughter to the dentist or eye doctor.

### **Care Received Without Opportunities to Participate**

In most cases ( $n = 5$ ), students were found to have opportunities to be involved in their SHCP at school; however, in the remaining cases ( $n = 4$ ) students were almost always observed to be a passive recipient of their SHCP. Specifically, school personnel implemented the SHCP without eliciting student involvement in SHCP or responding to students' attempts to partially participate in their procedures. In cases where students received care without opportunities to be directly involved in their SHCP, the student presented with behavior challenges ( $n = 1$ ) or were students that had profound disabilities (co-existing sensory impairments [i.e., functional blindness], physical, and communication impairments;  $n = 3$ ). Lack of opportunities for students to participate in their SHCP appeared to be directly connected to school personnel engaging in caretaking practices (e.g., patting or stroking the student in a nurturing manner), holding low-expectations for student involvement (e.g., not acknowledging students observed attempts to partially participate as volitional), and viewing the SHCP as students' relaxation time (e.g., time to sleep).

Caretaking practices were observed in Cases 2, 5A, 5B, and 6. Across these cases, school personnel interacted with students in a caretaking manner by patting and stroking students' heads, backs, and extremities. For female students, school personnel were observed to fix or re-braid students' hair immediately before or after a SHCP (Cases 2 and 5A). School personnel were also observed to address students with seemingly affectionate and childish nicknames, such as "monster." While it is reasonable to assume the prevalence of school personnel's tactile interactions with students were due to three students' functional blindness, school personnel did not use other forms of tactile communication specific to SHCP (e.g., tactile object schedule). In

general, school personnel reported that the purpose of students' SHCP was to ensure that they were comfortable and taken care of medically at school.

Low expectations on behalf of school personnel also appeared to be an issue. Across the four cases, students were observed to orientate towards school personnel and relevant materials or equipment during key steps in SHCP. School personnel somewhat consistently responded to students with a tactile social interaction (e.g., pat on the back), but were not observed to acknowledge the students' behavior as potentially demonstrative of understanding their SHCP. Specifically, school personnel did not respond to students' behaviors as teachable moments to narrate what was happening in their care, or otherwise reinforce students' potential awareness of and/or interest in their SHCP. Instead the paraprofessional and classroom nurses who provided students their SHCP used predominantly abstract expressions such as "Here we go" or "Ok Buddy [*or* Girly]" when beginning or ending the SHCP. In Case 6 the classroom nurse connected the feeding extension tube without saying anything to the student. The classroom nurse turned on the feeding pump, which then beeped. The student vocalized an "ah" sound and orientated his head in the direction of the feeding pump and smiled. After no response from the classroom nurse, the student vocalized "ah" again. The classroom nurse did not appear to acknowledge the student's behavior. For example, the classroom nurse did not say: "Yes. The pump beeped. Your food has started." Instead, he simply patted the student's leg, without giving the student eye contact, and then walked away.

In three cases, school personnel did not consider it possible for students to understand, or demonstrate understanding, of their SHCP. In Case 2, the student was observed to respond to the paraprofessional who would ask: "Does it register that you have something in your tummy?" with a smile and cooing sound, which was documented in the student's PLAAFP section of the

IEP as a “yes” response. However, the paraprofessional did not regard the students’ communication as intentional or accurate, believing that the student was simply responding to the sound of her familiar voice. Case 5A Student was one exception, as school personnel and the parent believed she was capable of partially participating in her care, but were unsure how to address instruction in SHCP.

Additionally, school personnel appeared to treat the SHCP as relaxation time for students. They made comments such as “time to sleep” while providing students’ SHCP (except in Case 5A). In Case 6, the SHCP was specified by the special education teacher as the student’s scheduled relaxation time, and therefore she did not consider the SHCP as a period in the student’s school day when instruction might occur. “The g-tube feeding is the time I know he’s comfortable, so I can go work with another student. So that is his downtime. They all have their different down times because they tire so easily” (Case 6, Special Education Teacher). Interestingly, this student’s g-tube feeding was administered as a slow drip, via a pump, over a duration of two hours.

A possible explanation for the prevalence of caretaking practices, low-expectations, and viewing the SHCP as relaxation time was an apparent lack of shared knowledge across IEP team members with respect to students’ SHCP. Parents reported that they did not know what happened during their child’s SHCP at school (Cases 2, 5A, 5B, and 6). In addition, school nurses were infrequently involved in students’ SHCP due to the use of a longtime 1:1 paraprofessional (16 years; Case 2) and classroom nurses (Cases 5A, 5B, and 6) to deliver SHCP. In addition, IEP goals, informal goals, and specialized health care plans were not on file to outline students’ learning outcomes in their SHCP.

## **Beliefs About Involving Students in SHCP at School**

The findings on school personnel and parent beliefs were based on interview data. Four themes emerged from the data. These were: (a) so many obstacles; (b) must be safe and appropriate; (c) working together is essential; and (d) enhances well-being and adult outcomes.

### **So Many Obstacles**

Participants spoke at length and in depth about numerous perceived obstacles to student involvement in SHCP at school. They attributed most obstacles to the severity of students' disabilities and participants' discernments about the capabilities of students to play a role in their health care at school. Participants talked specifically about the following disability traits as obstacles: (a) severe intellectual disabilities (ID;  $n = 7$ ); (b) developmental age; ( $n = 3$ ), (c) sensory and/or physical disabilities; ( $n = 6$ ), (d) communication disabilities; ( $n = 6$ ), and (e) behavior challenges; ( $n = 4$ ). Beliefs across cases and among individual participants were reported to be rooted in assumptions about students' abilities based on current endeavors to promote student participation in their SHCP at school (Cases 1, 4A, 4B, and 7), or were beliefs about students' limitations that were admittedly conjecture as no previous attempts had been made to involve students in their SHCP at school. The latter was associated with cases centered on middle school students, who were younger in comparison to other focus students in this study sample (i.e., 12-14-years-old versus 16-21-years-old; Cases 3, 5A, and 5B); or in cases where participants directly stated that therapy and socialization were the principle goals of students' educational programs (Cases 2 and 6). Although obstacles to student involvement in SHCP at school were primarily associated with the severity of students' disabilities and specific disability traits, school personnel identified one additional obstacle. This was insufficient time or

scheduling constraints during the school day to support student involvement in SHCP (Cases 1, 3, 4A, 5A, and 7).

All students in this study's sample presented with severe ID. In three cases, students' severe ID was viewed as a barrier to learning and sequencing complex steps in SHCP (Cases 1, 4A, and 7). Case 1 Parent explained "My daughter cannot do most steps in her feeding because she is cognitively really low. For example, she doesn't know how to pour, what amount to give herself, how fast to go, or when to stop." In these cases, participants believed students' severe ID made it difficult to identify realistic ways to increase students' partial-participation in their SHCP at school, and would likely prevent students from achieving independent self-care in the future. In four cases, students' severe ID was believed to preclude (Cases 2, 5A, and 6) or severely limit (Case 5B) the likelihood of students benefitting from instruction targeting participation in health care. Case 6 Classroom Nurse felt "At his cognitive level, I think teaching participation in his g-tube feedings or nebulizer treatments is moot because he cannot comprehend the education process." Participants also felt that in general these students struggled with making any educational progress, and that targeting instruction in SHCP was neither realistic, nor a good use of students' time. Across cases, beliefs about obstacles posed by students' severe ID were consistent among participants (i.e., no discrepant evidence) except in Case 5A. In this case, only the school nurse viewed the student's severe ID as an obstacle explaining, "She had neurological damage that happened in utero. I just don't see her being anything other than a recipient of her care."

In three cases, parents regarded students' developmental age as an obstacle to involvement in their SHCP at school (Cases 2, 3, and 6). Two school personnel shared parents' beliefs (Case 2 Paraprofessional and Case 6 School Nurse). Developmental age refers to an

individual's intellectual, physical, and social-emotional level of maturity, as opposed to chronological age. Parents believed developmental age was an obstacle because their children required a level of care consistent with what a very young child may need. Case 6 parent reflected on her 16-year-old son: "He is mentally like a baby. It would be like teaching a 3-month-old to participate in their care. I don't see how that is possible aside from crying." This parent's belief about her son's level of functioning was echoed by a parent of a 20-year-old student (Case 2). "She is not able to do anything herself. My daughter is like a 5-month-old because of the brain damage [traumatic brain injury]." These parents believed that their children's developmental age was fixed and that further improvement was not possible. Case 3 parent explained: "She is at the maximum capacity of functioning. She will not progress anymore. We do all of her care for her because she can't do it on her own." Participants who identified developmental age as an obstacle shared a common belief that their child or student was incapable of learning. They struggled to understand how devoting time to instruction on SHCP would increase students' participation.

School personnel and parents also described students' sensory and physical disabilities as further compounding students' SD (i.e., severe ID and developmental-age). They viewed students as unable to physically participate because they "can't see" what is happening in their care and lacked the motor ability needed to do physical steps in their SHCP (e.g., grasp and hold a tube; Cases 1, 2, 5A, and 6). In these cases, as well as Case 5B, participants also regarded lack of muscle control (shaky and jerky movements) as a major obstacle to physical participation in SHCP. Participants appeared to view sensory and physical disabilities as evidence that students' physical participation in their SHCP was not feasible. Case 2 Special Education Teacher believed "With her brain injury, vision impairment, and inability to move her arms or use her

hands, she just doesn't have the ability to physically do anything in her own care." In cases where participants did not highlight students' severe ID as a significant obstacle, sensory and/or physical disabilities were not perceived to rule out the possibility of students' physical participation in SHCP (Case 5A), or independent self-care (Case 4B). Case 4B School Nurse explained:

Without much mobility, it is hard for her to open her legs fully. She also doesn't have the hand strength to spread her labia with one hand while inserting the catheter with her other hand. Although she has these physical challenges, with time, practice, and strength training, independent self-catheterization is possible.

Beliefs about sensory and physical disabilities appeared to intersect with participants' views on students' severe ID and developmental age, possibly exemplifying low-expectations or a quandary on how it might be possible or meaningful to teach involvement in SHCP to students who present with multiple SD. Where concerns about students' severe ID were less apparent, participants appeared to view sensory and physical disabilities as an obstacle to physical participation in SHCP that was indeed a challenge, but one that did preclude students' participation.

In six cases, participants believed students' communication disabilities posed an acute obstacle to students reliably communicating basic health care needs (e.g., hunger, pain; Cases 1, 2, 4A, 5A, 5B, and 6). Participants were ardent that communicating basic health care needs was a critical form of student participation in their SHCP and overall health care at school, and conveyed both frustration and distress that students struggled in this area. Participants reported having to rely on physical symptoms to "guess" students' health needs because they were "non-verbal" and had no functional means of communication, or students' communication abilities were limited to very concrete skills, such as requesting a preferred object. Case 5B Classroom Nurse lamented:

He is not able to tell me if he is full. Since his g-tube feeding is supplemental, if he eats anything by mouth I have to guess how much can I give him. He needs his nutrition, but I don't want the other side of it. If he vomits or refluxes from being over fed that can cause health issues in the throat and mouth. So, I have to try and find that magic amount. It is very frustrating. I wish he could tell me.

School personnel and parents believed that communicating basic health care needs was a very important and foundational way for students to participate in their care, but felt uncertain how to teach such “abstract” communication skills given students’ rudimentary communication abilities.

The last obstacle identified by participants related to the severity of students’ disabilities and specific disability traits was behavior challenges. School personnel and parents in four cases identified this obstacle to student involvement in SHCP at school. Participants described some behavior challenges as minor. For example, students sometimes tensed up or vocalized loudly to protest a g-tube gravity feed (Cases 2 and 5B), or were reluctant to participate in their SHCP (Cases 3 and 4B). School personnel believed these behaviors were attributed to anxiety and learned helplessness, respectively. Participants identified other behavior challenges as posing a more serious obstacle to student involvement in SHCP at school (Cases 3 and 5B). Case 3

Special Education Teacher believed:

Her behavior is probably the biggest issue around teaching her how to do her g-tube feeding. Instructional demands can trigger her behaviors, which can get very intense very quickly. My main concern would be when she’s having a behavior that she’s being unsafe. I would be worried in a rage she might, pull on her tube.

Challenging behaviors that raised concerns about students pulling out their g-tubes were particularly disconcerting to school personnel and parents. Subsequently, they reported reservation about teaching self-care skills within the context of students’ SHCP.

Lastly, special education teachers and school nurses judged that time and scheduling constraints were obstacles to teaching student involvement in SHCP in five cases (1, 3, 4A, 5A, and 7). Related to this concern, special education teachers expected students to require more

time to learn skills due to their severe ID and fine motor difficulties. Special education teachers believed that the extra time required to teach skills in SHCP may be difficult to carve out, or adhere to, given students' already busy schedules and unforeseen schedule changes or day-to-day program issues (Cases 1, 3, and 7). School nurses also felt that they were "stretched thin" with large caseloads that did not always allow the flexibility to spend extra time with one student. School nurses shared that this was especially a concern during lunchtime when they had to administer medication to "back-to-back students."

### **Must Be Safe**

A theme that was especially salient, woven throughout all nine cases, was participants' resolute conviction that the major purpose of health care at school was to ensure that students with CHCN and SD were safe above all else. School personnel and parents elaborated on what "keeping students safe" meant to them by describing the vital need for ethical and quality health care at school that benefited students' overall health, including students' own sense of "feeling safe." Participants' viewpoints on student involvement in SHCP appeared to strongly intersect with this core commitment to students' safety. Their comments focused on three types of beliefs. They believed the safety of students (a) determines if and how students participate; (b) is promoted through adult monitoring; and (c) may be improved by teaching students to safeguard their own health (if possible). Safety concerns also intersected with beliefs about the severity of students' disabilities. Specifically, participants regarded attempts to involve students in their SHCP in ways that extended beyond students' perceived abilities as "unethical" because it could potentially "compromise the safety component" of students' health care at school.

Serious safety concerns were highlighted by school personnel in Cases 2 and 6 that were perceived to preclude any possibility for students to safely participate in their SHCP at school.

In both cases, students were identified as likely requiring physical prompting (i.e., “hand-over-hand”) to physically participate in their SHCP given their severe ID and physical disabilities. Conversely, these students were also described as having brittle bones and bruising easily. Subsequently, school personnel felt that physically assisting students to participate in their SHCP could be “dangerous”.

In three cases, most school personnel and parents believed that if students were safe that student involvement in SHCP at school was a worthwhile educational endeavor (Cases 3, 5A, and 5B). Case 5A Parent stressed: “Her safety is ‘ground zero,’ but I can see potential participation in her healthcare as a benefit.” In these cases, school personnel and parents clearly identified safety as a precondition for student participation, but were not specific about what safe participation in SHCP at school may look like for these students. The latter was attributed to participants admitted lack of forethought on the matter due to students’ younger age and grade level (i.e., middle school), compounded with the perceived severity of students’ disabilities.

School personnel and parents believed that the safety of students determined what specific steps the students were able to learn or perform on their own (Cases 1, 4A, 4B, and 7). Several participants, most notably special education teachers and paraprofessionals, believed that students were already participating to the maximum extent that was safe. Case 1 Paraprofessional candidly expressed: “To be perfectly honest, I really don’t think there is anything else that she can do as far as her g-tube feeding goes. I think it would be possibly dangerous.” School nurses and parents, however, were more likely than special education teachers to identify areas where students could safely build on their current participation in their SHCP at school. Case 7 School Nurse rationalized:

I think his current level of participation is a very safe way for him to participate, but it may also be possible for him to learn to inject his insulin if it were drawn up in advance. This would allow more participation without any serious safety concerns.

School nurses and parents appeared to have a deeper technical knowledge of students' SHCP and were therefore more likely to identify ways that were safe to expand on students' current levels of partial participation.

Across seven cases, school personnel and parents believed (irrespective of how students participated in their SHCP at school, or may participate in the future) that adult monitoring was necessary to ensure the safety of students (Cases 1, 3, 4A, 4B, 5A, 5B, and 7). Adult monitoring was described as diligent observation and prompt intervention (as needed) to address potential student errors, unforeseen procedural issues (e.g., expired or missing supplies), and possible complicating health issues (e.g., infection). Case 4A Special Education Teacher explained:

“There is always a potential for disaster. It is very important to continuously monitor the student while she does her g-tube feeding. It only takes a moment for something to go wrong.” School personnel and parents anticipated, due to the severity of students' disabilities, that students would permanently require adult supervision to ensure their safety whenever they participated in their SHCP at school. Case 4B was one exception, as both school personnel and the parents believed that supervision would no longer be needed once the student had mastered independent self-catheterization.

School personnel and parents also believed that teaching students to safeguard their own health, if possible, might enhance students' safety. In three cases, participants hoped that students would learn to recognize and report errors made in their SHCP by a caregiver (Cases 3, 4B, and 7; except Case 3 Parent). This hope stemmed from the reported concern that sometimes there were substitute caregivers, or caregivers may change across school settings (e.g., middle to

high school), or during transition to adult life. Case 3 School Nurse believed that the student “would be safer, if she could learn to identify if a caregiver did something wrong in her care, say ‘stop,’ and then tell the caregiver what is the correct step.” Participants surmised that students might safeguard their own health if they were able to reliably communicate health concerns (e.g., illness, fullness, inappropriate treatment; Cases 1, 4A, 5A, 5B, and 7). Case 4A Special Education Teacher explained:

If she could accurately tell me what is wrong, I would be better able to address her overall health by contacting the school nurse or Mom to get more information on ways to help her. In addition, this may lead to catching an infection or other health issue before it becomes serious.

Participants emphasized that communicating basic health concerns was an important health advocacy and safety skill. Case 5A parent poignantly expressed that without “communication in place for her to say what is wrong or how she is being treated; She is neither safe, nor in control.” School personnel and parents (except for 5A School Nurse) expressed the hope that over time student involvement in SHCP, and instruction in AAC within the context of SHCP, may promote students’ abilities to reliably communicate their basic health concerns thereby enhancing their health and safety.

Finally, in three cases school personnel and parents believed that students could safeguard their health by learning to follow dietary restrictions (Cases 4A, 5B, and 7). Students 4A and 5B both had dysphagia and were restricted from eating most foods by mouth to prevent choking or aspiration. 5B School Nurse poignantly shared:

We had a student in the district die because the student fed himself a marshmallow and choked on it. If this [focus] student could learn to refrain from eating restricted foods, not only is it an important safety goal, it might save his life.

Although school personnel and parents did not appear to exactly know how to effectively teach students to safeguard their own health, participants conveyed genuine concern that not every

potential threat to students' safety was within the realm of their control. Subsequently, students themselves should, to whatever extent possible, learn how to protect their own health and well-being during their SHCP and overall health care. In short, participants described students as the "last line of defense" to protect their own physical health, social-emotional health, and even their mortality.

### **Working Together is Essential**

In seven cases school personnel and parents viewed working together as essential to promoting student involvement in SHCP at school. Beliefs about working together focused on the importance of (a) the IEP team agreeing student involvement in SHCP is an educational need ( $n = 5$ ); (b) using the professional expertise of the school nurse ( $n = 6$ ); (c) working with related services to identify needed intervention and supports ( $n = 5$ ); and (d) coordinating care across school and home ( $n = 4$ ). School personnel and parents appeared to equally value working together, but in some cases, there was frustration (or other difficulties) expressed amongst school personnel, or between school personnel and families, around effectively reaching this goal.

In five cases, special education teachers emphasized that the IEP team should foremost agree that student involvement in SHCP is an educationally relevant and meaningful goal for individual students (Cases 1, 3, 4A, 4B, and 7). Special education teachers regarded SHCP as self-care skills, but ones that were very different than more commonly taught self-care skills (e.g., brushing teeth, toileting). Due to the "medical" and "complex" nature of SHCP, special education teachers believed that addressing instruction in SHCP at school required explicit buy-in and approval from parents and school nurses. Special education teachers trusted that school nurses and parents already were, or would likely be, very supportive of involving students in their SHCP at school. Comments shared by school nurses and parents confirmed special

education teachers' assumptions, except for Case 3 Parent who considered involvement in SHCP an unrealistic goal for her daughter.

Participants also believed that they should work together to promote student involvement in SHCP by incorporating the professional expertise of school nurses into students' educational planning. In six cases, special education teachers perceived working with school nurses as important because nurses augmented teachers' own knowledge base and/or training (Cases 3, 4A, 4B, 5A/B, and 7). Special education teachers felt that their respective training had neither prepared them to work with students who have CHCN, nor incorporate health care into students' curriculum. Case 4A special education teacher acknowledged:

It is so important to be able to work with a nurse. None of my training as a special education teacher emphasized health care needs from a learning standpoint. It was as if students' health care was separate from their education, but of course with our students this just isn't true.

Special education teachers looked upon school nurses as an expert resource for explicating the overall SHCP, technical details (e.g., clean versus sterile technique), and potential safety risks (e.g., aspiration). This information was considered critical for task analyzing the SHCP and developing appropriate learning objectives for students. Although special education teachers considered utilizing the professional expertise of school nurses as essential to involving students in their SHCP, they also felt that it was sometimes challenging to access school nurses at schools where nurses were itinerant and/or had large caseloads. Nurses, however, held a contrary viewpoint.

Four school nurses (Cases 1, 3, 4A, and 7) and one classroom nurse (Cases 5A and 5B) expressed concern that they were not always valued as a full member of the IEP team. Case 7 School Nurse passionately shared her perspective, one that appeared to mirror the beliefs of other nurses, as follows:

Having a nurse at the table brings a different set of eyes. I'm not looking at the student from a grade-level or Common Core perspective. Of course, these pieces are important, but what I see is the health component to their education. It is important to be able to sit down with teachers and parents and be able to say, here is what I see as a need or pattern. 'Can we work on some interventions here at school?' What is hard is when I go into an IEP and I am asked to present quickly and leave. This is frustrating because I am not provided the opportunity to participate in the IEP in a way that will best meet the student's needs.

Additionally, nurses reported concern that students' SHCP were sometimes viewed as a perfunctory task to be done expediently to get students back to their academic schedules. Case 3 School Nurse reflected: "I always have the impression that they want her to hurry up and get back to class quickly. We can't just rush, rush, rush because her motor skills are not the same as ours." Subsequently, despite a clear desire on behalf of these nurses to participate in the IEP team planning process and promote student involvement in SHCP, they sometimes felt undervalued and underutilized as an IEP team member for students with CHCN and SD. Relationships between special education teachers and nurses, however, were reported as overwhelming positive. Overall, special education teachers and nurses appeared to value working with one another, but seemingly had not communicated with one another, or otherwise found a resolution, to address their respective concerns regarding working together to promote student involvement in SHCP.

In five cases, school personnel and parents talked about the importance of working with related services personnel, specifically speech-language pathologists (SLP) and occupational therapists (OT), to support student involvement in SHCP (Cases 1, 3, 4B, 5A, and 5B). Participants tended to describe this belief in a simplistic fashion, such as "We would need the SLP's help." or the "OT might have some ideas." While all participants mentioned the importance of working with related services, only one special education teacher provided a clear example as follows: "To address communication in the student's SHCP, we would really need to

have the speech therapist on board too so she can help to show us how to implement instruction correctly.” This type of framing around working with related services personnel may have been due to the fact that special education teachers, nurses, and parents understood related services to be mostly consultative, and/or based on a limited number of minutes allowable for direct student intervention, depending on students’ respective IEPs. Overall, participants perceived working with related services as an important means of supporting current or future endeavors to promote student involvement in SHCP.

Beliefs about the importance of working together also emerged in the area of care coordination. In five cases, participants (especially parents) believed that efforts needed to be coordinated across school and home, and different caregivers where possible, to promote skill acquisition and generalization (Cases 1, 4A, 4B, 5A, and 7). In Case 5A, the parent expressed the following conviction about the importance of care coordination around teaching her daughter involvement in her SHCP.

We need to know in a meaningful way, so that we can carry over what she learns at school at home. I think this is an important piece for my daughter. Often, she has been taught to do something with one person and then it is not transferable. They should give us homework so that we are aware of what is going on at school, and likewise we need to coordinate with them what we are trying to do at home.

Parents expressed the importance of ensuring that everyone is “on the same page” regarding current or future measures to promote student involvement in their SHCP at school and home.

In two cases, school personnel and parents reported conflicting perspectives on care coordination (Cases 4A and 4B). In Case 4A, the parent was satisfied with her daughters near independence in her g-tube feeding, however school personnel were deeply concerned that their efforts to promote care coordination across school and home fell amiss. The special education teacher, school nurse, and paraprofessional all believed that there was a “close to reportable”

lack of attention at home regarding basic health care needs (i.e., hygiene, dental, vision) that adversely impacted the student's overall performance at school, including her self-care skills in SHCP. The student's dental abscesses were viewed as a serious risk for sepsis, and significant source of ongoing pain. School personnel reported that the family was struggling financially, and information shared by the parent during the interview confirmed this report. Demographic data also indicated that the parent had a less than high school education. In this case, it appeared that the goal of care coordination was hindered by lack of training or resources on behalf of school personnel to support families who had lower socioeconomic status.

Conflicting perspectives were also present in Case 4B, where the special education teacher and school nurse looked upon the parents as "coddling" the student, believing that the parents "do not support her independence" in her SHCP. In contrast, the parents were frustrated because they very much wanted their daughter to be independent in her health care across environments, but felt unsupported by the school to handle their daughter's behavioral challenges (i.e., verbal protesting, refusal) around self-care at home. Both parents participated in the interview and appeared to share and echo the same convictions. The mother was adamant: "If they can get her to do better that would be great. She doesn't listen to us. Maybe she will listen to someone else." The father emphasized, "If she could be independent that would change everything. She could go places by herself." The mom added, "I could get a better job. I wouldn't have to work part-time to take care of her." Both school personnel and parents appeared to deeply value the student's independence, but did not believe that they were supported by each other. This was apparently due to a seemingly guarded stance about each party's respective point-of-view, and a lack of communication necessary to foster a supportive working relationship.

## **Enhances Well-being**

In all cases, except Case 6, participants believed that student involvement in SHCP at school had the potential to enhance students' well-being in their current day-to-day lives, which in turn, may carry over into students' well-being in their future adult lives. Areas of improved well-being identified by participants included: (a) self-esteem, (b) personal control and reduced anxiety, (c) a sense of normalcy, and (d) independence. Participants from cases that centered on middle school students were less likely to identify positive effects of student involvement in SHCP on future adult well-being. School personnel and parents from these cases reported nominal consideration of adult planning due to the relatively young age of these students. None of these students had transition plans on file yet. Additionally, some parents of high school and post-secondary students very candidly and sorrowfully shared that they were unsure how long their child would live, therefore their focus was on keeping them safe, cared for, and happy (Cases 2 and 6).

Improved self-esteem emerged as the most common perceived outcome from student involvement in SHCP (Cases 1, 2, 3, 4A, 4B, and 7). School personnel and parents felt that students gain self-confidence and pride through involvement in SHCP at school. Case 1 Special Education Teacher spoke excitedly about Student 1 and her partial participation in her g-tube feeding explaining, "She gets this enthusiastic vibe when she participates in her feeding, and the biggest smile and look of pride on her face." Parents also shared this sentiment. The parent in Case 1 believed that her daughter experienced improved self-confidence knowing that "It is important that people feed themselves, and I need to feed myself. This can help her see her own capabilities." Case 4A parent believed "I think she's proud of herself that she can do her g-tube feeding without help." Even in cases where students were perceived to present with many

challenges to participating in their health care there was the belief that even the smallest measure of independence can “promote self-esteem and give students confidence to know that ‘I can do this part on my own’” (Case 2 School Nurse).

Personal control also emerged as an important area of well-being achieved from participation in SHCP (Cases 1, 2, 3, 4A, 4B, 5A, 5B, and 7). Across cases, participants perceived student involvement in SHCP as facilitating students’ control over their bodies and ownership of their health care needs at school, and potentially in adult life. Participants described personal control in similar but different ways. Case 3 School Nurse felt that if Student 3 could learn to participate more in her SHCP, “she would feel more control over what was going on and [that the procedures would] not just be something that was being done to her.” In cases where students had CIC, a more private SHCP, participants believed that participation helped students understand their bodies, and allowed (Case 4B) or could promote (Case 5A) a greater sense of control and feeling that they were a part of their care. Case 5A parent reflected on her daughter getting older, and emphasized the following:

My daughter’s involvement [in SHCP] could become increasingly important for her because we are not around all the time. She has so many different caregivers. Participating in her care can help her have a feeling of control, especially in new environments [i.e., high school] and/or with new caregivers in the school and home settings.

Related to personal control over one’s body, in four cases, school personnel and parents perceived that students benefited from involvement in SHCP through reduced anxiety (Cases 2, 5A, 5B, and 7). Students were believed to be more likely to experience anxiety around their health care when they were not provided opportunities to exercise personal control over their bodies through participation in their care. In Case 7, the school nurse and parent both explained that as a result of teaching the student the importance of rotating injection sites, the student was

beginning to choose his “tummy” as a site without anxiety. This was important because he had many tough spots on his arms from repeated injections. The school nurse explained:

When he has choices and a sense of control, he is more likely to use his voice. Having choice has helped him start to independently choose different injection sites that support his skin health, even though they may cause more discomfort. When it is his choice he is more comfortable even though it hurts more.

Inherent in participants’ beliefs was the perception that feeling out of control or helpless in one’s care could be harmful to students’ emotional well-being with respect to adapting to their daily health care needs and routines.

In some cases, school personnel and parents also believed that students taking part in their care fostered a sense of normalcy. Case 3 nurse explained as follows:

Self-care fits just like with any chronic illness. Health management is a part of her normal day-to-day routine. She can have a sense of normalcy about it. ‘I’m going to do my feeding, and then I’m going to do whatever it is I love to do.’ It doesn’t change who she is. It is just an extra bonus in her daily schedule.

Additionally, in Case 4B, the parents believed that their daughter learning how to self-catheterize would “help her all around, give her more confidence and help her feel like, I am in a wheelchair, but I’m just like another person” (Case 4B Father).

Students were also perceived to benefit from involvement in SHCP by gaining independence, thereby decreasing their reliance on others (1, 3, 4A, 4B, 5B, and 7). In most cases, full independence was regarded as unlikely. Case 5A and 5B School Nurse explained, “Future goals around partial participation in both students’ SHCP may help them become more in touch with their needs as a person and give them as much independence as possible, even though they will always need assistance.” In Case 3, the school nurse believed, “Learning how to participate in her g-tube feeding is a life skill that can help her to be more independent as an adult though she may continue to need supervision and assistance.” In these and similar cases

(i.e., Case 1), independence was viewed as relative to students' overall abilities, yet notably valued.

In other cases, where students were in a secondary transition program and had more skills in their SHCP, involvement in SHCP was viewed as fostering important skills needed for independence in adulthood. Case 4A paraprofessional felt, "She is a 21-year-old adult. By understanding what she needs to do for herself, and feeling capable to do those things, she is benefitting. She is working towards becoming a self-sufficient adult, at least in feeding herself." Case 7 Special Education Teacher (Co-Teacher A) believed that the student's participation in his SHCP was critical to his adult life, explaining, "The more independence he has as an adult the better his life will be, because one-day mom and dad are not going to be there anymore." The significance of independence in SHCP was further highlighted in two cases where students were working towards independence (Cases 4A and 4B). All school personnel believed that these students would have improved access to independent living options as adults, or other adult services (including vocational services) if students were independent in managing their SHCP.

Lastly, in one Case 6, school personnel and parents did not perceive student involvement in SHCP at school as relevant, believing that teaching or supporting involvement in his SHCP would have no impact on the student at school or in his adult life. Reasons were attributed to his disability characteristics and the high level of care he required. All participants indicated that socialization was a larger priority for this student, so that he could experience "happiness." The classroom nurse captured this shared sentiment as follows: "I am not sure that medical education or involvement is going to directly affect his happiness during school or in his adult life."

Apart from Case 6, school personnel and parents reported valuing student involvement in SHCP at school based on the afore described benefits to well-being. This was clear through

comments such as this one from a Classroom Nurse (Case 5A), “I would love for her to be involved. I mean it is their life. It is their body. I think it is only appropriate.” Several school professionals also identified themselves as an advocate for students, stating that their role was to empower students and foster independence (Cases 1, 3, 4B, 5A, and 5B). Case 1, School Nurse gave the following impassioned explanation:

Although she cannot do all the steps independently, there are steps that she can do. We are not here to be an enabler or disable her further. We want to give her the responsibilities that she can handle to participate in her care. As with any student that I care for, we want to advocate for them, but also we also want to empower them. The ultimate goal is for them to provide safe effective care for themselves. The goal is not place care upon them, and disable them in a way, that when they leave these walls they don't have the skills, or the techniques they need, to care for themselves. We won't always be with them.

## **Chapter 5**

### **Discussion**

The purpose of this investigation was to understand how transition-age students with complex health care needs (CHCN) and severe disabilities (SD) are currently involved (or not involved) in specialized health care procedures (SHCP) at school, and the beliefs of school personnel and parents about student involvement in SHCP at school. This chapter begins with a reflection on how this investigation's conceptual framework compared to the findings, followed by a discussion of the central findings. The discussion is organized by three main issues: (a) involvement realized and unrealized; (b) missing plans, goals, and systematic instruction; and (c) ensuring high expectations for *all* learners. This chapter concludes with a description of limitations, and implications for practice and research.

#### **Reflections on the Conceptual Framework**

Based on a review of the literature, the author developed a conceptual framework as an advisory tool to focus data collection and deepen understanding of the findings (see Figure 1). Embedded circles make up the framework. The outer circle includes two related theories—self-care and causal agency. These theories respectively describe how individuals can achieve self-care skills and assert causal agency (i.e., self-determination) in ways that align with the special education process. The author also hypothesized that these theories may be consistent with beliefs and values potentially held (or not held) by school personnel and parents that would support (or impede) utilizing the special education process to teach involvement in SHCP for students with CHCN and SD at school. The second embedded circle within the conceptual framework illustrates the special education process. The core of the conceptual framework shows the CEC, DPHMD recommended learning outcomes for students with disabilities who

have SHCP. These outcomes are consistent with the principles of self-care and causal agency (e.g., demonstrating self-care and agency in one's health care through partial participation in SHCP).

Many school personnel and parents expressed beliefs supportive of self-care and causal agency theory, including the belief that students should learn to take care of their own health care needs to the greatest extent possible (e.g., partial participation) and learn how to advocate for their health needs (e.g., communicate pain or discomfort). However, students with profound disabilities and behavior challenges did not receive opportunities to be involved in SHCP despite demonstrating an interest in their care (e.g., orientating towards care providers and supplies during SHCP). School personnel expressed uncertainty on how to teach “complex” skills demonstrative of self-care and causal agency to students with profound disabilities and behavior challenges (i.e., the CEC, DPHMD recommended learning outcomes for student involvement in SHCP). While self-care and causal agency theory may potentially inform pedagogy to teach involvement in SHCP at school, it may be necessary to deconstruct these theories in practical and applied ways to ensure translation to educational planning and instruction.

Additionally, the data showed that socialization with adults during SHCP was meaningful for several focus students, particularly when positive age-appropriate social interactions with school personnel promoted student engagement in SHCP. In these cases, socialization during SHCP appeared to normalize medical procedures as everyday school activities for students. Participants reported valuing students' competencies and emphasized that student involvement in SHCP resulted in students achieving improved self-esteem, personal control, and independence. The author did not originally factor into this investigation's conceptual framework the role of socialization. It may be useful to consider Wolfensberger's (1983) *social role valorization*

(originally termed the principle of normalization; Wolfensberger & Tullman, 1982) as an additive theory to the conceptual framework.

Students with CHCN and SD may be at risk for social devaluation; enhancing their social image (e.g., age-appropriate socialization during SHCP) and personal competencies (e.g., partial participation in SHCP) may enable this population to experience socially valued roles and in turn improved access to enriching life experiences (Wolfensberger & Tullman, 1982; Wolfensberger, 1983). It is important to note that Wolfensberger and Tullman (1982) emphasize, “image enhancement and competency enhancement are believed to be reciprocally reinforcing, both positively and negatively” (p. 135). In cases where school personnel provided students’ care without opportunities to participate, and socialized with students in age-inappropriate ways, this treatment may have socially devalued these students, potentially causing or reinforcing learned-helplessness. The concept of social role valorization may be useful to consider when conducting future investigations, particularly since complex and chronic health conditions have implications for how schools, communities, and society may perceive and treat this population (Falvo, 2014).

The findings showed that the special education process was underutilized to teach student involvement in SHCP (i.e., the cycle of assessment, goals and objectives, and instruction). Notably absent from the data were school personnel’s and parents’ references to the role of assessment in planning for student involvement in SHCP at school. It is possible given that many participants reported not previously considering student involvement in SHCP as an educational priority, that they did not pay attention to basic educational planning considerations (i.e., assessment). In addition, when school personnel did reference goals, select IEP members (e.g., school nurses, parents) described goals informally (e.g., “I want the student to learn...).

This finding suggests that formal measures to systematically address student involvement in SHCP through the special education process did not occur (i.e., IEP team-based planning).

Target learning outcomes, shown in the inner circle of the conceptual framework were based on the CEC, DPHMD's recommendations. These were challenging to apply to this investigation's findings. These learning outcomes are (a) independent care, (b) partial participation in care, (c) directing care, and (d) knowledge of care (CEC, DPHMD, 2008). The findings indicate that the CEC, DPHMD target learning outcomes overlap considerably suggesting that they are not distinct. For example, knowledge of care is necessary for partial participation in SHCP. The findings suggest that participants who had identified formal or informal goals for students tended to focus on partial participation. In general, they did not emphasize knowledge of care or directing care.

Additionally, directing care (though not observed in this study) represents a form of partial participation that would similarly require knowledge of care. The CEC, DPHMD target learning outcome of directing care may be perhaps most relevant to students with profound disabilities who are non-verbal, and have very limited mobility as well as sensory impairments. However, focus students in this study who had profound disabilities did not have access to augmentative and alternative communication (AAC). School professionals generally did not provide these students opportunities to communicate during SHCP or instruction in AAC to learn how to direct their care. Participants may have also viewed directing care in SHCP as a difficult and abstract skill for students to learn; they may have also questioned its value and meaningfulness. However, without the functional ability to physically assist or even see what is happening, it may be even more important to find meaningful ways to support students to direct their care through AAC. Behavioral shaping procedures could also over time enable this

population to understand that they are in fact directing their care through AAC, thus providing them the opportunities to feel more independent and in control of their SHCP.

Overall the biggest challenge of the CEC, DPHMD guidelines for student learning outcomes in SHCP at school was the implicit overlap and lack of practical ways to apply these desired outcomes to individuals who have the most significant CHCN and SD. If mapping the CEC, DPHMD guidelines recommended learning outcomes onto the findings of this study were difficult, this may tentatively suggest that they may be difficult for practitioners and families to understand and apply. It is also unknown to what extent school personnel and parents who have students or children with SHCP are aware of the CEC, DPHMD recommended learning outcomes, and if aware, to what extent they may perceive them as useful.

### **Involvement Realized and Unrealized**

In several cases, students were actively involved in partially participating in their care. Participants reported valuing any measure of students' participation in SHCP, however finite, as essential to students' well-being and independence. It is important to emphasize that students with CHCN and SD may never achieve *full* independence in SHCP. In general, this population has a need for ongoing supports from care providers, and other social and environmental supports (Feldman, 2013; World Health Organization, 2001). This study's findings support the extant literature that partial participation is a way for students to be involved in SHCP when full independence is not possible (CED, DPMHD, 2008; Heller, 2017; Heller & Tumlin, 2004; Lehr & Harayama, 2015; Ward & Ward, 2014).

The principle of partial participation is a long-standing premise in the field of special education. The principle posits that students with SD "can acquire many skills that will allow them to function, at least in part" in a broad range of inclusive, age-appropriate, and functional

environments and activities through systematic planning and individualized adaptations (Baumgart et al., 1982, p. 19; Ferguson & Baumgart, 1991). Through partial participation several students demonstrated that they had learned or were in the process of learning steps in their SHCP. Partial participation appeared to be a viable way for students with CHCN and SD to realize involvement in their SHCP. School personnel and parents also viewed students' partial participation in their care as age-appropriate and beneficial to students even though full independence was unlikely. These findings are encouraging because they illustrate that students with CHCN and SD can be involved in SHCP through partial participation and there is a value-base among school personnel and parents to support this type of involvement in students' health care.

Despite these encouraging findings, there did not always appear to be a systematic approach, observed or reported, by school personnel to address the principle of partial participation in ways that were reflective of best practices. Missing from the data was evidence that these participants consistently acted upon their reported values in the school setting. This finding indicates that student involvement in SHCP was frequently unrealized. A common reason for lack of student involvement was due to school personnel automatically completing target steps in SHCP for students. This occurred almost exclusively in self-contained classrooms, and often when several adults were present and preoccupied in conversation with each other. Kurth, Born, and Love (2016) found that students with SD served in self-contained classrooms did not receive instruction one-third of the time due to staff talking amongst each other. The data in this study also show that conversation between school personnel interfered with students receiving instruction on a consistent basis.

A second explanation for lack of student involvement was that some school personnel, particularly school and classroom nurses, expressed that they were reticent to require students to partially participate due to fear of potential student behavioral manifestations. When appropriate behavioral supports are not in place, school personnel may feel apprehensive towards students and be less willing to work with them (Lohrmann & Bambara, 2006). School nurses may also lack experience and formal training in addressing challenging behaviors in students with SD (Strunk, 2009; Singer, 2013). Consequently, school personnel may have found it easier or less risky to simply perform SHCP for students, even when they reported valuing students' partial participation. The data also suggest that this approach may have inadvertently reinforced students' challenging behaviors. This issue can occur during health care activities when providers do not understand functions of behavior (Gorski, Slifer, Kelly Suttka, & Lowery, 2004; Kazdin, 2012). Subsequently, unintended reinforcement of students' challenging behaviors may have further increased school personnel's reluctance to place instructional demands on students during SHCP.

The principle of partial participation is perhaps most applicable to students who present with profound disabilities (Ferguson & Baumgart, 1991; Kregel, 2012). However, school personnel and parents did not afford students with profound disabilities the opportunity to partially participate in their health care, uniformly resulting in involvement in SHCP unrealized for this sub-set of students. They reported not viewing partial participation in SHCP as important for these students because it would not change their ongoing need for high levels of dependent care. This finding is consistent with the concern identified by Ferguson and Baumgart (1991) that a primary focus on independent performance may beget considering the possibility of students achieving relative independence through partial participation.

School personnel and parents also stressed a need for students with profound disabilities to learn prerequisite skills prior to addressing involvement in SHCP. Kregel (2012) emphasizes that partial participation is in fact a way to teach “entry behaviors” and “prerequisite skills” within the context of a target activity by designing alternative ways in which students can meaningfully participate in steps within the task. Participants in this study appeared to struggle with how to identify ways in which students might partially participate in their care given the multiplicity and complexity of their disabilities. However, skill acquisition in self-care skills (e.g., SHCP) for students with profound disabilities is achievable when taught within the natural context of the activity (Brown et al., 1979; Kregel, 2012; Wood & Spooner 2012).

The ability to actively partially participate in one’s health care, and achieve whatever measure possible of independence therein, has the potential to enhance individual well-being, inclusion, and participation in society irrespective of disability (Feldman, 2013). Many school personnel and parents in this study expressed beliefs supportive of the afore statement. At the same time, several participants also seemed genuinely confounded by “where to begin,” or if it was even possible for students with profound disabilities to meaningfully take part in their health care. The extant intervention literature that addresses instructing individuals with SD to partially participate in SHCP is dated and limited; however, the findings of these studies suggest partial participation is a promising approach that may eventually lead to higher levels of independence over time (Bosner, & Belfiore, 2001; Clarkson, 1982).

### **Missing Plans, Goals, and Systematic Instruction**

A wide body of literature clearly delineates the need for effective planning, including the development of goals, to ensure students are involved in their SHCP and general health care. Chief among the types of planning cited in the literature are the IHCP (Algozzine & Ysseldyke,

2006; Heller et al., 2009; Heller & Avant, 2011; Lehr & Harayama, 2015; Obsusek et al., 2014), IEP goals (Collins, 2007; Heller, 2004; Heller & Avant, 2011; Lehr, 2014), and transition plans (Bargeron et al., 2014; Collins, 2007; Hackett-Hunger & White, 2014; Morningstar et al., 2001; Targett et al, 2013). Equally important, students with SD must receive consistent and systematic instruction to reach their goals (Browder & Spooner, 2011; Bruce, 2011; Dragow, Wolery, Halle, & Hajiaghamohseni, 2011).

An unexpected and perplexing finding in this study was the notable absence of an IHCP on file for students. Students who need SHCP at school, particularly low-incidence medical procedures, require an IHCP written by a school nurse. The IHCP is a comprehensive plan attached to the students' IEP (AAP, 2016); Heller & Avant, 2011; Herrman, 2005; Obusek et al., 2014) that incorporates school nursing diagnosis, goals, interventions, expected nursing outcomes, staff training, emergency action plans, as well as, goals, training, and instructional safety measures (i.e., intrusive prompting strategies in the form of caution-steps or time-limited steps). According to the Illinois State Nurse Practice Act (2007), the practice of nursing includes the development and implementation of a plan of nursing care. The National Association of School Nurses (2008) asserts that school nurses are “responsible and accountable” for developing and implementing IHCP for students whose health care needs are chronic and complex.

A likely reason for the absence of IHCPs across the large majority of cases was that no school nurses in this study's sample were certified school nurses. This is not surprising due to the national shortage of certified school nurses (American Federation of Teachers, 2009; Foustoukos et al., 2014; Resha, 2010). Well-trained school nurses play a pivotal role in the health, well-being, and education of students with CHCN (NASN, 2016; AAP, 2016). Given the

importance of specialized training in school nursing, the absence of certified school nurses in this study's sample likely posed a barrier to planning for student involvement in SHCP (Foustoukos et al., 2014).

Additionally, several special education teachers indicated that they had not previously considered writing IEP goals addressing student involvement in SHCP, although they reported frequently targeting self-care skills (e.g., toileting) in students' IEPs. It is possible that the medical nature of SHCP resulted in some participants not equating SHCP with self-care skills, (e.g., Clean Intermittent Catheterization [CIC] as a toileting skill). Subsequently, special education teachers may not have viewed SHCP as learning opportunities. Without an IHCP on file to identify self-care goals from the school nursing perspective, special education teachers and parents may have been less informed, comfortable, or otherwise situated to propose formal IEP goals and objectives that addressed student involvement in SHCP.

Transition plans included in students' IEPs were also found to overwhelmingly omit any reference to students' health care needs. The finding that students' transition plans did not include health related goals, or even general health considerations for the future is consistent with other studies that examined transition planning for students with disabilities and special health care needs (Barger et al., 2014; MCHB, 2014; Morningstar et al., 2001; Selekman, 2013). The literature identifies health planning across transition domains as critical to improving the lives of individuals with CHCN and SD in adulthood (Collins, 2007; Hackett-Hunger & White, 2014; Morningstar et al., 2001). Specifically, inclusion in society for this population may be enhanced through the management of health care in supported independent living, vocational, and community settings (Agran, 2012; Feldman, 2013; Hackett-Hunter & White, 2014; Targett et al., 2013). Researchers have also found a relationship between self-care skills and improved

post-school outcomes, such as employment and independent living (Carter, Austin, & Trainor, 2012; Test et al., 2009). A majority of participants in the study associated student involvement in SHCP at school with improved post-school outcomes but may have lacked the experience or expertise to address students' health care needs in transition planning.

Another problematic issue identified in the findings was related to instruction in SHCP. Instruction observed in cases wherein students partially participated in SHCP did not appear consistent (e.g., trials omitted) or systematic (e.g., rapidly repeating verbal prompts without giving students response time). Special education teachers in this study sample likely had knowledge of systematic instruction given their teacher preparation programs, and direct experience working with students who have SD; however, they did not oversee students' SHCP. School nurses, classroom nurses, and paraprofessionals were responsible for SHCP. Subsequently, school personnel who oversaw students' SHCP likely lacked knowledge of effective instructional technology to teach student involvement in SHCP. Further, special education teachers may not have felt comfortable generalizing their teaching skills to a medical procedure.

Without appropriate planning, goals, and systematic instruction, students with CHCN and SD are at greater risk of care dependency and learned helplessness (Tork, Lohrmann, & Dassen, 2007). This may also lead to poor psychological well-being in children with disabilities and health care needs (Falvo, 2014). Many school personnel in this study appeared to lack the skill set necessary to design individualized education programs that addressed student involvement in SHCP, even when they recognized its value.

### **Ensuring High Expectations for *All* Learners**

The need for *high expectations* is a mantra in every seminal textbook for individuals with SD (e.g., Agran, Brown, Hughes, Quirk & Ryndak, 2014; Brown et al., 2016; Collins, 2007; Westling et al., 2015). Once believed incapable of learning, a substantive body of research now demonstrates the capacity of individuals with SD to learn both functional and academic skills (for a review, see Browder & Spooner, 2011; Brown et al., 2016; Downing & MacFarland, 2010). Downing and MacFarland (2010) posit, “the field of special education has moved from a perspective of caretaking and protecting to an expectation of learning and growth” (para. 6). The findings of this investigation suggest that expectations for students with CHCN and SD may be a step behind other populations of students with disabilities.

Some of the most substantive (i.e., voluminous) sources of data in this study, were participants’ lengthy descriptions of students’ disability related deficits and concerns regarding their safety. Some have argued that the perceived vulnerability of students with CHCN and SD may result in professionals and parents emphasizing custodial care at the expense of teaching this population self-care (and other functional) skills (see Zijlstra & Vlaskamp, 2005). School personnel and parents in this study may have struggled with reconciling their students’ and children’s need for highly specialized and complex medical care alongside having high expectations for their involvement in SHCP and other health management skills at school. As previously described, participants may have been unsure how to operationalize student involvement in SHCP while also ensuring students’ safety.

Conflicting beliefs and actions were also reported and observed in many cases. Specifically, school personnel and parents emphasized that they wanted their students and children to receive compassionate caregiving that was responsive to changes in health care status (e.g., pain, illness). They wanted their students and children to be able to communicate their

health care needs and to feel in control of their bodies, and expressed a belief that student involvement in SHCP may yield many positive benefits (e.g., self-esteem, personal control, independence). However, many school professionals performed all or parts of SHCP on students without explanation or eliciting their involvement. Additionally, some students were treated in age-inappropriate ways and possible student attempts to involve themselves in SHCP went unnoticed. Descriptive literature on integrating health care into the educational programs of students with CHCN and SD emphasizes the importance of regarding this population as capable learners, not as passive recipients of health care (Brown et al., 2016; Heller, 2017; Lehr & Green, 2002; Lehr, 2014). School personnel may not have perceived an incongruence between their reported beliefs and the way they provided students' health care in the school setting. It is also important to realize in the recent past that students with CHCN and SD did not live long enough to attend school, or they were relegated to nursing facilities (Lehr, 2014). Given the low-incidence of this population, and relatively short historical time span in which they have attended public school, involvement in SHCP likely represents a new genre of self-care skills (Lehr, 2014). It is likely that school personnel may be grappling with how to teach student involvement in SHCP in ways that they identified as valuable, given the limited research available in this area.

Policy on curriculum foci for students with SD may also influence what skills are targeted for instruction in this population. Currently a major emphasis in the field of special education is to ensure that students with SD are afforded the right to meet the same educational expectations for academic achievement as their peers without disabilities (Jackson, Ryndak, & Wehmeyer, 2008; Thurlow & Quenemoen, 2011). Researchers have raised the concern that the emphasis on teaching students with SD standards-based curriculum may overshadow "other curriculum not defined as part of the general education curriculum (e.g., self-care...)" (e.g., Halle

& Dymond, 2008, p. 198), costing students with SD the acquisition of relevant functional life skills, in exchange for achievement in splintered academic skills (Ayres, Douglas, Lowrey, & Sievers, 2011; Ayres, Lowrey, Douglas, & Sievers, 2012).

Although students with SD should have equitable access to the general education curriculum, they also have unique goals that should be incorporated into their IEP (Brown et al., 2016). To draw upon Brown et al. (1976), the question should be asked can students “function as adults if they did not acquire the skill?” (p. 9). Participants in this study clearly identified that student involvement in SHCP can improve students’ current and future well-being by improving independence in their health care. Without involvement in SHCP, students may indeed function if a caregiver provides their SHCP for them, but they would lose important benefits that would otherwise improve their quality of life in significant ways.

The findings of this study and the extant literature suggests that teaching student involvement in SHCP at school may result in immediate and long-term benefits that include adjustment to progressive illness and reduce anxiety (Falvo, 2014) and improved adult outcomes (Agran, 2012; Feldman, 2013; Hackett-Hunter & White, 2014; Targett et al, 2013). Academic achievement is an important endeavor, but it should not overshadow access to curriculum that may potentially improve quality of life and adult outcomes. Health extends into many facets of the daily and future routines of individuals with CHCN and SD. High expectations in the areas of self-care, other health management skills (i.e., health advocacy) are necessary for this population to realize the benefits that participants in this study and the literature identify.

### **Limitations**

There are several limitations of the study that warrant discussion. First, the study sample included a disproportionately high number of focus students with g-tube feedings ( $n = 7$ ).

Although three other types of SHCP (i.e., CIC, insulin injections, nebulizer treatments) were present among focus students, the findings may not be representative of students with these and other types of SHCP (e.g., tracheostomy care) in schools. Readers should carefully consider whether or not the findings and implications are relevant to their situations before drawing their own conclusions (Brantlinger et al., 2005). Second, observations occurred in the natural school setting where students' SHCP routinely happen, including small treatment areas in school nurses' offices and bathrooms. As a result, the researcher was sometimes in extremely close proximity to participants (e.g., 2 feet away), which may have inadvertently influenced how participants behaved during observations. Third, focus students were only observed three times. It is possible that additional observations may have yielded different data. Finally, the data do not address the perspectives of students with CHCN and SD about their own involvement in SHCP at school. Students' perspectives may be different than the perspectives of school personnel and parents.

### **Implications for Research**

Currently, there is a limited body of research available to guide special education practices that address involving students with CHCN and SD in SHCP, and their overall health care, at school. The author proposes several recommendations for future research to address the research gaps identified in the current study, and to develop a research base for educational practices supportive of student involvement in SHCP.

Given the plethora of implications for research that are discernable from the findings, it may be important to start with what potentially matters most—outcomes. A majority of school personnel and parents believed that student involvement in SHCP at school may promote students' improved well-being, including the ability to safeguard their own health and improve

adult living options (e.g., supported independent living). The current literature on individuals with CHCN and SD, suggests poor adult outcomes for this population (MCHB, 2013; Morningstar et al., 2001). Research is needed to investigate adult outcomes (e.g., employment, independent living) that may or may not result from students' involvement and non-involvement in SHCP at school.

Related to outcomes, it is important that future investigations tease out what specific potential benefits students who participate in SHCP at school may garner with respect to well-being. While adult outcomes are a pressing concern, any outcome that can immediately promote student agency in health care at school, and in other relevant environments (i.e., home and community), is important to investigate. Several participants noted that student involvement in SHCP may also decrease anxiety and increase personal control. Therefore, it is important that future research seek to identify immediate, as well as adult, outcomes associated with student involvement in SHCP at school.

School professionals and parents may benefit from more specific examples of partial participation in SHCP, backed by research. Specifically, what interventions support different forms of partial participation in SHCP based on specific student characteristics. It is important that research focuses on validating instructional interventions for the wide range of student characteristics that students with CHCN and SD present, in order for school professionals and parents to be able to apply research findings where appropriate to the unique characteristics of their respective students and children.

School professionals must have at their disposal research-based instructional methods to effectively teach students with CHCN and SD involvement in SHCP at school, as well as, methods to generalize these skills to the home and community. Without knowledge in

instructional technology, school professionals cannot support students to realize potentially beneficial outcomes specific to involvement in their health care. Participants in this study that valued student involvement in SHCP, frequently expressed that they were unsure how to teach students, particularly students who presented with profound disabilities and behavior challenges. Future research must demonstrate the efficacy of specific instructional interventions to teach student involvement in SHCP at school. This research should especially address the sub-set of students with CHCN and SD who present with profound disabilities.

Students with CHCN and SD are extraordinarily heterogeneous; as such, there are a wide variety of SHCP students may require. A limitation of this study is that focus students had only four types of SHCP (i.e., tube feedings, clean intermittent catheterization [CIC], insulin injections, nebulizer treatments). Future investigations exploring student involvement (or non-involvement) in SHCP at school should address other types of SHCP required by students. Specific SHCP may present unique considerations when planning for student involvement therein at school.

Additionally, health management skills may vary tremendously based on students' specific health care needs. A surprising finding in this study was that health management skills were not adequately addressed through behavioral interventions. Several participants expressed concern that students may pose a health risk to themselves. Additional research is needed to address effective behavioral interventions supportive of health management skills in students with CHCN and SD, including adherence to general health restrictions (e.g., following dietary restrictions) and promotion behaviors (e.g., exercise), as well as cooperative behaviors during SHCP (e.g., refraining from pulling on feeding extension tubing).

Finally, a clear take away from this investigation was that several school personnel and parents valued including their student or child in SHCP, but were unsure how to act upon this potential goal. Future research on student involvement in SHCP at school should also address the efficacy of ongoing professional development and parent training for school professionals and parents who are seeking practical ways to support their students'/children's involvement in their SHCP and other health management skills at school and home. Although one-day trainings may show improved receptivity on behalf of school professionals and parents to target student partial participation or independence in SHCP for IEP goals (i.e., Heller & Tumlin, 2004), it is unknown what additional types of professional development may be needed (e.g., coaching) to adequately support IEP teams.

### **Implication for Practice**

The findings support several implications for practice. Foremost, there is a need for IEP teams to recognize that SHCP are a form of self-care skills. Self-care skills are important for *all* students to learn and are especially relevant to individuals with CHCN and SD, who have substantially more self-care needs than individuals without CHCN. School personnel, particularly special education teachers, need to recognize that while SHCP are medical procedures, they are also teachable self-care skills at school. Special education teachers should collaborate with school nurses to address students' individualized educational needs related to health care. School nurses and other relevant school personnel (e.g., special education teachers, paraprofessionals) also require pre-service training and professional development on how to involve students with CHCN and SD in their SHCP and other health care needs at school.

Findings indicated that students who had learned skills to partially participate in SHCP at home exhibited higher levels of involvement in SHCP at school. The data suggest a relation

between home skill acquisition and greater student involvement in SHCP at school. However, it is unknown if these parents had not taken the initiative to teach their children how to partially participate in SHCP if students would have otherwise acquired these skills. Many parents may not have the instructional know how, or other resources (e.g., time), to teach their children how to partially participate in SHCP. Parents who want their child to learn these self-care skills should not have to bear this task on their own. IEP teams are well equipped (from an instructional technology vantage point) to provide the systematic instruction students require to learn SHCP, and generalize these self-care skills to home and other community settings.

In order for IEP teams to systematically address student involvement in SHCP at school, and in home and community environments, IHCP, IEP goals, and transition plans should be in effect. The IHCP should identify student goals for self-care, and necessary student training to achieve those goals. Furthermore, these goals should be reflected in the IEP in the form of supporting IEP goals (if appropriate; Heller & Avant, 2011; Obusek et al., 2014). Given the national shortage of certified school nurses (Foustoukos et al., 2014), it is critical that non-certified school nurses receive the necessary training to develop comprehensive IHCP that include self-care goals, and training to both understand and participate in the IEP process. School nurses are a valuable resource to the IEP team, representing the role of the school medical professional and the expert in SHCP at school. As such, all school nurses should receive adequate training to develop IHCP for students and to participate in the IEP process in informed ways. School nurses and other school personnel, including administrators, should be knowledgeable of their respective state Nurse Practice Act, requiring comprehensive nursing plans (IHCP) for students who have medical needs that necessitate nursing services at school.

Additionally, formal IEP goals are necessary to promote student involvement in SHCP. This study identified several cases wherein goals were informal, and did not include input from all IEP team members, including team members who are knowledgeable about assessment and systematic instruction. While informal goals identified by specific school personnel are laudable, they lack the formality necessary to ensure systematic instructional supports to promote students' skill acquisition.

Several participants also identified serious safety concerns. It is important for the IEP team to discuss and agree upon what specific skills are safe and most relevant for students to learn in SHCP. No participants in this study mentioned the use of more intrusive prompts, such as recommended by Heller and Tumlin (2004; i.e., caution and time-limited steps). This suggests a need for IEP teams to better familiarize themselves with specific instructional strategies that can promote student involvement without compromising student safety. Also related to safety, some students presented a health risk to themselves during their SHCP. However, no systematic behavioral supports were in place. IEP teams should carefully consider what health management skills students need to learn to promote students' health and safety (e.g., cooperative behaviors).

Another key finding in this study was the importance of the SHCP as a time for socialization. Some SHCP are an alternative form of common social activities, such as eating. Yet, there was no evidence of social interactions with peers without disabilities. Depending on the type of SHCP (e.g., g-tube feeding) and student variables (e.g., ability to partially participate in care while simultaneously socializing), it may be important to incorporate socialization with peers without disabilities to help further normalize the SHCP as an everyday routine (e.g., eating a meal). While some SHCP, such as CIC are more private, traveling to and from the nurse's

office with a peer without a disability could also help promote peer interactions without compromising student privacy during the SHCP itself.

## **Conclusion**

Health is a central aspect of the human condition. CHCN have a direct impact on students' daily functional routines, and necessitate self-care in SHCP and other health management skills (e.g., adherence) in order to realize social-emotional well-being, health advocacy, health promotion, and positive adult outcomes (e.g., inclusion). Students with CHCN and SD require systematic planning and instruction to realize self-care in their health care in school. This study's findings indicated that school personnel and parents predominately valued student involvement in their health care at school; however they may have limited awareness and knowledge of how to teach student involvement in SHCP, particularly for students who present with profound disabilities and behavior challenges. Students with CHCN and SD should be afforded the right to learn to take part in their health care, have personal control over their bodies, and learn to safeguard their own health. The implications for research and practice proposed in this manuscript address these identified areas of need.

## Figures

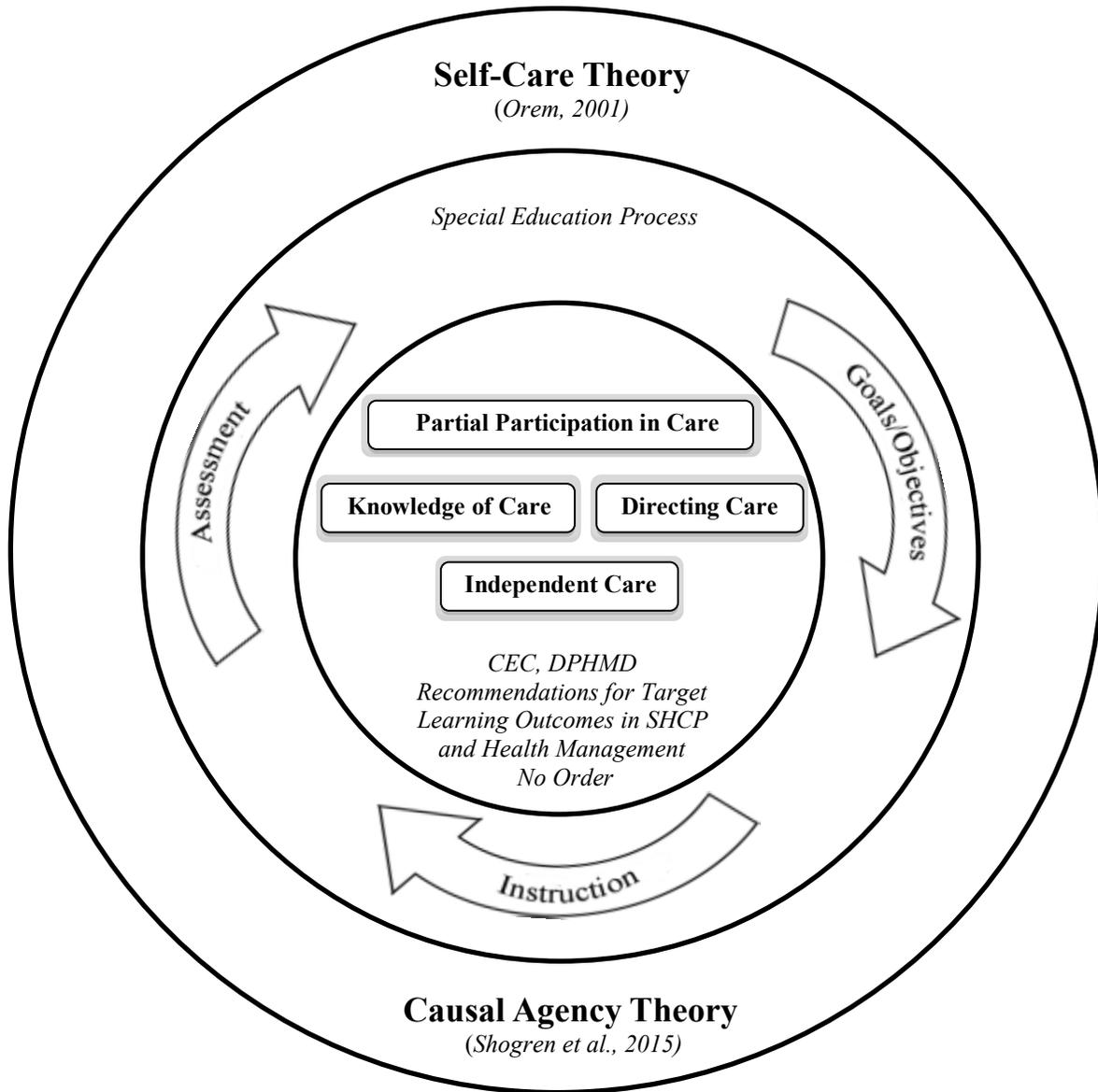
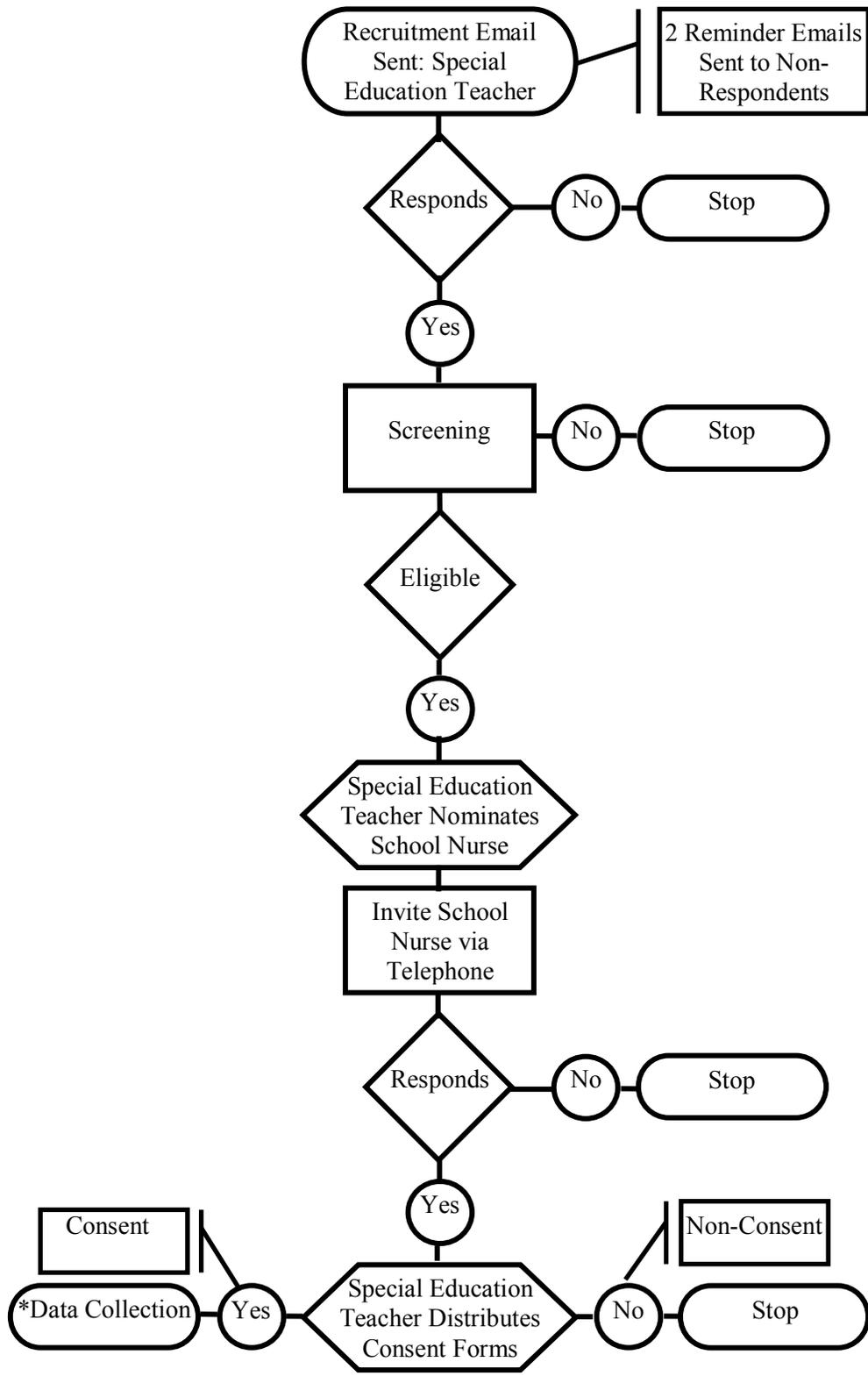


Figure 1. Conceptual Framework



\* Data collection commenced following approval for in school research from the Superintendent and school principal for each research site.

Figure 2. Recruitment Flowchart

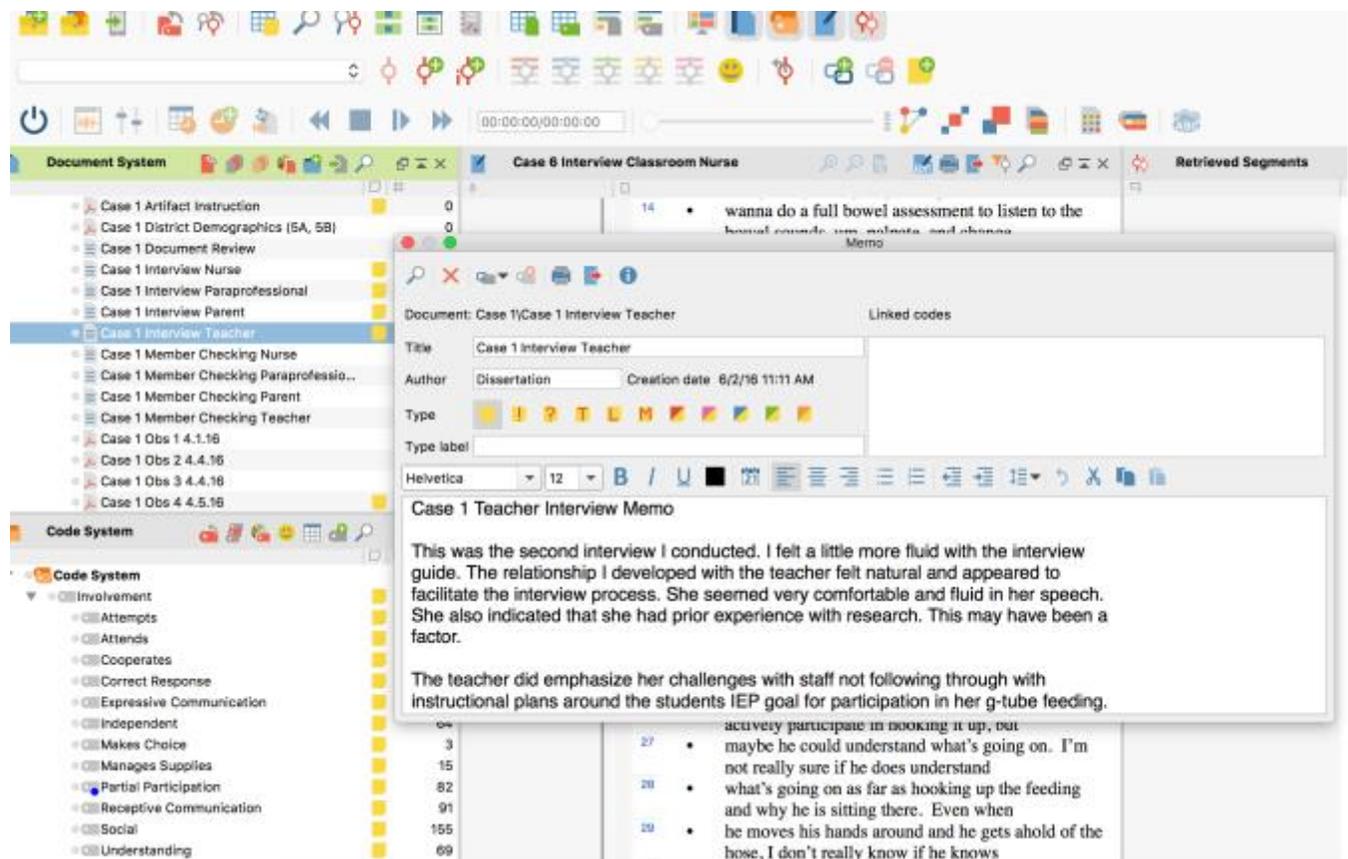


Figure 3. Example Analytic Memo in MAXQD

## Tables

**Table 1**

*Studies on Teaching Involvement in Specialized Health Care Procedures*

Citation	Skill/Type of Involvement	Method	Participants/Setting	Intervention	Results
Babbitt, Parrish, Brierley, & Kohr, 1991	Swallow medication*  Independent performance	Single-case research A-B design, multiple baseline across 4 subjects	2 female 17-year-olds with severe ID and chronic illness, a 7-year-old with moderate ID and chronic illness, 2 male 4-year-olds with moderate ID, asthma and ADHD and 1 male 3-year-old with moderate ID and chronic illness  Inpatient pediatric hospital	Shaping (gradual increase of practice pill size), in vivo (swallow real medication), reinforcement	Subjects (except for the male 3-year-old) learned to swallow medication, generalized to the home setting, and were independent across follow-up data (1 month to 1 year +)  The 3-year-old was discharged early and placed outside of home therefore no follow up data were available
Beck, Cataldo, Slifer, Pulbrook, & Ghuman, 2005	Swallow medication <sup>a</sup>  Independent performance	Single-case research A-B design, multiple baseline across 4 subjects	6 male and 2 female 4-9-year-olds with Autism and/or ADHD  Outpatient pediatric clinic	Shaping (gradual increase of practice pill size), in vivo (swallow real medication), reinforcement	7 out of 8 subjects learned to swallow their medication with a therapist  6 out of 8 generalized to parents across multiple settings, maintenance unknown

**Table 1 Continued**

*Studies on Teaching Involvement in Specialized Health Care Procedures*

Citation	Skill/Type of Involvement	Method	Participants/Setting	Intervention	Results
Bosner & Belfiore, 2001	Insulin administration  Independent performance and partial participation	Single-case research A-B design, multiple baseline design across 2 behaviors  Behaviors: 1) preparation, and 2) administration and cleanup	16-year-old female with moderate ID and Down syndrome  Home	Total task forward chaining, least-to-most prompting, reinforcement	Subject learned independent performance for task one and partial participation for task two  Generalized to (friend's house), 100% for task one and 88% for task two, 3 weeks' post across settings
Clarkson, 1982	Self-catheterization  Independent performance and partial participation	Longitudinal case study	8-year-old female with spina bifida followed until age 13  Home	Task analysis, Other not defined	Across 1-year subject learned to perform all steps with minimal assistance required for undressing/dressing  Independent across settings 2 years from start

**Table 1 Continued**

*Studies on Teaching Involvement in Specialized Health Care Procedures*

Citation	Skill/Type of Involvement	Method	Participants/Setting	Intervention	Results
Derrickson, Neef, & Parrish, 1991	Self-suctioning  Independent performance	Single-case research A-B design, multiple baseline across 4 subjects and 4 behaviors  Behaviors: 1) gathering equipment, 2) assembling equipment, 3) application of suctioning, and 4) cleanup	2 males and 2 female 5-8-year-olds  Preschool classroom for 2 subjects, home for 2 subjects	Simulation (doll and mirror <sup>a</sup> ) followed by in vivo (self and mirror <sup>a</sup> ), total task forward chaining, least-to-most prompting, reinforcement	Subjects learned independent performance for all 4 behaviors  91.7-100% correct across all 4 subjects and 4 behaviors in 2-6 weeks' follow-up
Ghuman, Cataldo, Beck, & Slifer, 2005	Swallow medication <sup>a</sup>  Independent performance	Intervention study	3 males and 1 female 4-6- year-olds with Autism  Outpatient pediatric clinic	Modeling, visual aids, shaping (gradual increase of practice pill size), least-to-most prompting, reinforcement	2 children swallowed 81-100% practice pills with the therapist and generalized to parent  1 child swallowed 54% of practice pills with the therapist but did not generalize to the parent; 1 child withdrew participation

**Table 1 Continued***Studies on Teaching Involvement in Specialized Health Care Procedures*

Citation	Skill/Type of Involvement	Method	Participants/Setting	Intervention	Results
Hannigan, 1979	Self-catheterization  Independent performance	Intervention study	1 male and 3 females 5-year-olds  Pediatric hospital	Simulation (doll and mirror <sup>b</sup> ) followed by in vivo (self and mirror <sup>b</sup> )	All 4 children demonstrated successful catheterization  In follow-up, 2 children were fully independent and 2 children were progressing towards independence
Neef, Parrish, & Hannigan, 1989	Self-catheterization  Independent performance	Single-case research A-B design, multiple baseline design across 2 subjects and 4 behaviors  Behaviors: 1) preparation, 2) mirror usage, 3) catheter insertion/removal, and 4) cleanup	1 female, 4-year-old and 1 female 8-year-old  Pediatric hospital	Simulation (doll and mirror) followed by in vivo (self and mirror), total task forward chaining, least-to-most prompting, reinforcement	Subjects learned independent performance (8-year-old required assistance with 1 step in catheter insertion)  Both children independent at 3 months' follow-up

**Table 1 Continued**

*Studies on Teaching Involvement in Specialized Health Care Procedures*

Citation	Skill/Type of Involvement	Method	Participants/Setting	Intervention	Results
Tarnowski & Drabman, 1987	Self-catheterization  Independent performance	Single-case research A-B design, multiple baseline across 2 subjects	2 male 6-year-olds with mild ID  Pediatric hospital	Total task forward chaining, least-to-most prompting, reinforcement	Both subjects learned independent performance for 19 out of 22 steps  Maintained independent performance for 19 out of 22 steps in 2-3 weeks follow-up

*Note.* ID = intellectual disabilities, ADHD = attention deficit hyperactivity disorder.

<sup>a</sup>Other health management, i.e., adherence.

<sup>b</sup>Mirror used with female children only.

**Table 2**

*Application of Patton's (2015) Twelve Core Strategies of Qualitative Inquiry*

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Strategies	Application
<b>Design Strategies</b>	
1. Naturalistic inquiry	Data were collected in naturally occurring contexts (e.g., routine SHCP in school). Conditions were not manipulated or controlled by the researcher.
2. Emergent, flexible	Post-observation and follow-up interviews allowed for the researcher to pursue questions and leads that arose from initial interviews and observations. Throughout data collection, the researcher remained open to adapting research procedures to pursue “new paths of discovery as they emerged” (p. 46).
3. Purposeful sampling	Participants who were most knowledgeable about the involvement of transition-age students with CHCN and SD in their SHCP at school were sampled (i.e., transition-age students who had CHCN and SD, as well as, SHCP at school, special education teachers, school nurses identified as the students’ case managers, delegated personnel, and the students’ parents).
<b>Data Collection and Fieldwork Strategies</b>	
4. Qualitative data	Ethnographic observation and field notes were used to produce thick descriptions. In depth, semi-structured interviews were conducted to elucidate participant perspectives and experiences. A careful review of students’ IEPs, transition plans, and health care plans were also completed.
5. Personal experience and engagement	The researcher had direct contact with participants across data collection and worked to get close to participants and situations through personal engagement in the field, interpersonal interactions with participants, and introspective reflection.
6. Empathic neutrality and mindfulness	The researcher maintained a non-judgmental stance towards participants’ perspectives and experiences based on cognitive and emotional understanding. This was achieved through reflexive journaling and a deliberate endeavor to bracket the researcher’s personal reactions in order to remain open, sensitive, and responsive to participants’ unique viewpoints and experiences. During fieldwork, the researcher achieved mindfulness through full attention and focus on research activities.

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**Table 2 Continued**

*Application of Patton's (2015) Twelve Core Strategies of Qualitative Inquiry*

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Strategies	Application
7. Dynamic systems perspective	The researcher anticipated encountering changes in individuals, teams, and school settings and was prepared to be flexible both in data collection and analysis. For example, health can fluctuate or change suddenly in students with CHCN and SD. When this occurred, the researcher took steps to understand how this influenced student's involvement in their SHCP and participants' perspectives on adapting to these changes.
<b>Analysis and Reporting Strategies</b>	
8. Unique case orientation	Each case (i.e., student with CHCN and SD, and related participants) was treated as unique. As such the first level of analysis focused on in depth understanding of individual cases. Cross-case analysis then followed.
9. Inductive analysis and creative synthesis	Inductive analysis and creative synthesis were conducted for each case prior to cross-case analysis. No preconfigured categories or codes were used. Procedures were (a) multiple close readings of the data and memos; (b) initial categories were identified based on patterns that emerged from the data (approximately 10 initial categories); (c) data were then coded into small categories of information using detailed description (approximately 20-25 tentative codes); (d) categories and codes were revised through an iterative process as new codes emerged and others decayed based on the data; and finally, (e) themes and interrelationships across categories and codes were identified (5-7 themes). Qualitative data analysis software MAXQDA was utilized to facilitate creative synthesis, ensuring that the analysis and write-up were grounded in the data.
10. Holistic perspective	Multiple sources of data and perspectives were investigated to develop a holistic understanding of student involvement in their SHCP and beliefs about involvement. The researcher recognized that involvement is a "process rather than an event" (p. 67). As such, data collection measures included a focus on how involvement happens, and dynamics that influence this process based on the perspectives and experiences of participants.

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**Table 2 Continued**

*Application of Patton's (2015) Twelve Core Strategies of Qualitative Inquiry*

Strategies	Application
11. Context sensitivity	Case-by-case analyses, cross-case analysis, and write up all heeded the inherent understanding that knowledge constructed from this investigation is unique to the particular circumstances of individual students and corresponding participants. In order to promote transferability (naturalistic generalization) of findings, the write-up included sufficient detail and depth for readers to decide for themselves the application of findings to their unique circumstances.
12. Reflexivity	The researcher engaged in reflexivity in each stage of the research process, working to construct authentic descriptions and understandings grounded in the data by bracketing her personal views through introspective reflection. The researcher documented her reflections in field notes, and memos. The researcher also engaged in self-disclosure by (a) describing her personal experiences relevant to the phenomenon under study in the researcher identity statement, and (b) clearly delineating in the write-up of findings how her personal experiences informed her interpretations. As a personal writing preference, the researcher deviated from Patton's recommendation to use the first-person ("I"), instead of the third-person ("researcher"), in her writings except in the research identity statement.

*Note.* SHCP = specialized health care procedures, CHCN = complex health care needs, SD = severe disabilities, IEP = individualized education program.

**Table 3***Student Demographics*

Case Number	Gender	Age	Grade Level	Ethnicity	Primary Eligibility	Secondary Eligibility	Health Condition	Type of SHCP	IHCP on File
1	Female	18	12	Asian Indian	Multiple Disabilities	-	Trisomy 12, Seizure Disorder	G-Tube Feeding	Yes
2	Female	20	Secondary Transition	White	Traumatic Brain Injury	Visual Impairment	Spastic Quadriplegic Cerebral Palsy, Seizure Disorder, CVI	G-Tube Feeding	No
3	Female	13	6	White	Intellectual Disabilities	Other Health Impairment	Seizure Disorder	G-Tube Feeding	Seizure Action Plan Only
4A	Female	21	Secondary Transition	White	Intellectual Disabilities	Other Health Impairment	Coffin-Siris Syndrome	G-Tube Feeding	No
4B	Female	16	9	White	Intellectual Disabilities	Other Health Impairment	Spina Bifida	CIC	No
5A	Female	12	7	White	Multiple Disabilities	Deaf/Blindness	Spastic Quadriplegic Cerebral Palsy, Microcephaly, Seizure Disorder, CVI	G-Tube Feeding, CIC	No

**Table 3 Continued***Student Demographics*

Case Number	Gender	Age	Grade Level	Ethnicity	Primary Eligibility	Secondary Eligibility	Health Condition	Type of SHCP	IHCP on File
5B	Male	14	8	African American	Multiple Disabilities	-	Lennox-Gastaut Syndrome	G-Tube Feeding	No
6	Male	16	10	White	Multiple Disabilities	Visual Impairment	Spastic Quadriplegic Cerebral Palsy, Seizure Disorder, CVI	G-Tube Feeding, Nebulizer Treatments	No
7	Male	19	Secondary Transition	White	Intellectual Disabilities	Autism	Type 1 Diabetes	Blood Glucose Monitoring, Insulin Injections	No

*Note.* Secondary transition are programs that provide special education services to adult students ages 18-21-years-old under the Individuals with Disabilities Education Act (IDEA, 2004). SHCP = specialized health care procedures, IHCP = individualized health care plan, CVI= cortical vision impairment, CIC = clean intermittent catheterization.

**Table 4***Student Disability Characteristics<sup>a</sup>*

Case Number	Disability Level	Communication	Mobility	Vision	Hearing	Behavior <sup>b</sup>
1	Severe	Affect, gestures, vocalizations, and limited AAC use	Uses a wheelchair, walks with supervision, gross and fine motor difficulties	Vision Impairment	Normal	Behavior challenges reported
2	Profound	Affect and vocalizations for basic needs	Uses a wheelchair, limited gross and fine motor mobility	Functionally blind, CVI	Normal	None reported
3	Severe	Verbal speech	Full mobility, requires a wheelchair for fatigue	Normal	Normal	Behavior challenges reported
4A	Severe	Affect, gestures, vocalizations, and limited AAC	No reported difficulties	Wears glasses, needs an updated prescription <sup>c</sup>	Normal	None reported
4B	Severe	Verbal speech	Uses a wheelchair, ambulates with crutches, fine motor difficulties	Normal	Normal	None reported
5A	Profound	Affect, blinks for “Yes”	Uses a wheelchair, very limited gross and fine motor mobility	Functionally blind, CVI	Severe Hearing Impairment	None reported
5B	Severe	Affect, gestures, and vocalizations	Uses a wheelchair, walks with assistance, gross and fine motor difficulties	Normal	Normal	Behavior challenges reported

**Table 4 Continued**

*Student Disability Characteristics<sup>a</sup>*

Case Number	Disability Level	Communication	Mobility	Vision	Hearing	Behavior <sup>b</sup>
6	Profound	Affect and vocalizations	Uses a wheelchair, very limited gross and fine motor mobility	Functionally blind, CVI	Normal	None reported
7	Severe	Verbal speech	No reported difficulties	Normal	Normal	None reported

*Note.* AAC = augmentative and alternative communication, CVI = cortical vision impairment.

<sup>a</sup>Data on student characteristics were collected from a review of students' Individualized Education Program (IEP) documents.

<sup>b</sup>Behavior challenges reported that may affect students' involvement in their specialized health care procedures.

<sup>c</sup>Student had unmet health care needs (dental abscesses) and associated discomfort reported to affect involvement in her specialized health care procedures.

**Table 5***Personnel Demographics*

Case Number	Role	Gender	Age	Race/ Ethnicity	Grade Levels Served	Years in Current Role	CHCN/SD Caseload	Years of Experience CHCN/SD
1	Teacher	Female	20-29	White	9-12	3	1	2
	School Nurse	Female	40-49	Black	9-12	7	1	3
	Paraprofessional	Female	50-59	White	9-12	16	1	16
2	Teacher	Female	30-39	White	9-12, Secondary Transition	5	1	5
	School Nurse	Female	30-39	White	6-12	2	2	2
	Paraprofessional	Female	50-59	White	Secondary Transition	16	1	16
3	Teacher	Female	20-29	White	6-8	2	2	6
	School Nurse	Female	40-49	White	6-8	3	1	3
4A	Teacher <sup>a</sup>	Female	60+	White	9-12, Secondary Transition	8	1	1
	School Nurse <sup>b</sup>	Female	40-49	White	9-12, Secondary Transition	8	6	8
	Paraprofessional <sup>a</sup>	Female	40-49	Black	9-12, Secondary Transition	3	1	3
4B	Teacher	Female	60+	White	9-12	20	2	20
	School Nurse <sup>b</sup>	Female	40-49	White	9-12, Secondary Transition	8	6	8

**Table 5 Continued**

*Personnel Demographics*

Case Number	Role	Gender	Age	Race/ Ethnicity	Grade Levels Served	Years in Current Role	CHCN/SD Caseload	Years of Experience CHCN/SD
5A <sup>c</sup>	Teacher	Female	30-39	White	6-9	2	3	4
5B <sup>c</sup>	School Nurse	Female	50-59	White	Pre-K- 9	9	6	9
	Classroom Nurse	Female	30-39	White	Pre-K- 9	4	6	4
6	Teacher <sup>a</sup>	Female	30-39	White	9-12, Secondary Transition	6	2	6
	School Nurse <sup>a</sup>	Female	40-49	White	Pre-K-12, Secondary Transition	9	40	9
	Classroom Nurse <sup>a</sup>	Male	30-39	White	9-12, Secondary Transition	3	2	3

**Table 5 Continued**

*Personnel Demographics*

Case Number	Role	Gender	Age	Race/Ethnicity	Grade Levels Served	Years in Current Role	CHCN/SD Caseload	Years of Experience CHCN/SD
7	Co-Teacher A <sup>a</sup>	Female	50-59	White	9-12, Secondary Transition	26	2	26
	Co-Teacher B <sup>a</sup>	Female	20-29	White	9-12, Secondary Transition	1	2	1
	School Nurse	Female	50-59	White	9-12, Secondary Transition	2	8	2

*Note.* Secondary transition are programs that provide special education services to adult students ages 18-21-years-old under the Individuals with Disabilities Education Act (IDEA, 2004). CHCN = complex health care needs, SD = severe disabilities.

<sup>a</sup>Employed by an Illinois special education area cooperative, but located at a public school district site.

<sup>b</sup>4A and 4B school nurse is the same individual.

<sup>c</sup>School personnel were shared across cases 5A and 5B.

**Table 6***Parent Demographics*

Case Number	Parent Role	Age	Race/Ethnicity	Marital Status	Education Level	Primary Caregiver(s)	Adults in the Home	Siblings <sup>a</sup>	Supports Received <sup>b</sup>
1	Mother	50-59	Indian	Married	Graduate level	Mother Father	3	0	None
2	Mother	40-49	White	Married	Some College	Mother	3	0	SSI, Medicaid, HCBS
3	Mother	30-39	White	Single	Some College	Mother	1	2	SSI, Medicaid
4A	Mother	50-59	White	Single	Less Than High School	Mother	1	2	SSI, Medicaid
4B <sup>c</sup>	Mother	50-59	White	Married	Some College	Mother	2	1	SSI, Medicaid
4B <sup>c</sup>	Father	50-59	White	Married	High School Diploma	Mother	2	1	SSI, Medicaid
5A	Mother	50-59	White	Married	Graduate level	Mother Father	2	2	None
5B	Mother	30-39	Black	Single	High School Diploma	Mother Sibling	2	3	SSI, Medicaid
6	Mother	30-39	White	Married	Graduate level	Mother Father	2	1	None

**Table 6 Continued**

*Parent Demographics*

Case Number	Parent Role	Age	Race/Ethnicity	Marital Status	Education Level	Primary Caregiver(s)	Adults in the Home	Siblings <sup>a</sup>	Supports Received <sup>b</sup>
7	Mother	50-59	White	Married	Some College	Mother Father	2	0	SSI, Medicaid

*Note.* SSI = Social Security Income, HCBS= Home and Community Based Services Waiver.

<sup>a</sup>Numbers of siblings living in the home full-time with the focus student.

<sup>b</sup>Any additional supports that the family receives to provide care for the focus student.

<sup>c</sup>Duplicative data reported across both parents for adults in the home, siblings, and supports received.

**Table 7***School Demographics*

Case Number	Location	School Population	Grade Level	% White	% Black	% Hispanic	% Other	% Low Income	% English Learners	% With Disabilities	% Homeless
1 <sup>a</sup>	Small Urban	1,494	High School	45	34	7	14	55	3	12	2
2	Rural	442	High School	92	1	6	1	38	2	12	2
3	Small Urban	956	Middle School	38	36	13	13	71	6	9	2
4A <sup>a</sup> 4B <sup>a</sup>	Rural	740	High School	50	27	13	10	65	5	15	3
5A <sup>a</sup> 5B <sup>a</sup>	Small Urban	470	Grade School <sup>b</sup>	15	56	13	16	76	22	10	4
6	Rural	750	High School	88	4	2	7	56	0	17	1
7	Rural	963	High School	91	1	3	6	16	0	6	0

(Illinois State Board of Education, 2016)

<sup>a</sup>Cases indicated with a shared number, but different letter, were located at the same school site and district. Case 5B was also served by a special education cooperative.

<sup>b</sup>School site grade level does not match student's grade level, excluding post-secondary students located at high school sites.

**Table 8***Context and Duration of Specialized Health Care Procedures*

Case Number	Type of SHCP	Personnel Overseeing the SHCP	Location of SHCP	Duration of SHCP	Other Personnel Present	Peers Present
1	G-Tube Feeding	School Nurse Paraprofessional	Classroom	30	Yes	Yes
2	G-Tube Feeding	Paraprofessional	Therapy Room	30	No	No
3	G-Tube Feeding	School Nurse	Nurse's Office	30	No	No
4A	G-Tube Feeding	Special Education Teacher Paraprofessional	Classroom, Privacy Curtain	45	Yes	Yes
4B	CIC	School Nurse	Nurse's Office Bathroom	35	No	No
5A	G-Tube Feeding	Classroom Nurse	Classroom	15	Yes	Yes
5A	CIC	Classroom Nurse	Classroom Bathroom	25	No	No
5B	G-Tube Feeding	Classroom Nurse	Classroom	45	Yes	Yes
6	G-Tube Feeding via Pump	Classroom Nurse	Classroom	2 hours	Yes	Yes
6	Nebulizer Treatments	Classroom Nurse	Classroom	10	Yes	Yes

**Table 8 Continued**

*Context and Duration of Specialized Health Care Procedures*

Case Number	Type of SHCP	Personnel Overseeing the SHCP	Location of SHCP	Duration of SHCP	Other Personnel Present	Peers Present
7	Blood Glucose Monitoring, Insulin Injections	School Nurse	Nurse's Office	35	No	No

*Note.* SHCP = specialized health care procedures, CIC = clean intermittent catheterization.

**Table 9***Inclusion and Exclusion Criteria*

Participant	Inclusion Criteria	Exclusion Criteria	Definition
Student	Transition-age	Pre-Kindergarten, elementary, or exited public school system	Transition-age was defined as middle school, high school, and special education students ages 18-22.
	SHCP provided at school	SHCP provided outside of school	SHCP were defined as health care procedures that were (a) required by individual students to safely attend school, (b) provided by a RN or under the direction of a licensed school nurse or RN, and (c) identified in the focus student's IHCP.
	A minimum of one scheduled SHCP at school daily	Has no scheduled or regularly occurring SHCP	A scheduled SHCP means the SHCP occurred daily at school at pre-identified times or in a specific time range (e.g., tube feeding during lunch period, tracheostomy suctioning every 30 minutes).
	Has SD	Does not have SD	SD disabilities was defined as students who qualify to take the state's alternate assessment and/or are eligible for special education under the primarily eligibility category ID, multiple disabilities, or Autism.

**Table 9 Continued**

*Inclusion and Exclusion Criteria*

Participant	Inclusion Criteria	Exclusion Criteria	Definition
Special Education Teacher	Holds a current special education teaching license in the state of Illinois	Does not hold a current special education teaching license in the state of Illinois	A licensed special education teacher in the state of Illinois holds a Learning Behavior Specialist license.
	Located at a public-school site in a 2-hour driving distance	School sites greater than a 2-hour driving distance	A 2-hour driving distance was defined as 2-hours from the researcher according to Google Maps.
School nurse	A licensed school nurse or a RN	Does not hold a school nurse or RN license	A licensed school nurse holds a school nurse license through ISBE in addition to a RN license. A RN holds an RN license only.
Parent/ Legal guardian	Has custody or is the legal guardian of the focus student	Does not have custody or is not the legal guardian	Person or persons with the legal authority to give consent for the student's participation.

*Note.* SHCP = specialized health care procedures, RN = registered nurse, IHCP = individualized health care plan, ID = intellectual disabilities, ISBE = Illinois State Board of Education.

**Table 9 Continued***Inclusion and Exclusion Criteria*

Participant	Inclusion Criteria	Exclusion Criteria	Definition
One-to-one nurse	Identified by the school nurse as responsible to implement SHCP to be observed	Does not implement the SHCP to be observed	A one-to-one nurse is a nurse who has been assigned by the IEP team to provide health care at school for the focus student. A one-to-one nurse may or may not be employed by the school district.
Paraprofessional	Identified by the school nurse as delegated to implement SHCP to be observed	Is not delegated to implement the SHCP to be observed	Delegation is defined as the school nurse transferring responsibility of performing the SHCP to an unlicensed medical professional while retaining accountability for the outcome (NASN, 2014).

*Note.* SHCP = specialized health care procedures, RN = registered nurse, IHCP = individualized health care plan, ID = intellectual disabilities, ISBE = Illinois State Board of Education, IEP = individualized education program.

**Table 10**

*Recruitment Timeline*

Procedure	Date
First recruitment email	March 7, 2016
Second recruitment email	March 14, 2016
Screenings	March 7-21, 2016
Nominations	March 7-21, 2016
Informed Consent	March 14-28, 2016

**Table 11***Data Collection Timeline*

Case Number	Activity	Date
1	Questionnaires, observations, post-observation interviews	March 21-25, 2016
	Interviews, member checking	March 28-April 1, 2016
2	Questionnaires, observations, post-observation interviews	March 28-April 1, 2016
	Interviews, member checking	April 4-8, 2016
3	Questionnaires, observations, post-observation interviews	April 4-8, 2016
	Interviews, member checking	April 11-15, 2016
4A	Questionnaires, observations, post-observation interviews	April 11-15, 2016
	Interviews, member checking	April 18-22, 2016
5A, 5B	Questionnaires, observations, post-observation interviews	April 25-29, 2016
	Interviews, member checking	May 2-6, 2016
6	Questionnaires, observations, post-observation interviews	May 2-6, 2016
	Interviews, member checking	May 9-13, 2016
7	Questionnaires, observations, post-observation interviews	May 9-13, 2016
	Interviews, member checking	May 16-20, 2016

**Table 11 Continued**

Data Collection Timeline

Case Number	Activity	Date
4B	Questionnaires, observations, post- observation interviews	May 16-20, 2016
	Interviews, member checking	May 23-24, 2016

**Table 12**

*Research Question 1: Student Involvement Matrix, Theme 1*

Theme	Case	Initial Codes	Focused Codes	O	D	I	T	N	CN	PP	P
<b>Taking Part in One’s Own Health Care</b>  <b>Categories:</b> Involvement, Pathways to Involvement	1	Instruction (44)	Instruction	40	0	4	4	0	-	0	0
		Partial Participation (25)	Partial Participation	11	0	14	3	2	-	4	5
		Communication (24)	Communication	18	1	5	1	2	-	2	0
		Correct Response (16)	Correct Response	16	0	0	0	0	-	0	0
		Goals (10)	Goals	0	5	5	4	0	-	1	0
		Understanding (8)	Consistency/Routine	0	0	4	4	0	-	0	0
	Adaptation (7)										
	Independent (2)										
	Behavioral Supports (6)										
	Consistency/Routine (4)										
	Honor Communication (1)										
	Environmental Arrangement (1)										
	2	Communication (19)	Communication	17	0	2	0	1	-	1	0
		Partial Participation (5)	Partial Participation	5	0	0	0	0	-	0	0
		Cooperates (5)	Attends	4	0	0	0	0	-	0	0
		Attends (4)	Honor Communication	0	0	6	5	1	-	0	0
		Attempts (1)	Narration	0	0	3	2	0	-	0	1
	Correct Response (1)										
Understanding (1)											
Honor Communication (6)											
Behavioral Supports (5)											
Narration (3)											
Instruction (2)											
Consistency/Routine (1)											
3	Communication (13)	Communication	11	0	2	0	1	-	-	1	
	Understanding (11)	Partial Participation	9	0	1	0	1	-	-	0	
	Partial Participation (10)	Correct Response	7	0	0	0	0	-	-	0	
	Correct Response (7)	Instruction	6	0	0	0	0	-	-	0	
	Instruction (6)	Attends	3	0	0	0	0	-	-	0	
	Independent (4)	Choice	3	0	0	0	0	-	-	0	
Attends (3)											
Choice (3)											
Behavioral Supports (2)											
Cooperates (1)											
Consistency/Routine (1)											
Narration (1)											

**Table 12 Continued**

*Research Question 1: How Students are Involved, Cross Case Synthesis (Categories: Involvement, Pathways to Involvement)*

<b>Theme</b>	<b>Case</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>O</b>	<b>D</b>	<b>I</b>	<b>T</b>	<b>N</b>	<b>CN</b>	<b>PP</b>	<b>P</b>
<b>Taking Part in One’s Own Health Care</b>  <b>Categories:</b> Involvement, Pathways to Involvement	4A	Independent (32)	Independent	28	0	4	0	0	-	3	1
		Partial Participation (16)	Partial Participation	12	1	3	0	3	-	0	0
		Communication (13)	Communication	9	0	4	2	1	-	1	0
		Adaptation/Accommodation (10)	Adaptation/ Accommodation	10	0	0	0	0	-	0	0
		Monitoring (10)	Monitoring	10	0	0	0	0	-	0	0
		Instruction (9)	Instruction	9	0	0	0	0	-	0	0
		Correct Response (8)	Manages Supplies	5	0	0	1	1	-	1	0
		Managing Supplies (8)	Environmental Arrangement	2	0	2	0	0	-	0	0
		Understanding (5)	Cooperates (3)								
	Attempts (4)	Rehearsal (3)									
	Environmental Arrangement (4)	Behavior Supports (2)									
	Cooperates (3)	Consistency/Routine (2)									
	Rehearsal (3)	Goals (2)									
	Behavior Supports (2)	Narration (1)									
	Consistency/Routine (2)										
	Goals (2)										
	Narration (1)										
	4B	Instruction (31)	Instruction	31	0	0	0	0	0	-	-
Independent (16)		Independent	13	0	3	1	2	-	-	0	
Communication (13)		Communication	7	0	6	1	3	-	-	2	
Partial Participation (8)		Partial Participation	7	0	1	0	1	-	-	0	
Monitoring (8)		Monitoring	8	0	0	0	0	-	-	0	
Attempts (7)		Attempts	6	0	1	0	0	-	-	1	
Understanding (5)		Consistency/Routine	0	0	3	1	2	-	-	0	
Cooperates (4)		Goals	0	0	2	0	1	-	-	1	
Correct Response (3)		Task Selection	0	0	1	0	1	-	-	0	
Consistency/Routine (3)	Fading (1)										
Behavioral Supports (2)											
Environmental Arrangement (2)											
Goals (2)											
Rehearsal (2)											
Task Selection (1)											
Fading (1)											

**Table 12 Continued**

*Research Question 1: How Students are Involved, Cross Case Synthesis (Categories: Involvement, Pathways to Involvement)*

Theme	Case	Initial Codes	Focused Codes	O	D	I	T	N	CN	PP	P
<b>Taking Part in One’s Own Health Care</b>  <b>Categories:</b> Involvement, Pathways to Involvement	5A	Communication (33) Understanding (7) Cooperates (4) Attends (3) Partial Participation (2) Honor Communication (2, 1) Narration (2, 1)	Communication	29	0	4	1	1	0	-	2
			Attends	3	0	0	0	0	0	-	0
			Partial Participation	2	0	0	0	0	0	-	0
			Honor Communication	0	0	2	0	2	0	-	0
	5B	Communication (10) Environmental Arrangement (8) Behavioral Supports (7) Honor Communication (2) Instruction (1) Narration (1)	Communication	7	0	3	1	1	0	0	1
			Environmental Arrangement	6	0	2	1	0	0	-	1
			Behavioral Supports	0	0	7	1	3	2	-	1
	6	Cooperates (9) Communication (7) Attends (5) Understanding (5) Narration (4) Attempts (3) Consistency/Routine (3)	Communication	3	0	4	0	0	0	-	0
			Attends	4	0	1	0	0	0	-	0
			Attempts	3	0	0	0	0	0	-	0
			Consistency/Routine	0	0	3	1	2	0	-	0
	7	Communication (44) Understanding (27) Partial Participation (16) Cooperates (11) Independent (10) Instruction (10) Consistency/Routine (10) Rehearsal (9) Manages Supplies (7) Correct Response (5) Choice (5) Task Selection (4) Makes Choice (3) Behavioral Supports (3) Narration (2)	Communication	40	0	4	3	0	-	-	1
			Partial Participation	12	1	3	2	0	-	-	1
			Independent	7	0	3	2	0	-	-	1
			Instruction	6	0	4	4	0	-	-	0
			Consistency/Routine	0	0	10	4	6	-	-	0
			Manages Supplies	3	0	4	0	0	-	-	4
			Choice	2	0	3	0	3	-	-	0
			Task Selection	0	0	3	0	1	-	-	3

*Note.* O = observation, D = documents, I = interviews, T = teachers, N = nurses, CN = classroom nurses, PP = paraprofessionals, P = parents. Numbers were not analyzed quantitatively.

**Table 13***Research Question 1: Student Involvement Matrix, Theme 2*

<b>Theme</b>	<b>Case*</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>O</b>	<b>D</b>	<b>I</b>	<b>T</b>	<b>N</b>	<b>CN</b>	<b>PP</b>	<b>P</b>
<b>Category: Involvement</b>	1	Social (28)	Social	28	0	0	0	0	-	0	0
	2	Social (13)	Social	13	0	0	0	0	-	0	0
	3	Social (16)	Social	14	0	2	1	1	-	-	0
	4A	Social (14)	Social	14	0	0	0	0	-	0	0
	4B	Social (10)	Social	10	0	0	0	0	-	-	0
	5A	Social (20)	Social	19	0	1	1	0	0	-	0
	5B	Social (26) Rapport (3)	Social	25	0	1	1	0	0	-	0
			Rapport	0	0	3	0	3	0	-	0
	6	Social (11)	Social	10	0	1	0	0	0	-	0
7	Social (17)	Social	14	0	3	0	3	-	-	0	

*Note.* Numbers were not analyzed quantitatively. O = observation, D = documents, I = interviews, T = teachers, N = nurses, CN = classroom nurses, PP = paraprofessionals, P = parents.

**Table 14***Research Question 1: Student Involvement Matrix, Theme 3*

<b>Theme</b>	<b>Case*</b>	<b>Initial</b>	<b>Focused</b>	<b>O</b>	<b>D</b>	<b>I</b>	<b>T</b>	<b>N</b>	<b>CN</b>	<b>PP</b>	<b>P</b>
Posing a Potential Health Risk to Oneself  <b>Category: Non-Involvement</b>	4A	Health Risk Behaviors (6)	Health Risk Behaviors	1	0	5	1	0	-	3	1
	7	Health Risk Behaviors (7)	Health Risk Behaviors	3	0	4	0	3	-	-	1
	5B	Health Risk Behaviors (16)	Health Risk Behaviors	11	0	5	1	1	1	-	2

*Note.* Numbers were not analyzed quantitatively. O = observation, D = documents, I = interviews, T = teachers, N = nurses, CN = classroom nurses, PP = paraprofessionals, P = parents.

**Table 15**

*Research Question 1: Student Involvement Matrix, Theme 4*

Theme	Case	Initial	Focused	O	D	I	T	N	CN	PP	P	
<b>Care Received Without Opportunities to Participate</b>  <b>Categories: Non-Involvement, Pathways to Non-Involvement</b>	1	No Opportunity (21)	No Opportunity	20	0	1	0	0	-	1	0	
		Inconsistent (14)	Inconsistent	4	0	10	6	0	-	4	0	
		Off Task (13)	Off-Task	12	0	1	0	1	-	0	0	
		Staff Talking (11)	Staff Talking	11	0	0	0	0	-	0	0	
		Does For (4)	Don't Know	0	0	4	0	0	-	3	1	
		Don't Know (4)	No Response	2	0	0	0	0	-	0	0	
		No Forethought (3)										
	Restraint (2)											
	No Response (2)											
	Guessing (1)											
	Schedule Delay/Change (1)											
	Doesn't Communicate (1)											
		2	Guessing (13)	Guessing	0	0	13	0	1	-	9	3
	Negative Talk (8)		Negative Talk	7	0	1	0	0	-	1	0	
	Caretaking (6)		Caretaking	0	0	6	1	1	-	2	2	
	No Opportunity (4)		No Opportunity	4	0	0	0	0	-	0	0	
	Sleeping (3)		Sleeping	2	0	1	0	1	-	0	0	
	No Response (3)		No Response	0	0	3	1	0	-	1	1	
	Doesn't Communicate (3)											
	Unclear Response (1)											
	Don't Know (1)											
		3	No Opportunity (8)	No Opportunity	7	0	1	1	0	-	-	0
	Guessing (7)		Guessing	0	0	7	0	4	-	-	3	
	Sleeping (7)		Sleeping	5	0	2	0	2	-	-	0	
	Don't Know (4)		Don't Know	0	0	4	1	2	-	-	1	
	Status Quo (4)		Status Quo	0	0	4	1	3	-	-	0	
	Chooses Not To (3)		Chooses Not To	2	0	1	0	1	-	-	0	
No Response (3)	No Response		3	0	0	0	0	-	-	0		
Doesn't Communicate (2)												
No Forethought (3)												
Does For (1)												
Relaxation Time (1)												
	4A	Guessing (7)	Guessing	0	0	7	2	2	-	3	0	
No Forethought (5)		No Forethought	0	0	5	5	0	-	0	0		
Don't Know (4)		Don't Know	0	0	4	0	3	-	0	1		
No Response (1)												

**Table 15 Continued**

*Research Question 1: How Students are Involved, Cross-Case Synthesis (Categories: Non-Involvement, Pathways to Non-Involvement)*

Theme	Case	Initial	Focused	O	D	I	T	N	CN	PP	P
Care Received Without Opportunities to Participate	4B	Doesn't Communicate (5) Don't Know (3) Guessing (2)	Doesn't Communicate	4	0	1	0	1	-	-	0
			Don't Know	0	0	3	2	0	-	-	1
			Guessing	0	0	2	2	0	-	-	0
	5A	No Opportunity (38) Unclear Response (13) Guessing (10) Care Taking (8) Don't Know (6) Sleeping (6) No Forethought (5) Distracted (5) Staff Talking (5) Negative Talk (3) Relaxation Time (3) No Response (3) Off Task (2) Doesn't Communicate (1)	No Opportunity	37	0	1	1	0	0	-	0
			Unclear Response	13	0	0	0	0	0	-	0
			Guessing	0	0	10	3	4	3	-	0
			Caretaking	8	0	0	0	0	0	-	0
			Don't Know	0	0	6	0	3	1	-	2
			Sleeping	6	0	0	0	0	0	-	0
			Staff Talking	5	0	0	0	0	0	-	0
			No Forethought	0	0	5	3	0	2	-	0
			Distracted	5	0	0	0	0	0	-	0
			No Response	3	0	0	0	0	0	-	0
			5B	No Opportunity (14) Guessing (12) Staff Talking (9) Don't Know (7) No Forethought (7) Negative Talk (5) Sleeping (5) Caretaking (4) Off-Task (2) Distracted (1) Relaxation Time (1) Doesn't Communicate (1)	No Opportunity	13	0	1	1	0	0
	Guessing	0			0	12	4	3	3	-	2
	Staff Talking	9			0	0	0	0	0	-	0
	Don't Know	0			0	7	0	3	3	-	1
	No Forethought	0			0	7	3	0	2	-	2
	Sleeping	5			0	0	0	0	0	-	0
	Caretaking	3			0	1	0	0	1	-	0
	Relaxation Time	1			0	0	0	0	0	-	0

**Table 15 Continued**

*Research Question 1: How Students are Involved, Cross-Case Synthesis (Categories: Non-Involvement, Pathways to Non-Involvement)*

Theme	Case	Initial	Focused	O	D	I	T	N	CN	PP	P
Care Received Without Opportunities to Participate	6	Guessing (20)	Guessing	0	0	20	5	4	3	-	8
		No Opportunity (12)	No Opportunity	12	0	0	0	0	0	-	0
		Sleeping (10)	Sleeping	10	0	0	0	0	0	-	0
		Don't Know (8)	Don't Know	0	0	8	1	2	2	-	3
		Relaxation time (8)	Relaxation Time	1	0	7	7	0	0	-	0
		Doesn't Communicate (5)	Doesn't Communicate	0	0	5	1	1	1	-	2
		No Forethought (4)	Caretaking	0	0	3	0	2	1	-	0
		Caretaking (3)	Caretaking	0	0	3	0	2	1	-	0
		Staff Talking (3)	Staff Talking	3	0	0	0	0	0	-	0
	Negative Talk (2)	Staff Talking	3	0	0	0	0	0	-	0	
	Restraint (1)	Staff Talking	3	0	0	0	0	0	-	0	
	No Response (1)	Staff Talking	3	0	0	0	0	0	-	0	
	7	Don't Know (11)	Don't Know	0	0	11	9	2	-	-	0
		Guessing (10)	Guessing	0	0	10	7	3	-	-	0
Off-Task (7)		Off-Task	7	0	0	0	0	-	-	0	
Status Quo (5)		Status Quo	0	0	5	5	0	-	-	0	
No Forethought (3)		No Forethought	0	0	3	3	0	-	-	0	

*Note.* Numbers were not analyzed quantitatively. O = observation, D = documents, I = interviews, T = teachers, N = nurses, CN = classroom nurses, PP = paraprofessionals, P = parents.

**Table 16**

*Research Question 2: Beliefs About Involvement Matrix, Theme 2*

Theme	Case*	Initial Codes	Focused Codes	I	T	N	CN	PP	P
<b>Category: Constraints</b>  So Many Obstacles	1	Unable (12) Behavior (10) Legal Compliance (6) Teaming Issues (2) Time/Scheduling (1)	Unable	12	3	1	-	3	5
			Behavior	10	4	1	-	5	0
			Legal Compliance	6	1	0	-	5	0
			Teaming Issues	2	2	0	-	0	0
	2	Unable (28) Teaming Issues (7) Unsure (6) Discontinued Therapy (6) Behavior (4) Degenerative (4) Time/Scheduling (2) Legal Compliance (1) Unsafe (1)	Unable	28	7	7	-	7	7
			Teaming Issues	7	0	1	-	3	3
			Unsure	6	1	1	-	2	2
			Discontinued Therapy	6	1	0	-	2	3
			Degenerative	4	2	2	-	0	0
			Unsafe	1	0	0	-	0	0
	3	Time/Scheduling (9) Unable (7) Behavior (6) Disinterest (2) Teaming Issues (1)	Time/Scheduling	9	0	9	-	-	0
			Unable	7	1	0	-	-	6
			Behavior	6	2	4	-	-	0
	4B	Won't Generalize (8) Learned Helplessness (6) Teaming Issues (3) Unable (1) Behavior (1) Fluctuates (1)	Learned Helplessness	6	5	0	-	-	1
			Teaming Issues	3	0	0	-	-	3
			Won't Generalize	8	0	2	-	-	6
			Fluctuates	1	0	1	-	-	0
	5A	Unable (14, 3) Teaming Issues (6, 3) Behavior (3) Unsure (3) Fluctuates (3) Time/Scheduling (2, 2) Won't Generalize (2)	Unable	14	5	7	0	-	2
			Teaming Issues	6	0	0	4	-	2
			Unsure	3	3	0	0	-	0
Fluctuates			3	1	0	2	-	0	
Won't Generalize			2	0	0	0	-	2	

**Table 16 Continued**

*Research Question 2: Beliefs About Involvement, Cross-Case Synthesis (Category: Constraints)*

<b>Theme</b>	<b>Case*</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>I</b>	<b>T</b>	<b>N</b>	<b>CN</b>	<b>PP</b>	<b>P</b>
So Many Obstacles	5B	Behavior (20)	Behavior	20	3	3	5	-	9
		Unable (14, 3)	Unable	14	5	5	4	-	0
		Disinterest (7)	Disinterest	7	0	0	7	-	0
		Unsure (6)	Unsure	6	5	1	0	-	0
	6	Teaming Issues (4, 3)	Unable	18	4	9	3	-	2
		Fluctuates (3)	Unsure	5	1	1	0	-	3
	7	Time/Scheduling (2, 2)	Unable	15	7	6	-	-	2
		Unable (15)	Behavior	8	2	4	-	-	2
		Behavior (8)	Time/Scheduling	7	7	0	-	-	0
		Time/Scheduling (7)	Unsure	3	2	1	-	-	0
		Teaming Issues (2)							
		Unsure (3)							
	Disinterest (1)								

*Note.* Numbers were not analyzed quantitatively. I = interviews, T = teachers, N = nurses, CN = classroom nurses, PP = paraprofessionals, P = parents.

**Table 17**

*Research Question 2: Beliefs About Involvement, Cross-Case Synthesis (Categories: Constraints, Requisites)*

Theme	Case	Initial Codes	Focused Codes	I	T	N	CN	PP	P
Must Be Safe and Appropriate	1	Unsafe (12) Safety (3) Prerequisite Skills (2) Additional Staff (1) Realistic Goals (1) Safeguard (1)	Unsafe	12	4	2	-	3	3
			Safety	3	1	2	-	0	0
			Prerequisite Skills	2	1	0	-	0	1
			Realistic Goals	1	0	0	-	0	1
			Safeguard	1	0	0	-	0	1
	2	Prerequisite Skills (4) Realistic Goals (4) Safeguard (4)	Prerequisite Skills	4	0	4	-	0	0
			Realistic Goals	4	1	1	-	0	2
			Safeguard	4	0	4	-	0	0
	3	Prerequisite Skills (2) Safeguard (1)	Prerequisite Skills	2	1	0	-	0	1
			Safeguard	1	0	1	-	-	0
	4A	Unsafe (11) Supervision (4) Prerequisite Skills (3) Safety (3)	Unsafe	11	6	0	-	5	0
			Supervision	4	1	2	-	1	0
			Prerequisite Skills	3	2	0	-	1	0
			Safety	3	1	1	-	1	0
	4B	Prerequisite Skills (1) Supervision (1)	Prerequisite Skills	1	0	1	-	-	0
			Supervision	1	1	0	-	-	0
	5A	Prerequisite Skills (6, 3) Realistic Goals (5, 2) Safeguard (2) Additional Staff (2, 2)	Prerequisite Skills	6	3	0	3	-	0
			Realistic Goals	5	0	3	2	-	0
			Safeguard	2	2	0	0	-	0
	5B	Prerequisite Skills (13, 3) Realistic Goals (4, 2) Unsafe (3) Safeguard (3) Additional Staff (2, 2) Safety (1) Supervision (1)	Prerequisite Skills	13	5	2	2	-	4
			Realistic Goals	4	0	4	0	-	0
Unsafe			3	0	0	2	-	0	
Safeguard			3	1	2	0	-	0	
Additional Staff			2	0	1	1	-	0	
Safety			1	0	0	1	-	0	

**Table 17 Continued**

*Research Question 2: Beliefs About Involvement, Cross-Case Synthesis (Categories: Constraints, Requisites)*

<b>Theme</b>	<b>Case</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>I</b>	<b>T</b>	<b>N</b>	<b>CN</b>	<b>PP</b>	<b>P</b>
Must Be Safe and Appropriate	6	Realistic Goals (6) Prerequisite Skills (2) Safety (1) Additional Staff (1) Unsafe (1) Safeguard (1)	Realistic Goals	6	1	3	1	-	1
			Prerequisite Skills	2	0	1	1	-	0
			Safety	1	0	0	1	-	0
			Unsafe	1	0	0	0	-	1
			Safeguard	1	1	0	0	-	0
	7	Unsafe (8) Safeguard (8) Health Promotion (6) Realistic Goals (4) Safety (3) Supervision (4) Prerequisite Skills (2)	Unsafe	8	5	2	-	-	1
			Safeguard	8	8	0	-	-	0
			Health Promotion	6	0	4	-	-	2
			Realistic Goals	4	1	2	-	-	1
			Safety	3	1	2	-	-	0
			Supervision	4	4	0	-	-	0
			Prerequisite Skills	2	1	0	-	-	1

*Note.* Numbers were not analyzed quantitatively. I = interviews, T = teachers, N = nurses, CN = classroom nurses, PP = paraprofessionals, P = parents.

**Table 18**

*Research Question 2: Beliefs About Involvement Matrix, Theme 3*

<b>Theme</b>	<b>Case</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>I</b>	<b>T</b>	<b>N</b>	<b>CN</b>	<b>PP</b>	<b>P</b>
<b>Working Together is Essential</b>  <b>Category: Requisites</b>	1	Team Priority (2) Care Coordination (1) Related Services (1)	Team Priority	2	2	0	-	0	0
			Care Coordination	1	0	0	-	0	1
			Related Services	1	1	0	-	0	0
	2	Knowledge/Training (4) Related Services (2) Care Coordination (1) Nursing Perspective (1)	Knowledge/Training	4	1	1	-	1	1
			Related Services	2	0	0	-	1	1
	3	Team Priority (4) Care Coordination (3) Knowledge/Training (2) Related Services (1) Start Early (1)	Team Priority	4	4	0	-	-	0
			Knowledge/Training	2	2	0	-	-	0
			Start Early	1	0	1	-	-	0
	4A	Care Coordination (6, 1) Nursing Perspective (6, 2) Assessment (1, 1)	Care Coordination	6	0	6	-	0	0
			Nursing Perspective	6	4	2	-	0	0
	4B	Start Early (4) Care Coordination (4, 1) Nursing Perspective (3, 2) Team Priority (2) Assessment (2, 1)	Care Coordination	4	1	3	-	-	0
			Start Early	4	2	0	-	-	2
			Nursing Perspective	3	1	2	-	-	0
			Assessment	2	0	2	-	-	0
			Team Priority	2	0	2	-	-	0
	5A	Care Coordination (4) Related Services (2, 1) Start Early (1) Team Priority (1, 1)	Care Coordination	4	0	0	0	-	4
			Start Early	1	0	0	1	-	0
	5B	Related Services (2, 1) Care Coordination (1) Team Priority (1, 1)	Related Services	2	1	0	1	-	0
6	Assessment (2) Knowledge/Training (2) Related Services (1)	Assessment	2	0	0	2	-	0	
		Related Services	1	0	0	1	-	0	

**Table 18 Continued**

*Research Question 2: Beliefs About Involvement, Cross-Case Synthesis (Category: Requisites)*

<b>Theme</b>	<b>Case</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>I</b>	<b>T</b>	<b>N</b>	<b>CN</b>	<b>PP</b>	<b>P</b>
Working Together is Essential	7	Nursing Perspective (4) Care Coordination (3) Team Priority (2)	Nursing Perspective	4	0	4	-	-	0
			Care Coordination	2	2	0	-	-	0
			Team Priority	2	2	0	-	-	0

*Note.* Numbers were not analyzed quantitatively. I = interviews, T = teachers, N = nurses, CN = classroom nurses, PP = paraprofessionals, P = parents.

**Table 19**

*Research Question 2: Beliefs About Involvement Matrix, Theme 4*

Theme	Case	Initial Codes	Focused Codes	I	T	N	CN	PP	P
<b>Enhances Well-Being and Adult Outcomes</b>  <b>Categories: Outcomes, Philosophical, Well-Being</b>	1	Health Advocacy (5) Self-Determination (4) Self-Esteem (3) Autonomy (3) Independence (2) Assists Caregiver (1) Opportunity (1)	Health Advocacy	5	0	0	-	2	3
			Self-Determination	4	3	1	-	0	0
			Self-Esteem	3	2	1	-	0	0
			Autonomy	3	0	0	-	2	1
			Independence	2	0	0	-	0	2
			Opportunity	1	0	1	-	0	0
	2	Decrease Anxiety (3) Assists Caregiver (3) Quality of Life (2) Self-Determination (2) Independence (1) Self-Esteem (1)	Decreases Anxiety	3	0	3	-	0	0
			Quality of Life	2	2	0	-	0	0
			Self-Determination	2	0	2	-	0	0
			Self-Esteem	1	0	1	-	0	0
	3	Self-Esteem (5) Autonomy (5) Health Advocacy (3) Independence (3) Control (2) Self-Determination (1) Normalcy (1)	Self-Esteem	5	0	5	-	-	0
			Autonomy	5	2	1	-	-	2
			Health Advocacy	3	2	1	-	-	0
			Independence	3	2	1	-	-	0
			Control	2	2	0	-	-	0
			Self-Determination	1	0	1	-	-	0
			Normalcy	1	0	1	-	-	0
	4A	Self-Esteem (8, 1) Control (4) Independence (4, 1) Program Options (3) Assists Caregiver (3) Self-Determination (2) Health Advocacy (2) Decrease Anxiety (1) Autonomy (1) Normalcy (1)	Self-Esteem	8	2	1	-	2	4
			Control	4	3	1	-	0	0
			Independence	4	2	2	-	0	0
			Program Options	3	3	0	-	0	0
			Self-Determination	2	1	0	-	1	0
			Health Advocacy	2	0	2	-	0	0
			Autonomy	1	0	0	-	1	0
			Normalcy	1	1	0	-	0	0

**Table 19 Continued**

*Research Question 2: Beliefs About Involvement, Cross-Case Synthesis (Categories: Outcomes, Philosophical, Well-Being)*

<b>Theme</b>	<b>Case</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>I</b>	<b>T</b>	<b>N</b>	<b>CN</b>	<b>PP</b>	<b>P</b>
Enhances Well-Being and Adult Outcomes	4B	Self-Esteem (6, 1) Health Advocacy (5) Autonomy (5) Independence (4, 1) Normalcy (3) Quality of Life (3) Self-Determination (3) Program Options (2) Assists Caregiver (2) Opportunity (1)	Self-Esteem	6	2	2	-	-	2
			Health Advocacy	5	3	1	-	-	1
			Autonomy	5	3	1	-	-	1
			Independence	4	0	1	-	-	3
			Normalcy	3	0	0	-	-	3
			Quality of Life	3	1	1	-	-	1
			Self-Determination	3	2	1	-	-	0
			Program Options	2	2	0	-	-	0
			5A	Control (9, 5) Self-Determination (5, 2) Autonomy (3, 2) Quality of Life (3, 2) Health Advocacy (3, 1) Decrease Anxiety (1) Independence (1, 1) Assists Caregiver (1)	Control	9	2	0	4
	Self-Determination	5			3	0	0	-	2
	Autonomy	3			1	0	2	-	0
	Quality of Life	3			0	1	2	-	0
	Health Advocacy	3			1	0	0	-	2
	Decrease Anxiety	1			0	0	0	-	1
	5B	Control (5, 5) Autonomy (4, 2) Assists Caregiver (3) Quality of Life (3, 2) Self-Determination (3, 2) Independence (3, 1) Decrease Anxiety (1) Health Advocacy (1, 1)			Control	5	2	0	3
			Autonomy	4	2	0	1	-	1
			Quality of Life	3	0	2	1	-	0
			Self-Determination	3	3	0	0	-	0
			Independence	3	1	1	1	-	0
			Decrease Anxiety	1	1	0	0	-	0
			Health Advocacy	1	1	0	0	-	0
			6	Assists Caregiver (5) Health Advocacy (1) Independence (1) Self-Esteem (1)	Assists Caregiver	5	3	1	0
	Health Advocacy	1			0	1	0	-	0
	Self-Esteem	1			0	0	1	-	0

**Table 19 Continued**

*Research Question 2: Beliefs About Involvement, Cross-Case Synthesis (Categories: Outcomes, Philosophical, Well-Being)*

<b>Theme</b>	<b>Case</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>I</b>	<b>T</b>	<b>N</b>	<b>CN</b>	<b>PP</b>	<b>P</b>
Enhances Well-Being and Adult Outcomes	7	Independence (5)	Independence	5	5	0	-	-	0
		Self-Esteem (3)	Self-Esteem	3	0	1	-	-	2
		Health Advocacy (3)	Health Advocacy	3	2	1	-	-	0
		Normalcy (3)	Normalcy	3	0	0	-	-	3
		Decrease Anxiety (2)	Self-Determination	2	1	1	-	-	0
		Self-Determination (2)	Decrease Anxiety	2	0	1	-	-	1
		Autonomy (2)	Quality of Life	2	1	0	-	-	1
		Quality of Life (2)	Control	1	0	1	-	-	0
		Control (1)	Assists Caregiver (1)						

*Note.* Numbers were not analyzed. I = interviews, T = teachers, N = nurses, CN = classroom nurses, PP = paraprofessionals, P = parents.

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## Appendix A: Recruitment Emails

### Initial Special Education Teacher Recruitment Email

*Subject Heading:* Invitation to Participate in a Research Study

Dear Special Educator,

My name is Sarah Ballard and I am a doctoral candidate at the University of Illinois at Urbana-Champaign. I am currently conducting a research project with Dr. Stacy Dymond in the Department of Special Education.

You are invited to participate in a study designed to understand how students are involved in their health care procedures at school, and the beliefs of school personnel and parents about their involvement. This study will focus on middle school, high school, and post-secondary students with severe/multiple disabilities.

Your participation in this study is extremely important to helping us understand issues around students' involvement, or non-involvement, in their health care procedures at school. Participation in this study is voluntary and involves completing a 5-minute demographic questionnaire and a 60-minute in-person interview. If you assist with a student's health care procedures, participation will also involve 2-3 observations of you during the health care procedures and a brief 5-minute interview following each observation. Participants who complete the study will receive a \$40 Visa gift card.

If you are interested in participating or would like to learn more about this study, please contact me (Sarah Ballard) by email at [sballa2@illinois.edu](mailto:sballa2@illinois.edu) or call me at (707) 290-8312.

We appreciate your time. Thank you in advance for your assistance.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

Stacy Dymond  
Professor  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **Reminder Special Education Teacher Recruitment Email**

*Subject Heading:* Reminder Invitation to Participate in a Research Study

Dear Special Educator [or School Nurse],

This is a reminder email. If you have already responded, please disregard this email.

My name is Sarah Ballard and I am a doctoral candidate at the University of Illinois at Urbana-Champaign. I am currently conducting a research project with Dr. Stacy Dymond in the Department of Special Education.

You are invited to participate in a study designed to understand how students are involved in their health care procedures at school, and the beliefs of school personnel and parents about their involvement. This study will focus on middle school, high school, and post-secondary students with severe/multiple disabilities.

Your participation in this study is extremely important to helping us understand issues around students' involvement, or non-involvement, in their health care procedures at school. Participation in this study is voluntary and involves completing a 5-minute demographic questionnaire and a 60-minute in-person interview. If you assist with a student's health care procedures, participation will also involve 2-3 observations of you during the health care procedures and a brief 5-minute interview following each observation. Participants who complete the study will receive a \$40 Visa gift card.

If you are interested in participating or would like to learn more about this study, please contact me (Sarah Ballard) by email at [sballa2@illinois.edu](mailto:sballa2@illinois.edu) or call me at (707) 290-8312.

We appreciate your time. Thank you in advance for your assistance.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

Stacy Dymond  
Professor  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **School Nurse Recruitment Email**

*Subject Heading:* Invitation to Participate in a Research Study

Dear School Nurse,

Your contact information was shared with me by [Name of Special Education Teacher] for potential participation in a research study.

My name is Sarah Ballard and I am a doctoral candidate at the University of Illinois at Urbana-Champaign. I am currently conducting a research project with Dr. Stacy Dymond in the Department of Special Education.

The purpose of this research project is to understand how students are involved in their health care procedures at school, and the beliefs of school personnel and parents about their involvement. This study will focus on middle school, high school, and post-secondary students with severe/multiple disabilities. [Name of Special Education Teacher] shared your contact information with me because you were identified as the School Nurse. Participation in this research project is voluntary. Participants who complete the study will receive a \$40 Visa gift card.

Please reply to me (Sarah Ballard) at [sballa2@illinois.edu](mailto:sballa2@illinois.edu) or call me at (707) 290-8312 to let me know if you are potentially interested in participating in this study. I would like to schedule a brief telephone call (5-10 minutes) at your earliest convenience to discuss the details of this study and any questions you may have.

We appreciate your time. Thank you in advance for your assistance.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

Stacy Dymond  
Professor  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **Appendix B: Telephone Screenings**

### **Special Education Teacher Telephone Screening Protocol**

#### **Script**

Good morning/afternoon,

This is Sarah Ballard from the Department of Special Education at the University of Illinois. Is this still a good time for us to talk?

Per our email correspondence, I am calling you to see if you meet criteria to participate in a study I am conducting. The purpose of this study is to understand how students are involved in their health care procedures at school, and the beliefs of school personnel and parents about their involvement.

This screening will take approximately 5-10 minutes. Your participation in this screening is voluntary. You may refuse to answer any question, or choose to stop the screening interview at any time. Your responses will be kept confidential.

Do you have any questions? Then with your permission, we will begin.

1. What is your current position?
2. What are the grade levels of the students you teach?

Students with severe/multiple disabilities have moderate to severe intellectual disabilities and also have one or more co-occurring physical, health, sensory, communication, or behavioral disabilities.

3. Do you currently work with students who have severe/multiple disabilities?
4. How many students currently on your caseload have severe/multiple disabilities?

Health care procedures are a related service provided by the school to meet health care needs necessary for individual students to attend school. For example, tube feedings, ostomy care, and tracheotomy suctioning.

5. How many of your students with severe/multiple disabilities have at least one scheduled, or regularly occurring, health care procedure every school day?

I want you to think about this student/these students who have severe/multiple disabilities and at least one scheduled or regularly occurring health care procedure every school day as you answer

these next few questions. As you answer the questions, please do not use the name of any student. Simply refer to your student as Student 1 or Student 2.

6. What age is Student (1, 2, 3)?
7. What grade level is Student (1, 2, 3)?
8. What is the eligibility category that qualifies Student (1, 2, 3) for special education services?
9. How would you describe the intellectual disabilities of Student (1, 2, 3)?
10. Middle school and high school students only: What state assessments does student (1, 2, 3) take?
11. Does Student (1, 2, 3) have a legal guardian who resides in state?
12. Do you have any concerns regarding potential participation in this research project for Student (1, 2, 3)?

*If the special educator does not meet eligibility criteria for participation:*

Thank you for your helpful responses. At this time, you do not meet eligibility criteria for participation. Do you have any questions for me before we say good-bye? Thank you again for your time.

*If the special educator meets eligibility criteria for participation:*

Thank you for your helpful responses. It appears that you meet criteria for participation in this study based on the information you provided for [Enter Pseudonym]. Since this study requires the participation of the school nurse and parents, in order to proceed I must obtain agreement from all individuals. Since the school nurse oversees students' health care procedures, I would first like to speak with him/her to explain the details of the research project and see if he/she is interested in participating. In order to discuss this study with the school nurse, it would be helpful if you could talk with him/her in advance and share information about the students that are eligible to participate. Are you comfortable having this conversation with the school nurse?

*If no, stop recruitment. Thank the individual for their time. If yes:*

After I have confirmed interest in participation from the school nurse, I will contact the school administration to obtain approval for this study. I will ask for your help in communicating your interest in participating in the study to your school principal. If your school administration approves this study, I will then ask you for your help in distributing consent forms to students' parents. I will also provide you with a consent form. How does this sound to you?

*If no, stop recruitment. Thank the individual for their time. If yes:*

Do you have any questions for me? Thank you again for your time and your helpful responses to my questions. I look forward to speaking with you again soon.

## **Script for Telephone Conversation with Nominated School Nurse**

Good morning/afternoon,

This is Sarah Ballard from the Department of Special Education at the University of Illinois. Is this still a good time for us to talk?

I am calling you today about a research project I am conducting to understand how students are involved in their health care procedures at school, and the beliefs of school personnel and parents about their involvement. This study will focus on middle school, high school, and post-secondary students with severe/multiple disabilities.

I am contacting you because I am currently in the process of selecting study participants. As the school nurse, you are a valuable potential participant. Additional potential participants are the special education teacher, personnel who implement the student's health care procedures, and the student's parents. In order to select participants, I need to first determine potential interest in participation across all individuals.

Participation involves completing a 5-minute demographic questionnaire and a 60-minute in-person interview. If you assist with a student's health care procedures, participation will also involve 2-3 observations of you during the health care procedures and a brief 5-minute interview following each observation. Please note the purpose of observations is not to evaluate the health care procedure itself, but rather to see how the student is participating. During the observation, I will watch at a distance that allows me to see and hear what is happening, but I will not interact with anyone during the procedure.

No data will be collected without the written consent from adults. Additionally, prior to each observation I will ask the student if it is ok if I observe that day. Student answers will be confirmed with the help of the special education teacher or school nurse. If the student does not agree, I will not observe. All personal information will remain confidential. No real names for the site or participants will be used in the data, write up, or published findings. All participants who complete this study will receive a \$40 Visa gift card.

Do you have any questions for me right now?

*Answer questions. Proceed.*

Are you interested in participating in this study as the school nurse?

*If no, stop and say thank you. If yes:*

Thank you. As a next step, I will contact the school administration to obtain approval for this study. I will ask the special education teacher to inform the principal that both he/she and yourself are interested in participating in this study. Is this ok with you?

*If no, stop and say thank you. If yes:*

If your school administration approves this study, I will contact you again and provide you with a consent form. I will also ask you for your help in distributing consent forms to any personnel delegated to implement student's health care procedures. How does this sound to you?

*If no, stop and say thank you. If yes:*

Do you have any questions for me? Thank you again for your time and your helpful responses to my questions. I look forward to speaking with you again soon.

## **Appendix C: Notification of Ineligibility/Non-Selection to Participate**

*Subject Heading:* Research Study

Dear Special Educator [or School Nurse],

Thank you again for taking the time to speak with me on [Enter Date]. Unfortunately, at this time you were not selected to participate in the research study on student involvement in health care procedures for middle school, high school, and post-secondary students with severe/multiple disabilities. [Your student did not meet our criteria for participation. *Or:* Your administrator did not approve this study. *Or:* At this time, there is not a shared interest in participation. *Or:* We have already reached the maximum number of participants.]

Thank you again for your time and interest.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

Stacy Dymond  
Professor  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **Appendix D: Permission for In School Research**

### **Email to School Site Principal**

*Subject Heading:* Requesting Permission for On Site Research

Dear Principal,

My name is Sarah Ballard. I am a doctoral candidate in Special Education at the University of Illinois at Urbana-Champaign (UIUC). I am working under the guidance of Professor Stacy Dymond. I am writing to ask for your approval to conduct a research project at your school site. Your special educator [Name] and school nurse [Name] have expressed an interest in participation.

The research project is about how secondary students with severe disabilities are involved in their health care at school and school personnel's and parent's beliefs about their involvement. Potential participants will be one special education teacher, the school nurse, one student, and the student's parents. No identifying information on participants or the school will be reported. The UIUC Institutional Review Board has approved this project. As part of the UIUC research protocols, I have completed the proper criminal background check and training in ethical research.

This project will involve interviewing the special education teacher, school nurse, and parents. This project will also involve observing students during their health care procedures. All interviews, except for a brief 5-minute post-observation interview with the nurse, will occur outside of school time. No data will be collected without consent from participants and assent from the student. No data will be collected on school personnel or students who are not a part of the study.

Please respond to this email indicating if you approve. I will then contact the superintendent to obtain his/her permission. Participants will then decide for themselves if they want to participate or not. I have attached more detailed information for your review, including documentation of UIUC, Institutional Review Board approval. I can be reached at [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or 707-290-8312 if you have any additional questions.

Thank you for your consideration of this request.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **Email to Superintendent**

*Subject Heading:* Requesting Permission for On Site Research

Dear Superintendent,

My name is Sarah Ballard. I am a doctoral candidate in Special Education at the University of Illinois at Urbana-Champaign (UIUC). I am working under the guidance of Professor Stacy Dymond, who is an experienced researcher in Special Education at UIUC. I am writing to ask for your approval to conduct a research project at [Name of School]. [Name of Principal] has already expressed their support to have this research project conducted at this school site.

The research project is about how secondary students with severe disabilities are involved in their health care at school and school personnel's and parent's beliefs about their involvement. No identifying information on participants or the school will be reported.

The UIUC Institutional Review Board has approved this project. As part of the UIUC research protocols, I have completed the proper criminal background check and training in ethical research.

This project will involve interviewing the special education teacher, school nurse, parents, and paraprofessional or one-to-one nurse who assist the student with their health care at school. This project will also involve observing students during their health care procedures. All interviews, except for a brief 5-minute post-observation interview with the nurse, will occur outside of school time.

No data will be collected without consent from participants and assent from the student. No data will be collected on school personnel or students who are not a part of the study. I have attached a more complete description for your review.

In addition to the principal's approval, we would also like your approval to conduct this research project. Please respond to this email indicating if you approve. Participants will then decide for themselves if they want to participate or not.

I have attached more detailed information for your review, including documentation of UIUC, Institutional Review Board approval. You may also reach me at [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or 707-290-8312 if you have any additional questions.

Thank you for your consideration of this request.

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

**UNIVERSITY OF ILLINOIS AT URBANA-CHAMPAIGN  
COLLEGE OF EDUCATION RESEARCH PROJECT DESCRIPTION**

**Title of project:**

Involvement of Transition-Age Students with Severe Disabilities in Their Health Care at School

**Brief summary of project and procedure:**

The goals of this research project are to understand how transition-age students are involved in their health care at school and the beliefs of school personnel and parents about students' involvement in their health care. In special education, health skills are functional curriculum that can help students learn to be more independent. Currently, there is little research on this issue. Therefore, the findings from this study can help educational providers in the field of special education better understand how best to promote students' independence in their health care in ways that will improve adult outcomes for this population.

This is an exploratory qualitative study to better understand how students are currently involved in their health care at school. Data will be collected by means of a demographic questionnaire, document review of the students' individualized education program and health care plan, interviews (special education teacher, school nurse, parents, and personnel who are delegated by the school nurse to implement the student's health care procedures), and observations of the student during their health care procedures. No data will be collected without consent from participants. Given the low-incidence of this student population, this study will only involve 1-2 students and the above described related participants. The special education teacher and school nurse have expressed an interest in participation. No identifying information on participants or the school will be reported.

**Anticipated duration of school's involvement in project:**

This study will take place during March through May 2016.

**Research involvement of students:**

Students will be observed during naturally occurring and routinely scheduled health care procedures at school. Three to six observations will occur for each student whose parents consent for their participation in the study. Prior to each observation, students will have an opportunity to assent or not assent to being observed. If a student does not assent, the observation will not take place. If a student does not assent three times in a row, all research activities for this student will stop. Observations will not alter or interfere with the regular school routine for the student. No data will be collected on non-participants.

**Research involvement of teachers:**

Special education teachers will be asked to complete a 5-minute demographic questionnaire via email. Special education teachers will also be asked to complete a 60-minute in-person interview at a time and location the individual chooses, outside of school hours.

**Research involvement of parents and other adults:**

A 60-minute in-person interview will be conducted with student participants' parents at a time and location of their convenience. A 60-minute in-person interview will be conducted with the school nurses and personnel who implement the student's health care procedures (i.e., paraprofessional or classroom nurse) at a time and location the individual chooses. Interviews will be held outside of school hours. Additionally, a 5-minute post-observation interview will be conducted with the personnel who implemented the student's health care procedure. If a participant is unavailable immediately after the health care procedure, this interview will be conducted after school hours via the telephone.

**Use of audio or video recording:**

Interviews with the special education teacher, school nurse, parent, and personnel who implement the student's health care procedure will be audio recorded only. Interviews will not occur during school hours or in the presence of other school personnel or students. Observations of students during their health care procedures will not be audio or video recorded. The post-observation interview with the personnel who implements the student's health care procedures will not be audio or video recorded.

**Information needed from the cooperating teacher, school, or district:**

If the student's parent provides consent, the special education teacher will be asked to provide the researcher access to view the student's individualized education program and health care plan documents. No documents will be removed from the school site. Documents will be reviewed by the researcher in a private location identified by the school principal or special education teacher.

**Potential benefits to the participating school or school personnel:**

School personnel who participate in this study may benefit by sharing their personal beliefs about and experiences with teaching students to be involved in their health care at school. School personnel may also benefit by reflecting on how to teach students functional skills (e.g., independence) within the context of health care at school. Additionally, the research literature advocates for teaching student involvement in their health care at school as part of a functional curriculum that can lead to improved adult outcomes. However, limited research is available on this issue. Findings from this study can inform a research agenda to improve school and adult outcomes for students who have health care needs and severe disabilities.

## Appendix E: Emails Distributing Consent Forms

### Special Education Teacher Notification of Selection

*Subject Heading:* Research Study

Dear Special Educator,

Congratulations you have been selected to participate in the research project on student involvement in health care procedures for middle school, high school, and post-secondary students with severe/multiple disabilities. Your school site administrator and superintendent have approved this research project.

Please send the attached information flyer and parent consent form to the parent(s) of eligible students. Parents will be asked to return completed consent forms to you. I will collect the parent consent forms from you during my first visit. Please remind parents that I am available to answer any questions they may have prior to completing the consent form.

I have also attached a consent form for you to fill out which explains in greater detail what participation in this study involves. If you have any questions about the consent form please contact me by email at [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or by phone at (707) 290-8312. Email completed forms to [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or fax to (217) 333-6555.

Thank you for your assistance.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **Reminder Email for Special Education Teacher Notification of Selection**

*Subject Heading:* Research Study

Dear Special Education Teacher,

This is a reminder email. If you have already responded, please disregard this email.

Congratulations you have been selected to participate in the research project on student involvement in health care procedures for middle school, high school, and post-secondary students with severe/multiple disabilities. Your school site administrator and superintendent have approved this research project.

Please send the attached information flyer and parent consent form to the parent(s) of eligible students. Parents will be asked to return completed consent forms to you. I will collect the parent consent forms from you during my first visit. Please remind parents that I am available to answer any questions they may have prior to completing the consent form.

I have also attached a consent form for you to fill out which explains in greater detail what participation in this study involves. If you have any questions about the consent form please contact me by email at [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or by phone at (707) 290-8312. Email completed forms to [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or fax to (217) 333-6555.

Thank you for your assistance.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **School Nurse Notification of Selection**

*Subject Heading:* Research Study

Dear School Nurse,

Congratulations you have been selected to participate in the research project on student involvement in health care procedures for middle school, high school, and post-secondary students with severe/multiple disabilities. Your school site administrator and superintendent have approved this research project.

I have also attached a consent form for you to fill out which explains in greater detail what participation in this study involves. If you agree to participate, you will receive a \$40 Visa gift card after completing this study. If you have any questions about the consent form, please contact me by email at [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or by phone at (707) 290-8312. Email completed forms to [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or fax to (217) 333-6555.

As previously discussed, this study will also involve the personnel you delegate to implement the health care procedures required by the focus student(s). At this time, I would like to ask your help to forward the attached content form to these individuals. If you prefer, I can contact them directly if you provide me with their contact information.

Thank you for your assistance.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **Reminder Email for School Nurse Notification of Selection**

*Subject Heading:* Research Study

Dear [Name of School Nurse],

This is a reminder email. If you have already responded, please disregard this email.

Congratulations you have been selected to participate in the research project on student involvement in health care procedures for middle school, high school, and post-secondary students with severe/multiple disabilities. Your school site administrator and superintendent have approved this research project.

I have also attached a consent form for you to fill out which explains in greater detail what participation in this study involves. If you agree to participate, you will receive a \$40 Visa gift card after completing this study. If you have any questions about the consent form please contact me by email at [sballa2@illinois.edu](mailto:sballa2@illinois.edu) or by phone at (707) 290-8312. Email completed forms to [sballa2@illinois.edu](mailto:sballa2@illinois.edu) or fax to (217) 333-6555.

As previously discussed, this study will also involve the personnel you delegate to implement the health care procedures required by the focus student(s). At this time, I would like to ask your help to forward the attached content form to these individuals. If you prefer, I can contact them directly if you provide me with their contact information.

Thank you for your assistance.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **Recruitment Email to Personnel Delegated to Implement Health Care Procedures**

*Subject Heading:* Invitation to Participate in a Research Study

Dear [Name],

Your contact information was shared with me by [Name of School Nurse] for potential participation in a research study.

My name is Sarah Ballard and I am a doctoral candidate at the University of Illinois at Urbana-Champaign. I am currently conducting a research project with Dr. Stacy Dymond in the Department of Special Education.

The purpose of this study is to understand how students are involved in their health care procedures at school, and the beliefs of school personnel and parents about their involvement. This study will focus on middle school, high school, and post-secondary students with severe/multiple disabilities. The school nurse shared with me your contact information because you were identified as personnel currently implementing the focus student's health care procedure.

Your participation in this study is extremely important to helping us understand issues around students' involvement, or non-involvement, in their health care procedures at school. Participation in this study is voluntary and involves a brief demographic questionnaire, a 60-minute in-person interview, 2-3 observations of you during the provision of a student's health care procedures, and a 5-minute interview following each observation. Participants who complete the study will receive a \$40 Visa gift card. A consent form is attached to this email.

If you are interested in participating, please fill out the attached consent form. Please save a copy for your records, then email the completed form to Sarah Ballard at [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or fax to (217) 333-6555. If you have any questions about the attached consent form, please contact Sarah Ballard by email at [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or by phone at (707) 290-8312.

We appreciate your time. Thank you in advance for your assistance.

Sincerely,

Sarah Ballard  
Doctoral candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

Stacy Dymond  
Professor  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **Reminder Email to Personnel Delegated to Implement Health Care Procedures**

*Subject Heading:* Invitation to Participate in a Research Study

Dear [Name],

This is a reminder email. If you have already responded, please disregard this email.

Your contact information was shared with me by the school nurse (enter name) for potential participation in a research study. My name is Sarah Ballard and I am a doctoral candidate at the University of Illinois at Urbana-Champaign. I am currently conducting a research project with Dr. Stacy Dymond in the Department of Special Education.

The purpose of this study is to understand how students are involved in their health care procedures at school, and the beliefs of school personnel and parents about their involvement. This study will focus on middle school, high school, and post-secondary students with severe/multiple disabilities. The school nurse shared with me your contact information because you were identified as personnel currently implementing the focus student's health care procedure.

Your participation in this study is extremely important to helping us understand issues around students' involvement, or non-involvement, in their health care procedures at school. Participation in this study is voluntary and involves a brief demographic questionnaire, a 60-minute in-person interview, 2-3 observations of you during the provision of a student's health care procedures, and a 5-minute interview following each observation. Participants who complete the study will receive a \$40 Visa gift card. A consent form is attached to this email.

If you are interested in participating, please fill out the attached consent form. Please save a copy for your records, then email the completed form to Sarah Ballard at [sballa2@illinois.edu](mailto:sballa2@illinois.edu) or fax to (217) 333-6555. If you have any questions about the attached consent form, please contact Sarah Ballard by email at [sballa2@illinois.edu](mailto:sballa2@illinois.edu) or by phone at (707) 290-8312.

We appreciate your time. Thank you in advance for your assistance.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

Stacy Dymond  
Professor  
Department of Special Education  
University of Illinois at Urbana-Champaign

## **Appendix F: Consent/Assent Forms and Parent Recruitment Flyer**

### **Special Education Teacher, School Nurse, and Personnel Consent Form**

Dear [Name of Professional],

My name is Sarah Ballard. I am a doctoral candidate in the Department of Special Education at the University of Illinois at Urbana-Champaign. You have been selected to participate in a research project I am conducting with Dr. Stacy Dymond. The purpose of this research project is to understand how students are involved in their health care procedures at school, and the beliefs of school personnel and parents about their involvement. Your interest in participating in this study is greatly appreciated. Participation is voluntary. If you agree to participate, participation will involve the following:

- A demographic questionnaire I will send to you through email and ask you to email back to me (5-minutes).
- An in-person interview with you at a time and place that you choose interview (60-minutes). Interview will be audio-recorded.
- 2-3 observations of you during each type of health care procedure (if you are present during the health care procedure). Only written notes will be taken during observations.
- A brief interview after each observation (if you are present during the health care procedure) (5-minutes).
- A follow-up conversation with you through email. I will send you a summary of key points from your interview and ask you to check for accuracy (15-30 minutes).

The findings of this study may be published in a scholarly journal or presented at a conference or in a university course. When this research is discussed or published, no one will know that you were in the study. However, laws and university rules might require us to disclose information about you. For example, if required by laws or University Policy, study information which identifies you may be seen or copied by the following people or groups: a) the university committee and office that reviews and approves research studies, the Institutional Review Board (IRB) and Office for Protection of Research Subjects; and b) university and state auditors, and departments of the university responsible for oversight of research.

There is no cost associated with participation in this project. After successful completion of the questionnaire, interviews, observations, and the follow-up email correspondence, participants will receive a \$40 Visa gift card. The potential risks for participating in this project are anticipated to be no greater than those encountered in daily life. Research data collected on you won't be shared with school administrators or supervising nurses, unless there is a concern regarding a student's safety. Participants may potentially benefit from sharing and reflecting on their beliefs related to the involvement of students with severe/multiple disabilities in their health care procedures.

Participation in this project is voluntary. If you consent to participate, you can withdraw your consent at anytime without penalty. You will be given a copy of this consent form for your records. If you have any questions regarding this research project or any concerns or complaints, please contact Sarah Ballard (slballa2@illinois.edu or phone: 707-290-8312) or Dr. Stacy Dymond (sdymond@illinois.edu or phone: 217-244-9763). If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 217-333-2670 or e-mail OPRS at irb@illinois.edu. You may call this number collect if you identify yourself as a research subject.

If you have read and understand the above consent form and agree to participate in this study, enter X next to "Yes." If you have read and understand the above consent form and do NOT agree to participate in this study, enter X next to "No." Email completed forms to slballa2@illinois.edu or fax to (217) 333-6555.

PLEASE COMPLETE

I have read and understand the above consent form and voluntarily agree to participate in this study.

Yes  
 No

I am 18 years of age or older.

Yes  
 No

I agree to be observed if I am present during the student's/students' health care procedures.

Yes  
 No

We appreciate your time and willingness to review and complete this form. As a reminder, email completed forms to slballa2@illinois.edu or fax to (217) 333-6555.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
Department of Special Education  
University of Illinois at Urbana-Champaign

Stacy Dymond  
Professor  
Department of Special Education  
University of Illinois at Urbana-Champaign

Research Study for Students with  
Health Care Needs at School

# Parents Wanted!



The Department of Special Education at the University of Illinois at Urbana-Champaign invites parents and their children with health care needs to participate in a research study!



Help us learn about how your middle school, high school, or post-high school child with health care needs participates in their own care.

Questions or want more information? Call Sarah at (707) 290-8312

Participants Receive a \$40 Visa Gift Card



## Parent/Guardian Consent Form

Dear Parents,

My name is Sarah Ballard. I am a doctoral candidate. I work with Dr. Stacy Dymond in the Department of Special Education at the University of Illinois at Urbana-Champaign. Your child's special education teacher and school nurse nominated you and your child for participation in a research project. The purpose of this research project is to understand how students are involved in their health care procedures at school, and the beliefs of school personnel and parents about their involvement. Any interest you may have in participating in this research project is greatly appreciated.

Participation is voluntary. In addition to your permission, your child will also be asked if he or she would like to take part in this project. You are free to withdraw your permission for your child's participation at any time and for any reason without penalty. These decisions will have no affect on your future relationship with the school or your child's status or grades there. The information that is obtained during this research project will be kept strictly confidential and will not become a part of your child's school record.

If you give permission for yourself and your child to participate in this study, participation will involve the following:

- A 60-minute in-person interview with you at a time and place that you choose. Interviews will be audio recorded only.
- A demographic questionnaire I will ask you to fill out after the in-person interview (5-10 minutes).
- A follow-up conversation with you through email. I will send you a summary of key points from your interview and ask you to check for accuracy (15-30 minutes).
- Your permission to allow me to review your child's current IEP and health care plan.
- Your permission to allow me to observe your child during all of their health care procedures at school. I will observe your child 3-6 times for each procedure described in their school health care plan. Only written notes will be taken during observations.

The findings of this study may be published in a scholarly journal or presented at a conference or in a university course. When this research is discussed or published, no one will know that you or your child were in the study. However, laws and university rules might require us to disclose information about you. For example, if required by laws or University Policy, study information which identifies you may be seen or copied by the following people or groups: a) the university committee and office that reviews and approves research studies, the Institutional Review Board (IRB) and Office for Protection of Research Subjects; and b) university and state auditors, and departments of the university responsible for oversight of research. If the researcher observes any safety concerns involving your child, this will be reported to the school nurse or appropriate authority.

There is no cost associated with participation in this project. After successful completion of the interview, and the follow-up email correspondence, participants will receive a \$40 Visa gift card. The potential risks for participating in this project are anticipated to be no greater than those encountered in daily life. Participants may potentially benefit from sharing and reflecting on their beliefs related to the involvement of students in their health care procedures.

You will be given a copy of this consent form for your records. If you have any questions regarding this research project or any concerns or complaints, please contact Sarah Ballard (slballa2@illinois.edu or phone: 707-290-8312) or Dr. Stacy Dymond (sdymond@illinois.edu or phone: 217-244-9763). If you feel you or your child have not been treated according to the descriptions in this form, or if you have any questions about your rights or your child's rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 217-333-2670 or e-mail OPRS at irb@illinois.edu. You may call this number collect if you identify yourself as a research subject.

If you have read and understand the above consent form and agree to participate in this study, mark an X next to "Yes". If you have read and understand the above consent form and do NOT agree to participate in this study, mark an X next to "No." Please sign this form and return to your child's special education teacher.

\*\*\*\*\*

**PLEASE COMPLETE**

I have read and understand the above consent form and voluntarily agree to give my child permission to participate in this study.

Yes  
 No

---

I give permission for my child's teacher to share copies of my child's current IEP and school health care plan. All identifying information will be omitted from these documents.

Yes  
 No

---

I give permission for my child to be observed 3-6 times for each health care procedure described in my child's school health care plan.

Yes  
 No

---

I have read and understand the above consent form and voluntarily agree to participate in this study.

Yes  
 No

Continued on Next Page

\*\*\*\*\*

**I do/do not (circle one) give permission for my child \_\_\_\_\_ (name of child) to participate in the research project described above.**

\_\_\_\_\_  
(Print) Parent's name

\_\_\_\_\_  
Parent's signature

\_\_\_\_\_  
Date

You will be provided a copy of this letter for your records.

We appreciate your time and willingness to review and complete this form. As a reminder please return this form to your child's special education teacher.

Sincerely,

Sarah Ballard  
Doctoral Candidate  
University of Illinois at Urbana-Champaign

Stacy Dymond  
Professor  
University of Illinois at Urbana-Champaign

**Student Assent Form for Each Observation**

Hi [Name of Student]:



I'm Sarah. I came back to see you.



I want to learn what it is like for you [Name of Student] during your health care at school.



Can I watch and take notes today?

**YES NO**

*If no, confirm response with special education teacher or school nurse. Stop observation. Thank student and participants.*

*If yes, say thank you. Proceed.*

## Appendix G: Demographic Questionnaires

### Personnel Questionnaire

Please select the appropriate response or type in your answer to the following questions. I hope you will answer every question, but you may skip any question you do not wish to answer. I hope you will answer every question, but you may skip any question you do not wish to answer. Your information will be kept confidential.

1. What is your gender?
  - Female
  - Male
  - Other.
  
2. What is your age?
  - 20-29
  - 30-39
  - 40-49
  - 50-59
  - 60 and over
  
3. What is your race? Mark all that apply.
  - White
  - Black or African American
  - Asian
  - American Indian or Alaska Native
  - Native Hawaiian or Other Pacific Islander
  - Other. Please specify:
  
4. What is your ethnicity?
  - Hispanic or Latino
  - Not Hispanic or Latino
  - Other. Please specify:
  
5. What is your role?
  - School Nurse
  - Special Education Teacher
  - One-to-one Nurse
  - Paraprofessional
  - Other. Please specify:

6. How many years of experience do you have in your current role?

7. How many years have you worked with students with severe/multiple disabilities in a school setting?

8. How many years have you worked with students who have both severe/multiple disabilities and health care procedures in a school setting?

9. How many students, with severe/multiple disabilities and health care procedures, are you assigned to work with in your current role?

10. What are the grade levels of the students with whom you work?

Thank you for taking the time to complete this questionnaire. Please save this completed form to your desktop, and email the file to [slballa2@illinois.edu](mailto:slballa2@illinois.edu).

If you have any questions, please contact Sarah Ballard at [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or 707-290-8312.

## Parent Questionnaire

Please select the appropriate response or fill in your answer to the following questions. I hope you will answer every question, but you may skip any question you do not wish to answer. Your information will be kept confidential.

1. What is your gender?
  - Female
  - Male
  - Other
  
2. What is your age?
  - 20-29
  - 30-39
  - 40-49
  - 50-59
  - 60 and over
  
3. What is your race? Mark all that apply.
  - White
  - Black or African American
  - Asian
  - American Indian or Alaska Native
  - Native Hawaiian or Other Pacific Islander
  - Other. Please specify:
  
4. What is your ethnicity?
  - Hispanic or Latino
  - Not Hispanic or Latino
  - Other. Please specify:
  
5. What is your marital status?
  - Single
  - Living with partner
  - Married
  - Separated
  - Widowed
  - Divorced

6. What is your education level?
- Less than high school
  - High school diploma or equivalency
  - Some college (no degree)
  - Associates degree
  - Bachelors degree
  - Graduate level degree

**Note: “child” refers your child who is participating in this study.**

7. How many adults live in your child’s home?
- 1
  - 2
  - 3
  - 4+

8. How many siblings live with your child in the home?
- 0
  - 1
  - 2
  - 3
  - 4+

9. Who is the primary caregiver for your child?
- Myself
  - Other parent
  - Myself and the other parent share equally in caregiver responsibilities
  - Grandparent
  - Sibling
  - Home health care professional
  - Other. Please specify:

10. What supports do you receive to care for your child’s health care needs at home? Mark all that apply.
- Social Security Income
  - Medicaid
  - Home and Community Based Services (HCBS) Waiver
  - Home nursing services
  - Other. Please specify:

11. Does your child attend their neighborhood school (i.e., the same school he/she would attend if he/she did not have a disability?)

- Yes
- No

Thank you for taking the time to complete this questionnaire. Please return using the attached self-addressed prepaid envelope.

If you have any questions, please contact Sarah Ballard at [slballa2@illinois.edu](mailto:slballa2@illinois.edu) or 707-290-8312.

## Appendix H: Document Review Guide

<b>Document Review</b>			
Date of Review:		Researcher:	
Site Code:		Student Code:	
Gender:		Age:	
Ethnicity:		Race:	
Primary Eligibility:		Secondary Eligibility:	
Language:		Grade Level:	
Program Placement:		Minutes in Special Education:	
Minutes in General Education:		Related Services:	
Health Care Plan on File (Yes/No):			
Health Condition:			
Learner Characteristics:			
<b>Health Assessment, Health Goals, Health Interventions, and Health Outcomes</b>			
Document Source:			
Summary:			
<b>Baseline Performance and IEP Goals and objectives Specific to Involvement in Health Care</b>			
Document Source:			
Copied Verbatim:			
<b>Health Related Post-School Outcomes</b>			
Document Source:			
Copied Verbatim:			

### Appendix I: Field Notes Recording Sheet

Date:	Observer:	Student Code:	Site Code:
Location: (E.g., classroom, cafeteria)	Personnel Present During the Procedure: (E.g., teacher, school nurse)	Health Care Procedure (E.g., tube feeding)	Time Begin: Time End:
<b>Running Field notes</b> Record detailed description depicting the scene: concrete and sensory details, action, dialogue, and characterization.		<b>Reflections</b> Record the researcher's personal questions, reactions, ideas, and commentaries.	

## Appendix J: Post-Observation Interview Guide

### Script

I would like to speak with you briefly about the student's involvement in the health care procedure just completed. Is now a good time to speak?

*If no:*

When is a good time to speak with you today?

*If yes, (or at the preferred time indicated by the participant):*

1. Thinking about how the health care procedure went today, how would you compare it to a typical day?
2. Thinking about the student's involvement in their health care procedure today, how would you compare it to a typical day?
3. How do you think the student cooperated with their health care procedure today?
4. What do you think about the student's level of involvement in their health care procedure today?

Thank you for your time today.

## Appendix K: Interview Guide

### Script

I am meeting with you today to learn about your beliefs about the involvement of students in their health care procedures at school. If you need to stop, or take a break, please let me know. You may also withdraw your participation at any time without consequence. This interview will be audio recorded; I will also take handwritten notes. You will be given an opportunity to review and confirm the accuracy of interview transcripts and notes at a later date. Do you have any questions or concerns before we proceed?

Then with your permission we will begin. I will now turn on the audio recorder.

### Background

1. I am very interested in learning about your student's [*or* child's] health needs at school. What do you believe are the most important things I should know to understand your student's [*or* child's] health needs at school?
2. Many people believe that there are both challenges and benefits to teaching students with disabilities how to take care of their own health care needs. What do you think about teaching your student [*or* child] to take care of his/her own health care needs at school?

Some students [*or* children] do not cooperate during their health care procedures and have behavior challenges that can make providing their care difficult.

3. How would you describe your student's [*or* child's] cooperation with his/her health care procedures at school?
  - a. How important is his/her cooperation?
  - b. (If non-cooperative) Why do you think these behaviors occur?
  - c. (If non-cooperative) How are these behaviors addressed?
  - d. (If non-cooperative) What is being done to help him/her learn how to cooperate?
4. What does your student [*or* child] understand about his/her health care procedures?
  - a. (If knowledgeable) How does he/she show that he/she understands?
  - b. (If unknowledgeable) What makes you think he/she does not understand?
  - c. What are your thoughts about trying to improve his/her understanding?
  - d. What is being done to help him/her understand more about his/her health care procedures?

### Types of Involvement

Now, I want to understand better how your student [*or* child] is involved in his/her health care procedures at school. There are different ways students can be involved.

One type of involvement is when a student communicates to a caregiver what to do in his/her health care procedure(s). For example, when to start the procedure(s), what comes next in the procedure(s), or even communicating to the caregiver how he/she prefers to be cared for.

5. Does your student [*or* child] communicate to a caregiver what to do in any part of his/her health care procedures at school?
  - a. (If yes) What does he/she communicate?
  - b. (If no) What are the reasons why he/she does not communicate to his/her caregiver what to do in his/her health care procedures?
  - c. (If yes/no) Has anything been done to teach him/her how to communicate to his/her caregiver what to do in his/her health care procedures?
6. How do you feel about your student [*or* child] communicating [*or* learning to communicate] to his/her caregiver how to do his/her health care procedures at school?
  - a. How might he/she benefit?
  - b. What concerns do you have?

Another type of involvement is when a student helps with part of his/her health care procedure. This is different than communicating to a caregiver what to do because it involves your student [*or* child] physically doing one or more steps in his/her health care procedures. For example, gathering supplies or helping to hold a tube.

7. Does your student [*or* child] physically do one or more steps in his/her health care procedures at school?
  - a. (If yes) What does he/she do?
  - b. (If no) What are the reasons why he/she does not physically do one or more steps in his/her health care procedures?
  - c. (If yes/no) Has anything been done to teach him/her how to physically do one or more steps in his/her health care procedures?
8. How do you feel about your student [*or* child] physically doing [*or* learning to physically do) one or more steps in his/her health care procedures at school?
  - a. How might he/she benefit?
  - b. What concerns do you have?

The last type of involvement is independent self-care. This means a student does his/her health care procedures by himself/herself with or without supervision.

9. Does your student [*or* child] do their health care procedures at school by himself/herself?
  - a. (If yes) How does he/she do their health care procedures at school by himself/herself?
  - b. (If no) What are the reasons he/she does not do their health care procedures at school by himself/herself?
  - c. (If yes/no) Has anything been done to teach him/her how to do his/her health care procedures by himself/herself?

10. How do you feel about your student [*or* child] doing [*or* learning to do] his/her health care procedure at school by himself/herself?
  - a. How might he/she benefit?
  - b. What concerns do you have?
11. How satisfied are you with your student's [*or* child's] current involvement in his/her health care procedures at school?
12. What, if anything, would make you feel comfortable with increasing your student's [*or* child's] involvement in his/her health care procedures at school?
13. What, if anything, would need to change to make it possible for you to involve your student [*or* child] more actively in their health care procedures at school?
14. What do you think about including goals on involvement in health care procedures in your student's [*or* child's] IEP?
  - a. Is it important to include goals on involvement in health care procedures in the IEP?
  - b. (If important) What do you hope he/she will [*or* would] learn?
  - c. (If not important) Why are IEP goals not appropriate for your student [*or* child]?

### **Involvement and Transition Planning for Adult Life**

In this last set of questions, I would like to ask you about your student [*or* child] when he/she is an adult and finished with school.

15. How do you picture your student's [*or* child's] life when he/she is an adult and finished with school?
  - a. What are your dreams for your student [*or* child] for when he/she is an adult and finished with school?
16. Does involvement in health care procedures fit into what you want for your student [*or* child] when he/she is an adult and finished with school?
  - a. (If yes) How will it help your student [*or* child]?
  - b. (If no) Why is this not important?
17. If I had been sitting with you in the last IEP meeting, what discussion would I have heard about plans for your student's [*or* child's] health care needs when he/she is an adult and finished with school?
  - a. (If discussion occurred) What do you think about what was discussed?
  - b. (If no discussion occurred) Do you have any thoughts about why your student's/child's health care needs were not discussed?
18. If you could improve on how your student [*or* child's] health care needs are addressed in school, what would you change?

- a. How would this help your student [*or* child] when he/she is an adult and finished with school?

### **Conclusion**

19. Before we finish, is there anything else you would like to share with me today?

### **Probes (as needed):**

#### **Elaboration probes.**

- Tell me more about...?
- Tell me more about your thinking on that?

#### **Clarification probes.**

- What did you mean when you said...?
- Please explain what... is?

#### **Completion probes.**

- What happened next?

#### **Redirection probe**

- I'd like you to focus on.... when you answer.

Thank you for your time today. I appreciate your thoughtful responses. After I have had time to review what we discussed today, I would like to contact you again and provide you with a list of important quotes from your interview. In this list, I will include some of my preliminary interpretations. I would like you to review this list and make corrections, changes, and additions to the list as you wish.

Do you prefer me to send the list for you to check through email or standard mail? If you choose standard mail, I will provide you with a prepaid return envelope. After I received your feedback via email (*or* mail), I will send you a \$40 Visa gift card in approximately 1-2 weeks. I hope you will accept this small token as a thank you for your valuable participation in this study. Do you have any questions for me before we conclude? Again, thank you for a time.

## **Appendix L: Cognitive Interviewing Script**

During pilot procedures, interview protocols were administered from start to end (see Appendix B for the initial interview and post-observation interview protocols). The following think aloud strategy and follow-up prompts were used to evaluate how interviewees were interpreting specific questions:

### **Think Aloud Strategy**

As you answer the question, say aloud what you are thinking as you decide how to answer. I will give you an example. If I were asked “What is your favorite food?” I will think aloud as I answer this question by saying: “I think I am being asked to say what is my current favorite food. I also think I am being asked to name a specific dish versus a type of cuisine, so my answer is ‘enchiladas.’”

### **Follow-up Prompts**

Can you repeat the question in your own words?

What part of this question was unclear?

What do you think I meant by [phrase]?

Did you have the information or knowledge to answer this question?

## **Appendix M: Transcription Protocol**

### **File Name**

Save the word document using the same file name as the audio file (e.g., “Case 1”).

### **Time Stamps**

Enter a time stamp indicating the minutes and seconds in brackets before each new interview question. For example, 4 minutes and 30 seconds should be formatted as [4.30].

### **Question Number Formatting**

Format interview questions in an abbreviated format. For example, Question 1 should be Q1. Do not transcribe the primary interview questions (e.g., Q1, Q2, Q3) or explanatory text in the interview protocol. Do transcribe any sub-interview questions, prompts, or clarifying questions asked by the researcher.

### **Line Formatting**

Format each line of text with a number. All numbers should be continuous. For example, a complete transcript may have lines numbered 1 through 500. Use double-spacing.

1. Example line 1.
2. Example line 2.
3. Example line 3.

### **Assignment of Pseudonyms**

Do not transcribe names for people or school sites, instead enter [Name]. For example, “Snoopy loves to pretend to fly.” should be transcribed as “[Name] loves to pretend to fly.”

### **Verbatim Transcription**

All audio must be transcribed using standard spelling (e.g., no abbreviations) unless otherwise specified below. Do not omit any audio in the transcription. Use the following guidelines for transcribing unconventional language.

- Utterances—transcribe utterances phonetically. Some common utterances may be “huh,” “ugh,” “oh,” etc.

- Other audible sounds—transcribe other audible sounds made by the interviewee using description. For example, clearing the throat transcribe in parenthesis as (cleared throat) or a sigh as (sigh).
- Pauses—transcribe pauses by indicating duration of pause in parenthesis. For example, (2.0).
- Loud speech—indicate loud speech in CAPS. For example, “NO WAY”
- Inaudible audio—if the recording is not audible for any duration specify as follows (inaudible, 3.0).
- Sound interference—if there is a sound interference transcribe using a description of the sound and indicate duration as follows (school bell ringing, 5.0)

## **Punctuation**

Common punctuation should be applied, however punctuating verbal speech may not necessarily follow standard mechanics of style. Use the following definitions for common punctuation.

- Period—Indicates a stop at the end of a spoken sentence. It usually indicates a complete thought but not always. For example, “Changes in bell schedules are hard. But we manage.” If the speaker stops after “hard” then a period is indicated. If there is no stop then it is transcribed as one sentence.
- Comma—Indicates separate elements in a continuing thought. For example, “2nd period, 3rd period, and 4th period are the easiest.”
- Question mark—A question mark indicates a rise in tone. It may indicate a question. For example, “Are we finished?” The question mark can also be used to express uncertainty. For example, “Last week, or the week before that? He was sick.”
- Exclamation mark—An exclamation mark indicates an animated tone used to show emphasis. For example, “It was awful!”

## **Identifying the Speaker**

Use “R” to abbreviate “researcher” and “I” to abbreviate “interviewee.” For example:

1. R: How well is that working for you?
2. I: Well, I think (2.0) hmm pretty good. But its A LOT of work! It is worth it though
3. to see the excitement, pride, and happiness on their faces! It’s the BEST! (laughter)

## **Confidentiality and File Security**

Audio files will be shared via Box. Enable password protection on the personal computer or laptop that you will use to transcribe files. Please ensure no one has access to your Box account or your personal computer. Audio files must be transcribed in a private location. Private means no one can hear the audio files or see the transcriptions while you are working. Save the word document to Box. Keep a backup copy on your computer. After I have confirmed upload of the

transcript, you may delete data for that transcript from your personal computer. Please do not discuss the data with anyone.

## **Appendix N: Member Checking Email**

*Subject Heading:* Interview Feedback Requested

Dear [Name of Participant],

Thank you for taking time to participate in our study. We value the information you shared about your beliefs and experiences on involving transition-age students in their health care procedures. In order to ensure that we have accurately documented and interpreted your responses, we have attached a summary of preliminary interpretations and transcript excerpts for your review.

Please write your comments directly into the document using either CAPS or a **different color font**. Also, feel to write additional comments at the end of the document. Please save your changes to this document on your computer then email me the file.

If you would like a complete copy of the interview transcript, I am happy to send you the entire transcript. Thank you for taking your time to carefully review this attachment. Following receipt of your feedback, you will receive a \$40 Visa gift card in approximately 1-2 weeks.

Sarah Ballard  
Doctoral Candidate  
University of Illinois at Urbana-Champaign  
Department of Special Education  
slballa2@illinois.edu  
(707) 290-8312

## **Appendix O: Codebook**

### **1 Involvement**

This category includes codes on different types of involvement observed, documented, or reported.

#### **1.1 Involvement\Attempts**

The student is observed or reported to attempt a step in their procedure, or some form of communication.

#### **1.2 Involvement\Attends**

The student is observed or reported to intentionally watch and attend to the steps in their specialized health care procedure performed by the caregiver.

#### **1.3 Involvement\Cooperates**

Observation or report that the student does not resist care during their specialized health care procedure.

#### **1.4 Involvement\Correct Response**

The student provides the target response when provided an instructional prompt within the context of their specialized health care procedure.

#### **1.5 Involvement\Expressive Communication**

The student initiates communication, or responds to adult communication, related to a preference or a step within the specialized health care procedure using either verbal or non-verbal communication, including eye-gaze, affect, and gestures.

#### **1.6 Involvement\Independent**

Completes one or more steps without prompting.

#### **1.7 Involvement\Makes Choice**

The student is reported to communicate a choice or preference in their specialized health care procedure, such as which part of the body they will receive their injection.

#### **1.8 Involvement\Manages Supplies**

The student is reported or observed to manage their own supplies for their specialized health care procedure.

### **1.9 Involvement\Partial Participation**

Observation or interview data related to partial participation, specifically students participating in part of one or more steps in their health care.

### **1.10 Involvement\Receptive Communication**

Observed or reported instance of adults stating what procedure will happen or its function (e.g., “time for lunch” to indicate that a g-tube feeding procedure will happen) or narrating one or more steps in a health care procedure.

### **1.11 Involvement\Social**

An interpersonal interaction between the adult and student during the student’s specialized health care procedure that may or may not directly relate to the procedure itself, such as the adult asking the student about a special interest (e.g., music).

“Social” is categorized as a type of involvement in specialized health care procedures because socialization naturally occurs during eating for example. G-tube feedings are an alternate form of eating. Additionally, when individuals who do not have intellectual disabilities require personal physical care from another person, social interaction naturally occurs during this care and can make very private types of care (e.g., CIC) more comfortable and natural, and even more dignified. However, social interactions may potentially detract from student involvement in their specialized health care procedure if they become the main focus of the adult.

### **1.12 Involvement\Understanding**

A student demonstrates knowledge of, or is perceived to understand, the function or purpose of their procedure (e.g., receive nutrition, empty bladder), and/or one or more steps in their specialized health care procedure. Understanding may also refer to knowledge of health promotion behaviors related to their health care, e.g., refraining from pulling out their g-tube.

## **2 Pathways to Involvement**

Observed and reported ways or supports that lead to students’ involvement in their specialized health care procedures such as, the presence of an IEP goal, instructional plan, observer or reported instruction (e.g., prompting).

Although some codes may include reported data, this category primarily addresses Research Question 1. Therefore, reported data may emphasize more objective instances, such as reported instructional strategies (e.g., we use least-to-most prompting) versus more values-based perceptions such as “having high expectations promotes involvement.”

### **2.1 Pathways to Involvement\Adaptation/Accommodation**

Adaptions or accommodations made to facilitate participation in the specialized health care procedure based on disability characteristics or behavioral needs.

## **2.2 Pathways to Involvement\Behavioral Supports**

The use of behavioral supports to facilitate students' cooperation or involvement in their specialized health care procedure when the student is non-cooperative or refusing to participate. Examples, include clearly stating the expectation, providing wait time, use of a token reinforcement system and reducing demand.

## **2.3 Pathways to Involvement\Choice**

Observation or report on providing students a choice on whether or not they want to attempt to or perform a step in their specialized health care procedure.

## **2.4 Pathways to Involvement\Consistency/Routine**

Observed or reported consistent and routine ways of supporting student involvement in their specialized health care procedure. For example, consistently providing student's opportunities and instruction to participate.

## **2.5 Pathways to Involvement\Environmental Arrangement**

An identified strategy to facilitate the student's involvement by arranging the environment in a specific manner, such as locating supplies in a place that the student can access.

## **2.6 Pathways to Involvement\Goals**

Documentation or reported perceptions on the role of formal goals (IEP, ITP goals) or informal goals (e.g., nurse says: "My goal for her is to..." in promoting student involvement in their specialized health care procedures.

## **2.7 Pathways to Involvement\Honor Communication**

Adults are observed or reported to honor the needs or preferences students communicate during their specialized health care procedures.

## **2.8 Pathways to Involvement\Instruction**

Instructional strategies used (observed or reported) to promote student involvement in their specialized health care procedure.

### **2.8.1 Pathways to Involvement\Instruction\Encouragement**

Verbal encouragement is provided to the student during their specialized health care procedure to encourage making an additional attempt or to prevent discouragement and frustration.

### **2.8.2 Pathways to Involvement\Instruction\Natural Stimulus**

The student is presented with a natural stimulus to elicit a target response, such as positioned in front of the supply shelf as a natural cue to gather supplies.

### **2.8.3 Pathways to Involvement\Instruction\Partial-Physical Assistance**

A partial-physical assistance is a more intrusive prompt that entail the instructor partially physically motoring the student through the step.

### **2.8.4 Pathways to Involvement\Instruction\Pre-Teaching**

Report or observation of pre-teaching information important to the student's involvement in their specialized health care procedures.

### **2.8.5 Pathways to Involvement\Instruction\Redirection**

The student is off-task and a cue is given to redirect the student back to task.

### **2.8.6 Pathways to Involvement\Instruction\Reinforcement**

Verbal praise or a tangible reward given to reinforce a target behavior.

### **2.8.7 Pathways to Involvement\Instruction\Verbal + Gestural Prompt**

A verbal cue paired with a gestural cue (e.g., pointing) given by an adult to elicit a target response from a student in their specialized health care procedure.

### **2.8.8 Pathways to Involvement\Instruction\Verbal Prompt**

A verbal cue given by an adult to elicit a target response from a student in their specialized health care procedure.

### **2.9 Pathways to Involvement\Monitoring**

Observed or reported behavior of staff monitoring the student performing their specialized health care procedure. Typically, this entailed the adult periodically walking up to the student to check progress or glancing from across the room, or monitoring self-attempts to provide error correction.

### **2.10 Pathways to Involvement\Narration**

Observation or report of narrating what is being done during the specialized health care procedure, while it is happening to promote student understanding of their specialized health care procedures.

### **2.11 Pathways to Involvement\Rehearsal**

The report that verbally rehearsing with the student in advance or during their specialized health care procedure how to engage in health promotion behaviors supportive of their specialized health care, or steps in their procedure, is a means of supporting the student's involvement in their specialized health care.

## **2.12 Pathways to Involvement\Task Selection**

The belief that when expanding on student's current involvement in their specialized health care that the next step or skill to be targeted for instruction should be feasible, relevant, safe, and increase participation in a way that aligns with future care needs.

## **3 Non-Involvement**

This category addresses the absence of student involvement in their health care procedures, and includes codes related to adults not providing the student an opportunity to be involved, such as “no opportunity,” and “staff talking.” Additionally, this category includes codes related to students not responding to instructional cues to participate in their health care procedure such as “no response,” “does for,” and “off-task.”

### **3.1 Non-Involvement\Chooses Not To**

A student is provided a choice to attempt or do a step in their procedure, and chooses not to.

### **3.2 Non-Involvement\Doesn't Communicate**

The student is reported to not communicate their needs, preferences or aspects of their care during their specialized health care procedure. With additional probing during the interview process, participants would acknowledge other communicative behaviors that the student exhibits during their procedure. It is possible that participants initially interpreted “communication” as a higher order skill for some students, which were beyond the student’s abilities. Data coded as “doesn’t communicate,” frequently overlaps with other data coded as “guessing,” “unable,” or “disinterest” as participants appeared to be guessing if any communication was occurring, or stating the student was unable to communicate, or even that the student did not care or have any motivation to communicate during their procedure. Other types of communication were frequently reported and observed, however this code may illuminate a deeper trend or theme across several cases that connects to other codes like “no forethought” or even “status quo” — perhaps speaking to the issue that participants had not really considered student involvement and the many different ways students can be involved.

### **3.3 Non-Involvement\Health Risk Behaviors**

A behavior reported or observed that the student engages in during or related to their specialized health care procedures that is a health risk. This code has been tentatively categorized under the category "non-involvement." Although it is not non-involvement per se, it may be counterproductive to involvement and share some similarity with codes in non-involvement such as "choose not to." In addition, the pathways to non-involvement are also pathways to health risk behaviors.

### **3.4 Non-Involvement\No Response**

A stimulus prompt is provided to the student to elicit a target response specific to involvement in the student's specialized health care procedure, however the student does not respond.

It should be noted that observation data related to this code, indicates that insufficient wait time or visual cues may have been given to allow students to respond.

### **3.5 Non-Involvement\Off-task**

The student is attending to stimuli that is not related to the health care procedure.

Several coded instances of off-task behavior relate to the student not otherwise being engaged, and therefore distracted by surrounding stimuli such as peers across the room. Off-task seems to be somewhat of an unfair label for this code as the student may not have been given an opportunity to be engaged in the task at hand, however here this code means simply that the student's focus of attention is elsewhere.

### **3.6 Non-Involvement\Sleeping**

The student is reported or observed to fall asleep, or already be sleeping during their specialized health care procedure and is therefore unable to be involved.

### **3.7 Non-Involvement\Unclear Response**

An unclear response is when the student is observed or reported to possibly respond to a cue provided during their specialized health care procedure, however the response is not clearly intentional. For example, it may have been a spastic movement that happened to correspond when a verbal prompt was just given.

## **4 Pathways to Non-Involvement**

Observed and reported ways or supports that impede student's involvement in their specialized health care procedures.

### **4.1 Pathways to Non-Involvement\Caretaking**

The perception that the primary role of the adult or purpose of school is for caretaking purposes, such as maintaining physical health (e.g., stretching exercises done to the student), and to make sure the student is comfortable.

### **4.2 Pathways to Non-Involvement\Distracted**

The nurse or personnel responsible for implementing the student's specialized health care procedure is observed to be distracted by other student needs, or classroom responsibilities, i.e. their attention is not entirely on the procedure or the student who requires the procedure.

#### **4.3 Pathways to Non-Involvement\Does For**

Following a non-response from the student after prompting to participate in one or more steps in their specialized health care procedure, the adult completes the step for the student.

#### **4.4 Pathways to Non-Involvement\Don't Know**

The participant does not have information on an aspect of the procedure, condition, or the student's participation.

#### **4.5 Pathways to Non-Involvement\Guessing**

The reported perception, by adult participants, that they lack evidence on whether or not the student is behaving/responding purposefully, and/or are unsure how to accurately interpret the student's behavior.

#### **4.6 Pathways to Non-Involvement\Inconsistent**

Observed or reported inconsistent steps taken by adults to provide students opportunities to participate in their health care procedure.

#### **4.7 Pathways to Non-Involvement\Negative Talk**

Dialogue reported, or observed to be directed at the student, or said in front of the student that is negative such as, talking about the student's limitations or behavior in a non-constructive manner. This code may also be indicative of low-expectations, but this will be determined later after further analysis.

#### **4.8 Pathways to Non-Involvement\No Forethought**

Reflections reported by participants on having not previously (prior to participating in the study) thought about involving their student or child in their specialized health care procedures.

#### **4.9 Pathways to Non-Involvement\No Opportunity**

Adults do not provide an opportunity to the student to be involved in one or more steps in their specialized health care procedure counter to previously identified examples or expectations for student involvement (according to documents, interview, observation).

#### **4.10 Pathways to Non-Involvement\Relaxation Time**

The perception that the specialized health care procedure is a time for the student to relax, e.g., it is their down time and break from instruction. This belief appears connected, in some instances, to the perception that feedings relax and put students to sleep and this down time is important for them to be alert and ready to participate in other school activities.

#### **4.11 Pathways to Non-Involvement\Restraint**

The use of restraint to implement a health care procedure when the student is engaging in challenging behavior, such as blocking attempts to access the g-tube.

#### **4.12 Pathways to Non-Involvement\Schedule Delay/Change**

Observed or reported schedule delays or changes, which affects the student's routine such as atypical waiting time, change of staff performing the procedure, or a change in how the procedure is performed (e.g., the adult hurries due to time limitations).

#### **4.13 Pathways to Non-Involvement\Staff Talking**

Adults talking to either one another or another student during the student's specialized health care procedure, including conversation focused on unrelated topics (e.g., personal conversations between adults or adults and students other than the focus student).

#### **4.14 Pathways to Non-Involvement>Status Quo**

The reported perception that things are currently done as they are because they have been done this way in the past. Therefore, no additional planning or forethought on teaching or supporting the student's involvement in their health care procedures was considered. This is very similar to the code "no forethought" except that it perhaps provides insight into the "no forethought" code. This code may need to be collapsed.

### **5 Constraints**

Reported barriers to involving students in their specialized health care procedures, such as perceived student limitations, safety concerns, and legal/compliance concerns.

#### **5.1 Constraints\Behavior**

Observed or reported behaviors that may impede student involvement in their specialized health care procedures.

#### **5.2 Constraints\Degenerative**

The belief that expecting involvement and or substantial progress towards involvement may not be a realistic goal due to degenerative conditions, such as progressive worsening of contractures.

#### **5.3 Constraints\Discontinued Therapy**

Participant perception and report that potentially helpful services (e.g., OT, PT, SLP, Vision) were discontinued due to lack of student progress.

#### **5.4 Constraints\Disinterest**

The student is reported to not show an interest, or any preferences, or reactions to variables in their specialized health care procedures.

#### **5.5 Constraints\Fluctuates**

Perception that fluctuating health, behavior, or differences in cognitive processing skills day-to-day are obstacles to students maintaining an optimal level of involvement in their specialized health care procedure or fidelity of implementation in the procedure.

### **5.6 Constraints\Learned Helplessness**

The perception that some students have had no expectation to participate in their health care previously and are therefore currently reluctant to do so now, and show characteristics of "learned helplessness."

### **5.7 Constraints\Legal Compliance**

Interview reports related to following the requirements set forth in legal documents such as the IEP and doctor's orders. In addition, the code "compliance" includes references to adhering to priorities set forth by parents.

### **5.8 Constraints\Teaming Issues**

Reported or researcher inferred issues around teaming and communication among core team members involved in the student's specialized health care procedures, including non-attendance of IEP meetings and lack of shared knowledge among team members regarding student involvement in their specialized health care procedures at school or home.

### **5.9 Constraints\Time/Scheduling**

A perceived constraint around teaching or facilitating student involvement in their specialized health care procedures specific to scheduling issues. Such as time available in the school day schedule.

### **5.10 Constraints\Unable**

Perceived or reported inability of student to participate in one or all parts of their health care. Data coded as "inability" does not include pre-requisite skills as the perception is that the student will never be able to do the skill. For example, the student is blind and cannot see where to insert the tube, and the participant does not appear to believe there is an alternative such as using tactile senses to feel where to insert the tube.

### **5.11 Constraints\Unsafe**

The perception that involving students in certain aspects or all of their specialized health care procedures is a safety issue.

### **5.12 Constraints\Unsure**

Adult report that they value teaching involvement, but are uncertain how to teach skills that support student involvement in her specialized health care procedure.

### **5.13 Constraints\Won't Generalize**

The perceived importance that skills need to be generalized across home, school, and other environments, such as the community. However, the student will not generalize these skills due to behavior (refusal) although they are perceived to be capable of performing the skills across environments. Additionally, there was also sometimes a perception that the parent will not support or reinforce generalization at home.

## **6 Requisites**

Reported necessary or strongly desired program resources or student prerequisite skills required to promote student involvement in their specialized health care procedures.

### **6.1 Requisites\Additional Staff**

Reported need for additional staff, including direct support from related services, to balance instruction in involvement in health care procedures with safely implementing the procedure.

### **6.2 Requisites\Assessment**

The belief that conducting assessment or having access to assessment data is necessary to plan for or support student's involvement in their specialized health care procedures.

### **6.3 Requisites\Care Coordination**

The belief that communication and shared information is important to coordinate consistent care across environments, i.e., school, home, and community. Care coordination is a requisite to student involvement in their health care because it promotes consistency across environments.

### **6.4 Requisites\Health Promotion**

The perception that lifestyle choice and behaviors are important to student health management of their health care. For example, exercise and diet to manage diabetes, or refraining from eating restricted foods when diagnosed with dysphasia.

### **6.5 Requisites\Knowledge/Training**

The need to have more trained staff, who are knowledgeable about the student's care needs and are able to provide care in a consistent manner.

### **6.6 Requisites\Nursing Perspective**

The reported belief that the perspective nurses bring to the IEP team which is rooted in a medical perspective/training background is critical to IEP planning around student's involvement in their specialized health care procedures.

### **6.7 Requisites\Prerequisite Skills**

Reported or perceived prerequisite skills needed for student involvement in one or more steps in their specialized health care procedures.

### **6.8 Requisites\Rapport**

The perception that the student's rapport with a school professional who oversees their specialized health care procedure is essential to the student's involvement, even when that involvement might be more basic in nature such as cooperation or understanding.

### **6.9 Requisites\Realistic Goals**

Reported belief that IEP goals would be beneficial for addressing student involvement in their health care, if the goals were realistic (e.g., achievable), practical and beneficial (e.g., functional).

### **6.10 Requisites\Related Services**

A reported need for consult or direct services from related service to promote student involvement in their specialized health care procedures.

### **6.11 Requisites\Safety**

The belief that safety is the foremost priority and is a critical consideration when planning student involvement or may take priority over involving students.

### **6.12 Requisites\Start Early**

The perception that the need to start teaching students self-care in their specialized health care procedures should start at a younger age, before high school.

### **6.13 Requisites\Supervision**

The belief that students can be involved or increase their current involvement as long as they are supervised by a trained adult.

### **6.14 Requisites\Team Priority**

Participant indicates a willingness to teach involvement if identified as an IEP team priority.

## **7 Outcomes**

Beliefs about the outcome (including benefits) or consequences (including risks) of student involvement or non-involvement in their specialized health care procedures. This category does not encompass adult outcomes.

### **7.1 Outcomes\Assists Caregiver**

Student involvement is perceived to be helpful to the caregiver.

### **7.2 Outcomes\Control**

The perception that student's involvement in their specialized health care procedures gives students control over what is happening to them, instead of just having the procedure done to them.

### **7.3 Outcomes\Decrease Anxiety**

The belief that promoting involvement may decrease anxiety about what is being done during the specialized health care procedure.

### **7.4 Outcomes\Health Advocacy**

Health advocacy addresses a student's ability advocate for their own health needs and safety, and may include recognizing when a caregiver is doing a step wrong or providing care in a way that is uncomfortable to themselves. In addition, health advocacy includes understanding basic health promotion such as, "I need to eat to stay healthy. I eat through a g-tube." For some students, this may be a more simplistic or basic understanding.

### **7.5 Outcomes\Independence**

A perceived or reported benefit for student involvement in their specialized health care procedures.

## **7.6 Outcomes\Normalcy**

The perception that learning health management can promote normalcy in one's life, and make self-care around health care procedures part one's normal daily routine.

## **7.7 Outcomes\Self-Esteem**

The perception that student involvement in their specialized health care procedures may benefit students by increasing self-esteem. The code "self-esteem" also includes observed or reported student pride after participating in, or receiving praise for participating in one or more steps in their specialized health care procedure. Observed instances of self-satisfaction were documented when a student smiled or behaved in a way that indicated pleasure in direct response to their involvement. The researcher inferred this behavior to mean pride.

## **8 Philosophical**

Reported philosophical beliefs related to involving students in their specialized health care procedures.

### **8.1 Philosophical\Advocate**

Beliefs about the role of school personnel or parents to advocate on behalf of their student or child related to their health needs.

#### **8.1.1 Philosophical\Advocate\Empower**

Empower is the opposite of learned helplessness, and addresses observed or reported information on enabling students to take an active role in their health care. The code "empower" overlaps with "independence" and "value," however it is unique in that it emerges from the data as a clear counter agent to learned helplessness.

### **8.2 Philosophical\High Expectations**

The perception that it is important to provide students with the opportunity to be involved (e.g., narrating to promote understanding) even when it is unknown what the student may understand or be capable of. "Giving students the benefit of the doubt," but doing so in an ethical manner that does not put the student at risk. This code works alongside the code "realistic goals."

### **8.3 Philosophical\Humane**

The belief that it is humane, showing consideration and treating the individual with dignity, when the caregiver tells the student what they are doing to the individual during care.

### **8.4 Philosophical\Potential Pathways**

Potential strategies reported by participants that they want to or could provide to students to support their involvement in their specialized health care procedures. These potential strategies are not currently in effect, and frequently appeared to be thought of in the moment.

#### **8.4.1 Philosophical\Potential Pathways\Add goal**

The reported desire to improve student involvement in the future by adding an IEP goal.

#### **8.4.2 Philosophical\Potential Pathways\Assessment (2)**

Observed and reported information related to assessing the student's health status, ability to participate, and progress/lack of progress in participation in their health care. For example, if the student is in pain or the g-tube is not patent then the student is not able to participate, and a more basic health need may need to be addressed first.

#### **8.4.3 Philosophical\Potential Pathways\Behavioral Supports (2)**

Potential behavioral supports suggested by the participant as a way to promote student involvement in their specialized health care procedures in the future.

#### **8.4.4 Philosophical\Potential Pathways\Communication/Schedule**

Ideas and potential strategies to support student communication related to their involvement in their specialized health care procedures, including the use of schedules or timers to promote receptive understanding, e.g., time to eat.

#### **8.4.5 Philosophical\Potential Pathways\Fading**

The reported requisite that over time it will become important to fade support to promote student independence, especially with students who have already demonstrated an overreliance on adult supports.

#### **8.4.6 Philosophical\Potential Pathways\Narration (2)**

Reported potential strategy to improve student's understanding of their specialized health care procedures by telling them what you are doing and why. This is reported as a potential strategy rather than as something that is currently done.

#### **8.4.7 Philosophical\Potential Pathways\Teach Task/Knowledge**

A reported step that the participant believed that they could teach a student, e.g., clean the tube. Or teach information about the procedure.

#### **8.4.8 Philosophical\Potential Pathways\Teaming**

Participant report that in the future they will team with related services and other school personnel that can help identify strategies and assistive technology needed to promote student involvement.

#### **8.5 Philosophical\Questionable Importance**

Perceptions on the questionable importance of involving students in their specialized health care procedures.

#### **8.6 Philosophical\Relevant**

Teaching skills to promote student involvement in their healthcare procedures is perceived as relevant only when these skills can be taught/generalized across other activities, which are perceived to be more important, e.g., other health related care such as stretching or social skills.

### **8.7 Philosophical\Satisfaction**

Interview reports related to perceived satisfaction of current student involvement and/or how the student's health care procedures are currently provided. Note: Data coded here also includes general program satisfaction to elucidate that participants may be satisfied even when involvement has not been addressed.

### **8.8 Philosophical\Value**

Actions observed, and beliefs reported related to the importance or benefit (or lack thereof) on student involvement in their health care.

## **9 Well-Being**

The perceived relationship between student involvement in their health care and adult outcomes. And/or goals for continued student involvement in their health care post-school.

### **9.1 Well-Being\Autonomy**

The hope that students will feel autonomous and not have to rely entirely on others to have their care needs met.

### **9.2 Well-Being\Opportunity**

The hope that students will continue to have opportunities to participate in their health care as adults in order to promote their autonomy and overall well-being.

### **9.3 Well-Being\Program Options**

The belief that students who can learn to be as independent as possible in their specialized health care procedures may have improved program options available to them as an adult.

### **9.4 Well-Being\Quality of Life**

Beliefs about how involvement in specialized health care procedures may or may not impact quality of life.

### **9.5 Well-Being\Safeguard**

The hope that student involvement in their health care can mitigate potential safety concerns in their adult life when a caregiver is not present, or if there are less knowledgeable caregivers (e.g., no longer having a school nurse to oversee care) in their adult life. For example, having the ability to alert a caregiver when something is being done incorrectly in their procedure or if they are in pain.

### **9.6 Well-Being\Self-Determination**

Reported desire for students to be motivated to be involved and extend current involvement (or expand upon) in their adult lives.

## **10 Inconsequential**

Beliefs related to the unimportance of student involvement in their health care procedures in relation to adult life.

**10.1 Inconsequential\Cared For**

The belief that it is more important that the individual receives high quality care as an adult than it is for the student to be involved in that care.

**10.2 Inconsequential\No Impact**

The belief that involvement in one's care has no effect or impact on quality of life or happiness as an adult.