Transition of Adolescents and Young Adults with Spina Bifida into Adult Primary Care and Specialty Health Care Services

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Abstract

Spina Bifida (SB) is a complex multi-system birth defect. It is a congenital neural tube defect that occurs at conception. Those affected require lifelong surveillance with coordinated management. Thus, children and families need many services to address numerous physical, mental, and developmental needs which continue into adulthood. Since more children and adolescents are surviving into adulthood today, they have similar medical needs but need more adult services such as independent living, vocational rehabilitation, and sexuality education. As with children with special health care needs (CSHCN), adolescents and young adults living with SB need transition services to provide a medical home to support care coordination. While transition services are available in some areas of US, the access is lacking specifically in Ohio. Prior to establishing transition services, the engagement and commitment of health care professionals are required, especially adult providers. The proposed intervention is a one day educational summit for health care professionals, adolescents, and young adults living with SB and families with the goal to educate and explore objectives in developing transition protocols. This proposal describes the intervention and evaluation plans regarding this intervention. An APRN's involvement can be advantageous in bridging the gap between pediatric based services and transition to adult based services in not only primary care but subspecialty care services as well. This highly vulnerable population is conducive to continuing a medical home umbrella into adulthood to improve quality of life and prevent unnecessary complications from preventable chronic conditions.

Keywords: adolescents, Spina Bifida, medical home, transition, young adults, children with special health care needs

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Introduction

Spina Bifida (SB) is a congenital neural tube defect that occurs at conception and is considered a complex multi-system birth defect (NIH, 2013). The effects of SB can vary for an individual and depends on where the level of defect occurs along the neural tube. Therefore, some are more severely affected and have more deficits than others. Many have congenital hydrocephalus resulting in cognitive and social delays. Others have difficulty with ambulation requiring use of ambulatory aids like braces or forearm crutches while others severely affected will be wheelchair bound for their lifetimes. Bladder and bowel issues are very common and prevent independent continence. Thus many children will require careful management and constant care diligence to maintain healthy bladder and kidneys.

Due to the multi-system effect of SB, the children and families need many coordinated services from pediatric specialists to address the numerous physical, mental, and developmental challenges involved. These specialists can include pediatricians, developmental pediatricians, neurosurgeons, urologists, orthopaedic surgeons, neurologists, pediatric nurses (including advanced practice registered nurses), physiotherapists, physical therapists, occupational therapists, speech therapists, dieticians, social workers, and other health professionals (unknown author, 2002). Care for the child and family is usually coordinated within a SB clinic, or program, located at a children’s hospital.

In the last several decades, the rates of infants born with SB have declined most likely from the introduction of folic acid supplementation pre conception and during pregnancy and prevalent genetic features. But the lifespan of children living with SB has continually increased. Mukherjee (2007) noted survival into adulthood for people with SB now exceeds 85% due to improvements in medical and surgical management. This improved survival clearly supports the need to provide care across the continuum to include now more adult based services. Young adults with SB have unique medical and social needs that are not commonly addressed in a pediatric service. For example, young adults are continually asking for assistance with workforce or college preparation, starting a family, independent living, and insurance medical payment programs access. These issues of transition from pediatric to adult care present both barriers and challenges to the adult population living with SB, their families and healthcare providers.

The transition of children living with a special health care needs (CHSCN) from pediatric to adult service is a national goal established by the federal government, specifically the Maternal and Child Health Bureau of Health Resources and Services Administration (HRSA). Children living with SB are also CSHCN based on the following definition: “Those who have one or more chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally” (McPherson, et al, 1998). CSHCN require care coordination while receiving pediatric services and an important component of care coordination is establishing transition services from pediatric to adult providers with the goal to maintain a medical home (Strickland, McPherson, Weissman et al., 2004). American Academy of Pediatricians (AAP) consensus statement from 2011 recommended transition to adult services to a medical home for CSHCN and provided a tool kit with algorithms to support successful transition (American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians, Transitions Clinical Report Authoring Group, 2011), but the materials are not specific to the SB population. Although many descriptions are recommended, no outcome results have been demonstrated.

And while Brei (2007) reported the multidisciplinary clinic is the accepted model for health care delivery for those with SB, this standard for adults living with SB is lacking in the United States. There is an increased need to develop multi-disciplinary adult-based SB programs considering more adolescents with SB are surviving. This survival trend is expected to continue. It is imperative that adolescents and young adults living with SB are successfully transitioned from pediatric to adult services to prevent gaps in service delivery and to establish a medical home with adult providers. Medical home services for adults with SB include both primary care providers and adult specialists. While transition services models have been successfully established for other CSHCN, such as hemophilia and cystic fibrosis (Geerts, Van De Wiel & Tamminga, 2008, Kennedy & Sawyer, 2008), the transition services for children with SB lags behind in comparison.

Needs Assessment

Successful transition service models for adolescents with SB have been described in the literature (Sawin, Rauen, and Bartelt, 2015, Dicianno, et al, 2012, Cox, 2011). In Ohio, there are 8 children’s hospitals with pediatric SB programs. In 2012, the author conducted phone interviews with the coordinators of each of the Ohio programs as part of a needs assessment. The overall purpose of the phone interviews was to ascertain if the programs had established transition services, how these services were planned and implemented, and the outcome. Only 1 of the 8 programs had established a comprehensive adult transition service. Many coordinators reported they “held onto” certain persons into adulthood on a case by case basis because they had cared for them so long and no one would accept them into an adult practice group due to numerous complex specialty conditions. Some pediatric SB programs kept the adults until 25 years old and some programs to 35 years old, but no program was clear regarding what happened to the patients after aging out of pediatric services.

In 2016, the author attended the National Spina Bifida Association of America annual conference and learned 2-3 more Ohio SB programs were planning adult based transition services, but the programs experienced limited resources or limited sustainability. The programs that were able to provide adult based services concluded that a relationship with rehabilitation programs and professionals within their health care systems made the transition possible. Barriers to successful transition included lack of upper level administration support, lack of funding, lack of adult professionals who are comfortable providing care to people living with SB, and lack of physical space.

Statement of Problem

Transition services are important and needed for the SB population. SB Adult based services are available in some areas of the country, but are still lacking in NE Ohio in spite of the availability of adult health care specialists located within three major medical centers. Prior to establishing transition services, the engagement and commitment of key stake holders are needed. Key stakeholders include people living with SB, family members and both pediatric and adult health care professionals.

Purpose Statement

The purpose of this proposed Capstone project is to provide an educational Summit for people living with SB, families, and both pediatric and adult health care professionals. An educational Summit with these key stakeholders about transition services is first needed to promote engagement toward a common goal. The aim of the Summit is to establish a core group of people committed to plan, implement, and evaluate adult transition services for adolescents and young adults living with SB. The Summit's sponsor is the Spina Bifida Association of America (SBAA). The mission statement of the SBAA blends the education, prevention, research and support of the SB community through outreach and educational programs to improve the lives of those living with SB. This makes SBAA the ideal sponsor for this event. They are a proven neutral organization that advocates for transition as evidenced by their annual national conference agendas over the last 5-10 years. They are neutral in that they lack of formal relationship with one group of providers or health care system. They have developed a professional advisory board and a SB adult advisory group along with local chapter support groups comprised of knowledgeable and experienced parent members. Every conference or educational day event over the years has been very well attended by both people living with SB, families, and health care professionals.

Conceptual Design and Theoretical Framework

Lack of awareness and engagement in this area about transition still remains today. An educational Summit for key stakeholders is needed to initiate engagement and thus promote commitment to provide transition services from pediatric to adult care for adolescents and young adults living with SB. The conceptual framework by Imogene King, The Theory of Goal Attainment, is chosen for this Capstone since the goal of King's nursing framework "is to help individuals, groups, and society maintain health as they interact in their environments" (King, 1992, p. 20). According to King (1992), each of the following three systems comprises elements of the total environment: Person Systems (Individuals), Interpersonal Systems (Groups), and Social Systems (Society). King's Dynamic Interaction Systems is illustrated in Appendix A. King identified a set of behaviors, or interactions, which could occur between a nurse and client that led to transactions, resulting in goal attainment (King, 1992). The theory also included characteristics of general systems theory as defined by von Bertalanffy in 1956 since the nurse and client interaction is not isolated and health; the goal of King's theory is related to all three systems of individuals, groups, and society (King, 1990).

King identified the following interactions leading to goal attainment: Action, Reaction, Disturbance, Mutual Goal Setting, Explore Means to Achieve Goal, Agree On means to Achieve Goal and

Transactions. And while these interactions (illustrated in Appendix B) are labeled within an interpersonal dyad between the nurse and client, general systems theory and King's Dynamic Interaction System support the interactions involving interpersonal systems, or groups, to achieve mutually set goals. For example, a mutual goal among stakeholders is the successful transition of services from pediatric to adult services for CSHCN, including adolescents living with SB. Attempting this goal in NE Ohio (the action) leads to a reaction (lack of adult services) and results in a disturbance (a problem: unsuccessful transition). The next steps are mutual goal setting among stakeholders and the exploration of means to achieve the goal-activities during the Summit. The last two steps, Agreement on Means to Achieve the Goal and Transaction, are expected to occur after the Summit. Plans include establishing a core transition team to collaborate for establishing an adult SB clinic, a SBAA local Chapter in NE Ohio, and to continue to offer continuing education with guidance from established SBA memberships and chapters. This will be the sustainability link to keep the momentum moving forward.

Thus, the Summit will serve as the call to action to establish a core group to plan future transition services with adolescents with SB and their families to promote the achievement of successful wellness goals that lead to independent living and improved Quality of Life (QOL) upon entering adulthood. The interactions we established in the perinatal period through school age with the pediatric SB program has led to better health outcomes for the children and families. Since the SB population continues to live longer into adulthood, the same high quality, adult care is needed to promote wellness, independence, and optimal QOL. Healthcare professionals need to collaborate with the adolescent and family to develop seamless transition from pediatric to adult based services for the SB community.

Significance to Nursing

An advanced practice registered nurse (APRN) with expertise in providing care to children and adolescents living with SB can significantly contribute in the establishment of transition services with the SB program team. Educational preparation in a Doctorate of Nursing Practice (DNP) program prepares the APRN for a leadership position to implement and evaluate evidence-based interventions within health care systems. For example, a DNP prepared APRN could initiate the planning, implementation, and evaluation of transition services for adolescents living with SB and their families. This role should be formalized within the healthcare system as a navigation coordinator. This navigation role would assist both adolescents and their families to become familiar with resources to plan, coordinate, and implement a smooth transition to appropriate adult providers and services. A navigation coordinator can be the collaborative link to adult providers, community systems, and advocacy groups for persons with SB. The development of transition programs throughout the United States would allow for better access to care, better health care outcomes, and prevent complications in this population. The DNP-prepared APRN can foster the collaborative development, implementation, and evaluation of transition programs. This service then may translate to other CSHCN conditions like Cerebral Palsy, Down’s syndrome, and autism in the healthcare system.

Systematic Review

The following PICOT question was developed for the systematic review: Does participation in an Adult Spina Bifida Transition Program improve quality of life (QOL) and decrease Emergency Department (ED) visits compared with no participation over a 5 year period? The Melnyk and Fineout-Overholt (2015) framework was used for the review. Initially, the review occurred in 2012-13 followed by a repeat review in 2015. The inclusion criteria were: Adolescents and young adults with SB, transition, English language articles, full text, 5 year timeline (2010-present) and no grey literature. The exclusion criteria were: Children 0-10, non- English, no transition, not full text or accessible online, 2009-past and grey literature. The following levels of evidence were accepted: systematic reviews, randomized controlled trials (RCT) and quasi-experimental designs and cohort or case study designs.

The following databases were searched for this systematic review to evaluate the problem: Medline, Pub Med, CINAHL, Cochrane, ProQuest, and Virginia Henderson. Key words used were: Spina Bifida (SB) or Myelomeningocele, Adolescents and Young Adults, Transition or Adult Care, Quality of Life (QOL) or well-being or health, and Emergency Room (ER) visits. SB was initially keyed into the database search engines, followed by the edition of either SB or SB Myelomeningocele, and then the terms Adolescents and Young Adults were used. Next, each characteristic was added, subsequently, through each database. The initial search was conducted independently; a second search was performed with the assistance of the research librarian at the college. This process resulted in the identification of 50 articles which were then reviewed based on the inclusion/exclusion criteria. Of the initial 50 articles, 25 were retained and, upon further review, 8 articles met the criteria. None of the 8 articles included systematic reviews, the highest level of evidence. The following levels of evidence were found: IV and VI, meaning case control or cohort study and a descriptive or qualitative study. The summary of the 8 articles is presented in Appendix C. Most of the studies demonstrated the need for collaboration and assistance to transition into adult based services. The state of the science in relation to providing SB adult transition programs revealed the service is highly recommended for this population. According to Dicianno and Wilson (2010), reducing the number of secondary medical conditions with proactive and preventative approaches to health care led to a reduction in the morbidity, mortality and cost for health care for this group. The healthcare outlook for SB adults remains questionable for QOL and preventable illnesses that should be managed outside of EDs. The limitations appear to be multifactorial including readiness, cognitive, physical and emotional arenas. Using secondary data from some databases about hospitalizations may underreport actual ED usage and more data are needed concerning co-morbidities to predict reasons to access ED care and could be future research topics. The provider limitations included confidence to care for adults with SB, lack of resources, lack of knowledge to care for adults, and inaccessible facilities. The search was limited since grey literature was not included. Successful transition programs were limited to certain geographical areas in the United States and consisted of the established collaborative agreements among healthcare providers.

Literature Review of Transition for SB Adolescents

In a subsequent literature review including lower levels of evidence, several articles were found that described the successful transition of youth and adolescents with SB into adult based services. Several articles (Armour et al., 2009, Lewis & Slobodov, 2015) were specifically focused on urological services only. Many articles highlighted transition needs for CSHCNs which often mentioned the SB population but often the author did not delineate the unique specific needs of SB persons to accomplish seamless transition goals. One article by Schor (2015) recommended developing transition guidelines based on developmental skills versus age, depicting a picture that adulthood is a social marker rather than a developmental stage. There is a great variability with expected milestone achievement in regards to skills that constitute adult behaviors and who is legally an adult by this definition. Another article by Van Cleave, Boudreau, McAllister, Cooley, Maxwell and Kuithau (2015) examined how care coordination changes conceptually and gradually in primary care arenas when implementing the medical home concept. They measured Medical Home Index Scores six years after implementation of a 2003-2004 national learning collaborative to implement the medical home model for CSHCN. They studied care coordination in 12 pediatric practices with highest post intervention Medical Home Index scores which signified a high adoption of the model into practice. They examined data from interviews with 48 clinicians, care coordinators, and parents. Medical record reviews of 60 patients with SHCN receiving care from these practice groups were also conducted. Results in these high performing medical homes models found that care coordination activities did change from episodic reactive care to more proactive and comprehensive care over time. The following changes occurred internal and external to the practice: pre-visit phone calls, writing care plans, developing relationships with community agencies as well as motivation and creativity of medical home teams, organizational changes and funding to expand care coordination positions.

The International Federation for Spina Bifida and Hydrocephalus (IFSBH) is a global network governed by adults with SB and hydrocephalus (SBH) or parents of persons with SBH. The IFSBH mission statement is to reduce the incidence of SBH with primary prevention and improve QOL for persons with SBH and their families with advocacy, education and community building. They recently advocated for human rights of adolescents with SBH describing need for transitional care and empowerment through health education and self-management techniques as noted on their website: www.ifglobal.org. Therefore, transition is not just a national initiative but an international one.

Lomas (1993) developed a Coordinated Implementation Model. This is an active model of dissemination to adopt an evidenced based clinical practice change. A major cornerstone in the model is the practice of translating research knowledge into practice. The take home message is simple. Advocacy is getting the word out, implementation is creating the resources, and then we need outcome based evidence to support the transition to adult services that is meaningful and assist with improving QOL, reducing unnecessary ED visits, and hopefully decreasing mortality in the SB community. Therefore, the planned educational day Summit would hopefully be the first step to light a fire in our northeast Ohio community to advocate for both adult primary and specialty care services for adolescents and young adults affected by SB.

Project Plan/Intervention

The needs assessment and literature reviews identified the need to engage key stakeholders in the planning, implementation, and evaluation of transition services. Based on King's Theory of Goal Attainment, mutual goal setting and exploration of the means to achieve the goal are needed prior to establishing the means to achieve the goal. A one time, all day educational Summit with key stakeholders is proposed as an intervention to foster mutual goal setting and exploration. Key stakeholders are adolescents/adults living with SB, families, and health care professionals. Health care professionals include: physicians, primary care and specialty care providers, APRNs, PAs, nurses, social workers, therapists, counselors, and others. The goals of the Summit are two-fold: 1) to increase community and subspecialty provider awareness of the need for transition from pediatric to adult services for adolescents living with SB and their families, and 2) to identify participants who will be champions of transition care services in NE Ohio.

The aim of this project is to address the following question: For Summit participants, does the implementation of a one time, all day educational Summit about transitions from pediatric to adult services for adolescents living with Spina bifida and their families increase provider awareness of their current practice limitations in regards to transition compared to a practice group that has implemented transition models. The resultant establishment of a core group to develop transition service protocols that can be easily replicated across multiple facilities and CSHCN conditions.

Project Terms

- Summit- a meeting between those interested in the same thing.

  https://www.vocabulary.com/dictionary/summit

- Participants-Cambridge dictionary states a person who takes part in or becomes involved in a particular activity. http://dictionary.cambridge.org/dictionary/english/participant
- Transitions from pediatric to adult services-www.gottransition.org: Health care transition is the process of changing from a pediatric to an adult model of health care. The goal of transition is to optimize health and assist youth in reaching their full potential. To achieve this goal requires an organized transition process to support youth in acquiring independent health care skills, preparing for an adult model of care, and transferring to new providers without disruption in care.
- Adolescents-AAP defines early as ages 11-14 years, middle as ages 15-17, and late adolescence as 18-21 years old. Meanwhile American College of Clinical Oncology describes the age range more broadly 15-39 and varying determinants based on cancer staging. The Centers for Disease Control and Prevention (2014) defined adolescents from ages 10-19.
- Spina Bifida-according to NIH is a congenital neural tube defect in which the neural tube fails to close properly in development. www.spinabifidaassociation.org.
- Families-The word "family" refers to two or more persons who are related in any way—biologically, legally, or emotionally. Patients and families define their families. In the patient- and family-centered approach, the definition of family, as well as the degree of the family's involvement in health care, is determined by the patient, provided that he or she is developmentally mature and competent to do so. The term "family-centered" is in no way intended to remove control from patients who are competent to make decisions concerning their own health care. In pediatrics, particularly with infants and young children, family members are defined by the patient's parents or guardians. www.ipfcc.org.

Description of sequence of activities

The proposed sequences of activities include the following: 1) presurvey 2) Summit Participation 3) post survey 4) all participant evaluation of the conference program.

The Summit is scheduled for October 7 at the Wolstein Auditorium in Cleveland, Ohio from 7 am until 4 pm. The Summit schedule is located in Appendix D. A timeline description of the sequence of proposed activities is located in Appendix E.

Project setting

Wolstein Auditorium part of Case Western Reserve University campus community across the street from University Hospitals of Cleveland is a familiar conference venue for the participants. CEUs will be offered and included in registration fee. Participants who are health care professionals will be asked to sign in and complete Health Care Transition Survey: Provider Version modified with permission by Dr. Sarah Geenen. This survey measures the current knowledge and comfort level with transition services to those adolescents and young adults living with SB that they may care for in practice.

Project resources

The following resources have been identified for the Summit:

- Spina Bifida Association of America NE Ohio to sponsor the Summit and arrange on-line registration; disseminate marketing on their website, provide flyers to distribute
- Case Western Reserve University to secure venue (Wolstein Auditorium) and preferred college vendor arranges food and beverages, audio-visual equipment and services; tables/chairs rental
- University Hospital for arranging nursing CEUs (possible physician CME, social work CE)

- Case Western Reserve University School of Medicine establish account for costs associated with Summit
- Vendor list to contribute toward cost of Summit: Edgepark Surgical Supplies, Wellspect Health Care, Hollister, Inc., Coloplast, Color Your Corner, and SBAA.
- Speakers for the Summit (refer to Summit schedule in Appendix D) provided in kind donation.

To date 29 participants have registered representing 58% attainment of the goal of 50 participants.

Costs

Major estimated costs include:

- Wolstein Auditorium rental (free) if before 5pm in the evening weekdays
- Tables/chairs rental = $110.00
- Audio-visual equipment and technician = TBD
- Food and Beverages: $22.00/participant X 50 = $1100.00

Projected Revenue

- Vendor Fees = $1100.00
- Registration fee @ $35.00/participant X 50 participants = $1750.00

In-kind donations

- Wolstein Auditorium
- CEU application for nursing
- Marketing and Advertising
- Survey
- Speaker fees

Parking will not be covered. Participants will have to pay for parking unless there is enough revenue to arrange complimentary parking from University Parking, Inc. UH employees and staff will have access to parking through employment.

Evaluation

A logic model has been developed see Appendix F. The proposed evaluation of the Summit consists of 1) pre/post transition survey and 2) all participant evaluation. See Appendix G. The evaluation instrument is a modified survey used with permission by Sarah Geenen, MD. The program evaluation survey will be included with the hand out materials included in a packet upon registration day of the event.

Measurements

The Transition survey and program evaluation will be used for the Summit. Geenen (2003) developed the survey instrument to examine the reported level of provider involvement in specific transition activities. The provider survey was modified to inquire and rate health care providers' involvement in transition activities and the extent to which they felt it was a necessary job role function to provide those services. The published results noted standard alpha level was .83 for level of involvement and .87 for providers' responsibility to assist (Geenen, Powers, & Sells, 2003). The general educational evaluation survey will be used as part of the CEU requirement to receive a certificate at the end of the program. Participants will be required to be present for at least 80% of the educational activity. The Geenen Health Care Transition Survey: Provider Version was chosen to use because its variables matched those questions that the author was interested in evaluating.

Data Collection and Analysis Plan

The data collected from the pre and post Summit educational event anonymous surveys will be transferred to Access database developed and then exported to SPSS data base for analysis. Descriptive data from the participants will be collected to provide an overall description of attendees. The Health Care Transition Survey: Provider Version see Appendix G will be distributed to the participants upon registration and assigned Participant Number. The DNP student added a question to the post survey to identify persons willing to become more involved in a transition task force. The transition survey questions used a Likert scale of 1-5 (1 representing "not at all" and 5 representing "very much"). The results of the pre and post survey and evaluation of the education Summit to increase provider awareness of their current transition practice and barriers to provide transition services to adult based care will be analyzed in SPSS. Three primary outcomes will be identified by the analysis: 1) Results of the pre and post transition education survey, 2) document changes in expected role in transition access and provision, and 3) identify the number of volunteers interested in transition of care task force.

Protection of Human Subjects

An IRB application will be submitted to the Ursuline College Human Subjects Committee for an anonymous exempted questionnaire/survey. All SBA Educational Summit participants will be invited to participate upon on site check –in registration for the event. Healthcare provider participants will be asked to complete the pre and post Health Care Transition Survey: Provider Version and all participants a program evaluation at the conclusion of the educational event. No identifying data will be collected. Aggregated data will be analyzed and reported.

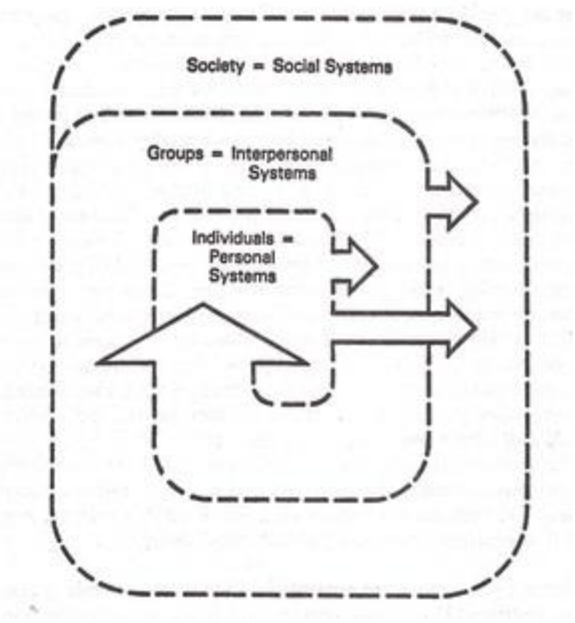
Dissemination plans

The following venues have been identified to share the results of the Capstone: 1) SBAA congress conference (March 2017), 2) SUNA local or national (Spring or Fall 2017), 3) presentation to local SB chapter, and 4) Grand Rounds Presentation.

Summary

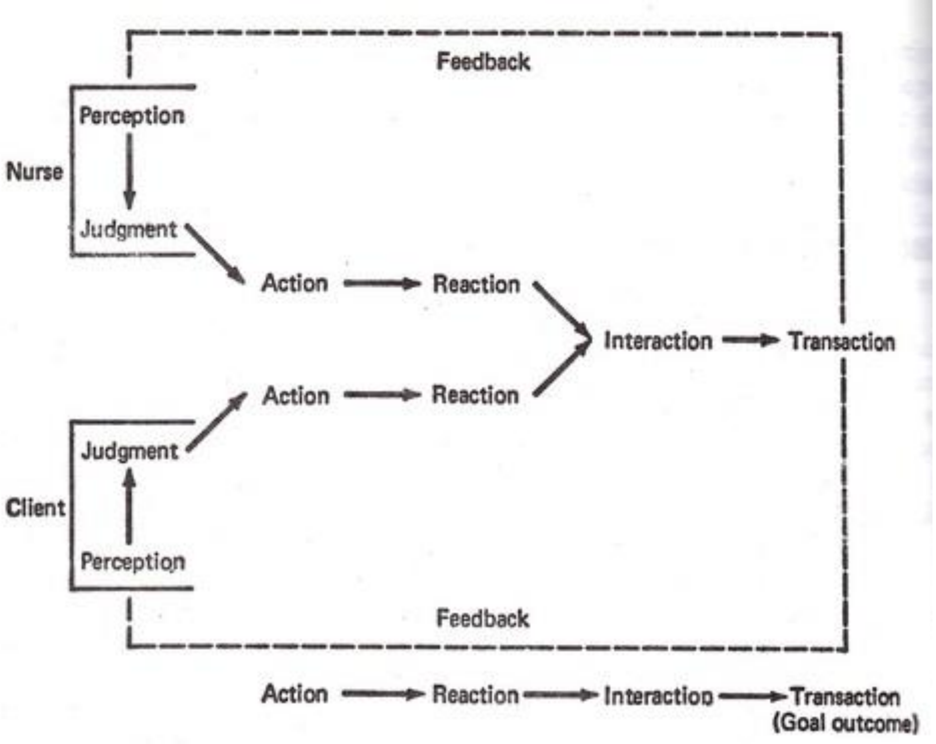
The increased life expectancy of adolescents and young adults with SB necessitates the continued provision of coordinated care throughout their lifespan. Transition from pediatric to adult based services, primary and subspecialty areas, requires a collaborative effort to make the process seamless and unencumbered by barriers. APRNs are a key component in bridging this transition gap between SB population, caregivers, and professionals. The community needs education about transition challenges and tools to develop the confidence in providing this care moving forward to prevent gaps in care and prevent complications from complex preventable chronic conditions.

Appendix A-Imogene King's A Conceptual Framework for Nursing: Dynamic Interaction Systems



Reprinted from King's Theory of Goal Attainment King, I. M. 1992, Nursing Science Quarterly, 5:1, Spring, pp. 19-26.

Appendix B-Imogene King's Interactions leading to Goal Attainment



Reprinted from King's Theory of Goal Attainment King, I. M. 1992, Nursing Science Quarterly, 5:1, Spring, pp. 19-26.

Appendix C-Transition to Spina Bifida Adult Care – refer to separate document

Appendix D-Summit Schedule

Cleveland Agenda

OCTOBER 7, 2016
WOLSTEIN AUDITORIUM
2103 CORNELL RD. CLEVELAND, OH 44106

6:30 – 7:00 am **Registration and continental breakfast**

7:00 – 7:15 am **Welcome and Introduction**

- **Suzanne Fortuna, MSN, RN, APRN-BC, CNS, FNP**

7:15– 8:15am **Crossing the bridge from Pediatric to Adult Care in Urology**

- **Hadley Wood MD, CCF, SBAA PAC member**

8:15 – 9:15 am **Transition from Teens to Adulthood: Barriers and Approaches to Care**

- **Irene Dietz MD**

9:15 – 10:00 am **Understanding Urological Reimbursement and Secure Start Services**

- **Hollister Inc.**

10:15 - 11:15 am **Legal Check-up for a Smooth Transition to Adulthood**

- **Laura McNally-Levine MLP Lawyer**

11:15 - 12:15 pm **Care of the Adult with Spina Bifida**

- **Brad Dicianno, MD**

12:15 – 1:15 pm **Lunch**

1:30 – 2:00 pm **Peristeen Bowel Management and Urologic Catheterization: Evolution & Reimbursement**

- **Coloplast**

2:00 - 2:45 pm **Breakout Sessions**

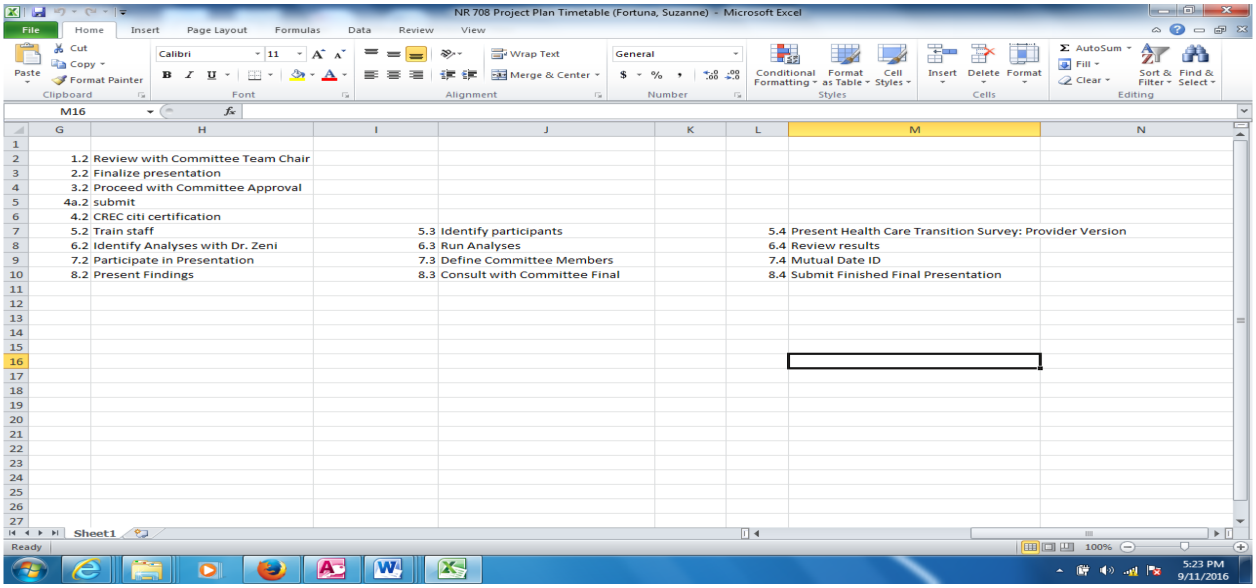
- **Concurrent Adolescent/Female Adult Sexuality/Building Provider Trust: Building Healthy Relationships (18 and older females only affected by Spina Bifida and or caregivers)**
  - **Suzanne Fortuna CNS, FNP and Lauren Burdett SW**
- **Concurrent Adult Sexuality:** Sexuality in Spina Bifida: a conversation **(18 year old males only and up affected by Spina Bifida and or caregivers)**
  - **Hadley Wood, MD**
- **Concurrent Mental Illness Prevalence and Risk Factors Among Transitional Youth with Spina Bifida (For Healthcare Providers only)**
  - **Theresa Hovanec Berger, MHNP**

3:00 – 3:30 pm **Adolescent/Young Adult Transition Discussion Panel**

3:30 – 4:00 pm **Closing Remarks**

REGISTER TODAY
www.sbeducationdays.org

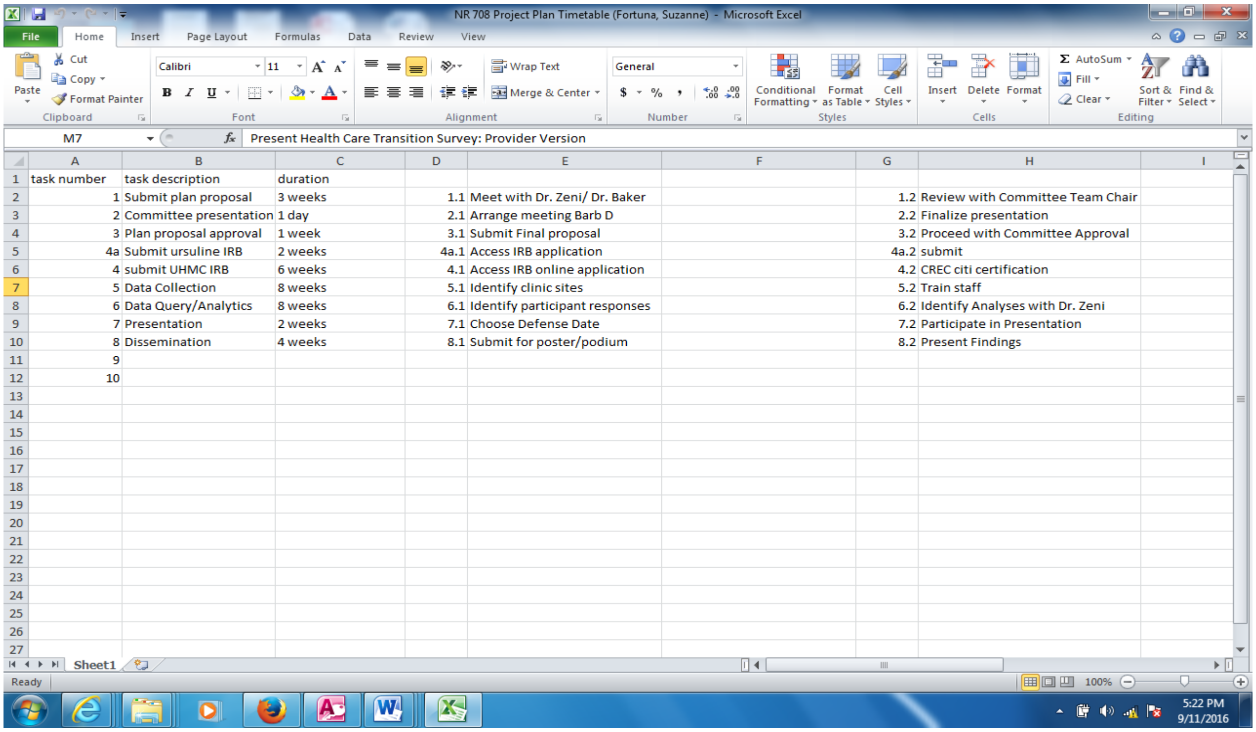
Appendix E-Sequence of Activities



NR 708 Project Plan Timetable (Fortuna, Suzanne) - Microsoft Excel

M16

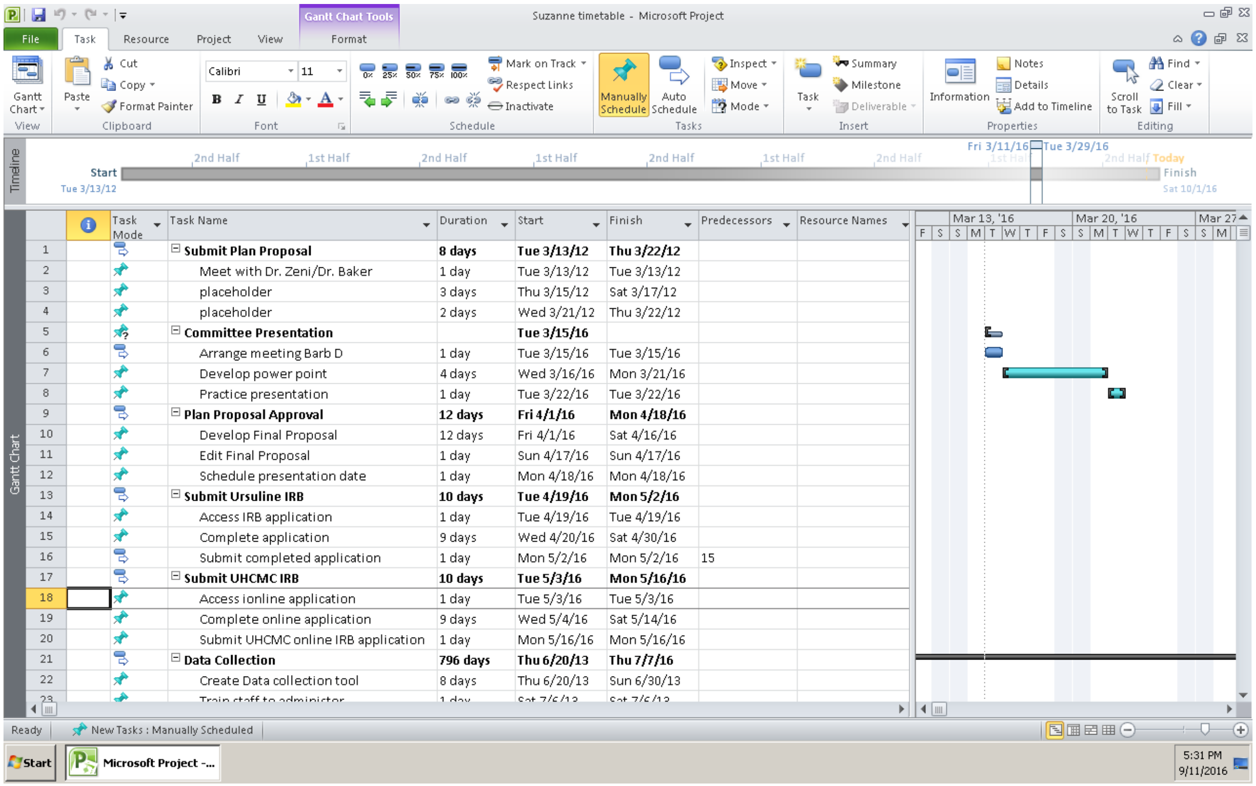
	G	H	I	J	K	L	M	N
1								
2	1.2	Review with Committee Team Chair						
3	2.2	Finalize presentation						
4	3.2	Proceed with Committee Approval						
5	4a.2	submit						
6	4.2	CREC citi certification						
7	5.2	Train staff	5.3	Identify participants		5.4	Present Health Care Transition Survey: Provider Version	
8	6.2	Identify Analyses with Dr. Zeni	6.3	Run Analyses		6.4	Review results	
9	7.2	Participate in Presentation	7.3	Define Committee Members		7.4	Mutual Date ID	
10	8.2	Present Findings	8.3	Consult with Committee Final		8.4	Submit Finished Final Presentation	



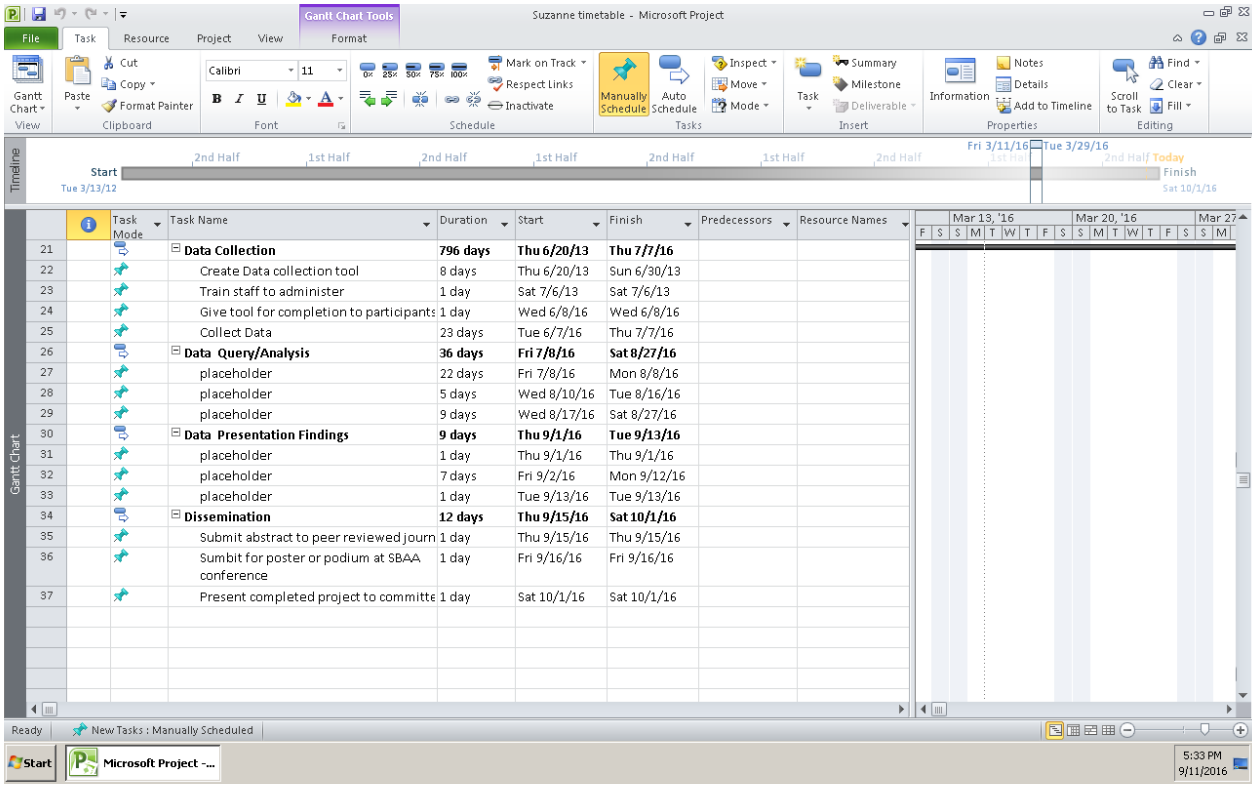
NR 708 Project Plan Timetable (Fortuna, Suzanne) - Microsoft Excel

M7 Present Health Care Transition Survey: Provider Version

	A	B	C	D	E	F	G	H	I
1	task number	task description	duration						
2	1	Submit plan proposal	3 weeks	1.1	Meet with Dr. Zeni/ Dr. Baker		1.2	Review with Committee Team Chair	
3	2	Committee presentation	1 day	2.1	Arrange meeting Barb D		2.2	Finalize presentation	
4	3	Plan proposal approval	1 week	3.1	Submit Final proposal		3.2	Proceed with Committee Approval	
5	4a	Submit ursuline IRB	2 weeks	4a.1	Access IRB application		4a.2	submit	
6	4	submit UHMC IRB	6 weeks	4.1	Access IRB online application		4.2	CREC citi certification	
7	5	Data Collection	8 weeks	5.1	Identify clinic sites		5.2	Train staff	
8	6	Data Query/Analytics	8 weeks	6.1	Identify participant responses		6.2	Identify Analyses with Dr. Zeni	
9	7	Presentation	2 weeks	7.1	Choose Defense Date		7.2	Participate in Presentation	
10	8	Dissemination	4 weeks	8.1	Submit for poster/podium		8.2	Present Findings	
11	9								
12	10								



	Task Mode	Task Name	Duration	Start	Finish	Predecessors	Resource Names
1		**⊟ Submit Plan Proposal**	**8 days**	**Tue 3/13/12**	**Thu 3/22/12**		
2		Meet with Dr. Zeni/Dr. Baker	1 day	Tue 3/13/12	Tue 3/13/12		
3		placeholder	3 days	Thu 3/15/12	Sat 3/17/12		
4		placeholder	2 days	Wed 3/21/12	Thu 3/22/12		
5		**⊟ Committee Presentation**		**Tue 3/15/16**			
6		Arrange meeting Barb D	1 day	Tue 3/15/16	Tue 3/15/16		
7		Develop power point	4 days	Wed 3/16/16	Mon 3/21/16		
8		Practice presentation	1 day	Tue 3/22/16	Tue 3/22/16		
9		**⊟ Plan Proposal Approval**	**12 days**	**Fri 4/1/16**	**Mon 4/18/16**		
10		Develop Final Proposal	12 days	Fri 4/1/16	Sat 4/16/16		
11		Edit Final Proposal	1 day	Sun 4/17/16	Sun 4/17/16		
12		Schedule presentation date	1 day	Mon 4/18/16	Mon 4/18/16		
13		**⊟ Submit Ursuline IRB**	**10 days**	**Tue 4/19/16**	**Mon 5/2/16**		
14		Access IRB application	1 day	Tue 4/19/16	Tue 4/19/16		
15		Complete application	9 days	Wed 4/20/16	Sat 4/30/16		
16		Submit completed application	1 day	Mon 5/2/16	Mon 5/2/16	15	
17		**⊟ Submit UHCMC IRB**	**10 days**	**Tue 5/3/16**	**Mon 5/16/16**		
18		Access ionline application	1 day	Tue 5/3/16	Tue 5/3/16		
19		Complete online application	9 days	Wed 5/4/16	Sat 5/14/16		
20		Submit UHCMC online IRB application	1 day	Mon 5/16/16	Mon 5/16/16		
21		**⊟ Data Collection**	**796 days**	**Thu 6/20/13**	**Thu 7/7/16**		
22		Create Data collection tool	8 days	Thu 6/20/13	Sun 6/30/13		



	Task Mode	Task Name	Duration	Start	Finish	Predecessors	Resource Names
21		**⊟ Data Collection**	**796 days**	**Thu 6/20/13**	**Thu 7/7/16**		
22		Create Data collection tool	8 days	Thu 6/20/13	Sun 6/30/13		
23		Train staff to administer	1 day	Sat 7/6/13	Sat 7/6/13		
24		Give tool for completion to participants	1 day	Wed 6/8/16	Wed 6/8/16		
25		Collect Data	23 days	Tue 6/7/16	Thu 7/7/16		
26		**⊟ Data Query/Analysis**	**36 days**	**Fri 7/8/16**	**Sat 8/27/16**		
27		placeholder	22 days	Fri 7/8/16	Mon 8/8/16		
28		placeholder	5 days	Wed 8/10/16	Tue 8/16/16		
29		placeholder	9 days	Wed 8/17/16	Sat 8/27/16		
30		**⊟ Data Presentation Findings**	**9 days**	**Thu 9/1/16**	**Tue 9/13/16**		
31		placeholder	1 day	Thu 9/1/16	Thu 9/1/16		
32		placeholder	7 days	Fri 9/2/16	Mon 9/12/16		
33		placeholder	1 day	Tue 9/13/16	Tue 9/13/16		
34		**⊟ Dissemination**	**12 days**	**Thu 9/15/16**	**Sat 10/1/16**		
35		Submit abstract to peer reviewed journ	1 day	Thu 9/15/16	Thu 9/15/16		
36		Sumbit for poster or podium at SBAA conference	1 day	Fri 9/16/16	Fri 9/16/16		
37		Present completed project to committe	1 day	Sat 10/1/16	Sat 10/1/16		

Appendix F-Logic Model

OUTCOMES

Inputs	Activities	Outputs	Short	Intermediate	Long
Determine Provider Educational Needs about Transition	**Attend SBAA National Conference**	**Providers participation in SB Educational Summit**	**Providers that attend Ed Summit will have increased knowledge about barriers to transition and challenges to provide seamless transition process**	**SBA local chapter development**	**APRNs and providers will apply principles of transition to adult based services into their daily practice for successful transition of adolescents and young adults with SB**
Determine key stakeholders	**Create a list of expert speakers in the field and invite to Summit**	**Identified and accepted speaker list finalized**	**Identify core transition champions**	**Establish transition protocols for SB Adolescents and young adults**	
Obtain funding for SB Ed Summit	**Select venue, date, time to hold event** **Marketing of SB Ed Summit** **-UH** **-SBA** **-ODH** **-APN list serve** **Create online registration platform**				

	Complete OBN CEU paperwork **Choose pre educational activity survey, post survey, and program evaluation**				

Appendix G- Health Care Transition Survey: Provider Version

SPINA BIFIDA SUMMIT PROVIDER SURVEY

This survey is being administered to learn about how health care providers view their roles in assisting teenagers with special health care needs or disabilities to prepare for successful transition to adulthood based services. The purpose of this survey is to get more information on the current involvement of health care providers in assisting youth with disabilities or special health care needs prepare for transition, and what providers believe their role in transition planning should be.

The information you give us will be confidential and your survey will be anonymous.

We really want to hear from you!

This Survey is modified with permission courtesy of Sarah Geenen, MD

OHSU Center on Self Determination

3608 SE Powell Blvd.

Portland, OR 97202

The questions in the survey are about the adolescent patients and young adults with chronic health care needs or disabilities you serve. We would like you to focus on those patients/clients specifically with Spina Bifida for this particular conference survey.

1. What type of health care provider are you? ***(check one)***

- ☐ Ambulatory/Primary Pediatrician
- ☐ Developmental Pediatrician
- ☐ Behavioral Pediatrician
- ☐ Adolescent Medicine
- ☐ Family Practitioner
- ☐ Internist
- ☐ Physician Assistant
- ☐ Nurse Practitioner
- ☐ Nurse
- ☐ Specialist (please describe):___________________________
- ☐ Social Work
- ☐ Therapist (OT, PT, SP)
- ☐ Other (please describe): ______________________________

2. What percentage of your professional activities is spent in each of the following employment settings?

(NOTE: Percent’s should sum to 100%)

Self-employed solo practice... __________%

Pediatric Group practice.. __________%

Multi-specialty group... __________%

HMO (staff model)... __________%

Medical school or public university... __________%

Private hospital.. __________%

City/county/state government hospital or clinic.. __________%

US government hospital or clinic.. __________%

Free-standing ambulatory care, surgical or emergency care center......................... __________%

Non-profit community health center.. __________%

Other (specify :______________________________)...................................... __________%

TOTAL

1
0
0
%

3. During a typical workweek, what percentage of your time do you spend in the following professional activities? If you do not spend any time in a particular activity, please indicate this by entering zero (0) in the appropriate space. (NOTE: Percent's should sum to 100%)

Direct patient care………………………………………………………… __________%

Administration…………………………………………………………… __________%

Academic medicine……………………………………………………… __________%

Research…………………………………………………………………… __________%

Training …………………………………………………………………… __________%

Other (specify :____________________________________)……………… __________%

TOTAL

100%

4. Please indicate your best estimate of the percentage of all your patients in the following age groups.

If you do not have patients in a specific age group, please place a zero (0) in that space.

(NOTE: Percent's should sum to 100%)

Under 2 years………………………………………… ___________*%*

3 through 5 years ………………………………………… ___________*%*

6 through 11 years………………………………………… ___________*%*

12 through 17 years………………………………………… ___________*%*

18 through 21 years………………………………………… ___________*%*

22 years and older………………………………………… ___________*%*

TOTAL

100%

5. For patients who are 21 years of age or younger, please indicate the percentage of youth you see who have <u>chronic health care needs or a disability and specifically Spina Bifida</u> *(check one)*

☐ Less than 10%

☐ 10% to 25%

☐ 26% to 50%

☐ 51 to 75%

☐ 76 to 100%

6. For patients who are 21 years of age or younger, please estimate what proportion of the youth you see are in the following ethnic or cultural groups? (NOTE: Percent's TOTAL should sum to 100%)

White, non-Hispanic.. __________%

Asian or Pacific Islander.. __________%

African-American.. __________%

Hispanic/Latino.. __________%

Native American.. __________%

Other (specify: ____________________).. __________%

TOTAL

100%

7. For patients who are 21 years of age or younger, please indicate what percentages of the youth you see through your practice (specifically, the practice where you spend MOST of your time) are covered by the following types of health insurance or methods of payment. If you have no patients who fall into one of the categories specified below, please place a zero (0) in that space.

(NOTE: Percent's should sum to 100%)

Private insurance (e.g. traditional fee-for-service, HMO, PPO, etc.)................... __________%

Public insurance (e.g. Medicaid, SCHIP, OHP, etc.).. __________%

TRICARE (military insurance)... __________%

Uninsured/self-pay... __________%

Other (specify :_______________________________).. __________%

TOTAL

100%

8. Indicate the community in which your main practice/office is located. (*check one*)

☐ Urban, inner-city

☐ Urban, not inner-city

☐ Suburban

☐ Rural

9. What is your gender?

☐ Male

☐ Female

☐ Other

10. In what year were you born? (Optional)

19____

Questions 11 through 23 are about things health care providers may do to help young people with Spina Bifida prepare for adulthood. In column B, please rate how much you typically help <u>young people with Spina Bifida</u> in this area. In column C, please rate the extent to which you feel it is within your role to assist in this area. For each rating, please circle the response that best matches your answer:

1 = Not at all

2 = A Little

3 = Sometimes/Somewhat

4 = Quite a bit

5 =Very Much

AREA	**B** **How much have you become involved with your patients in this area?**	**C** **Is it within your role to assist in this area?**
11. Taking care of my patients' disability or health condition.	Not at All Very Much 1 2 3 4 5	Not at All Very Much 1 2 3 4 5
12. Taking care of my patients' general health (e.g., accidents, flu &colds, immunizations, ob/gyn services).	1 2 3 4 5	1 2 3 4 5
13. Talking to my patients about sexual issues (e.g. sexual activity, sexually transmitted diseases)	1 2 3 4 5	1 2 3 4 5
14. Talking to my patients about drugs and alcohol.	1 2 3 4 5	1 2 3 4 5

AREA	**B** **How much have you become involved with your patients in this area?**	**C** **Is it within your role to assist in this area?**
15. Screening my patients for mental health problems (e.g. depression, suicide).	1 2 3 4 5	1 2 3 4 5
16. Coordinating my patients' health care with other health care providers my patients' are seeing.	1 2 3 4 5	1 2 3 4 5
17. Working with schools to coordinate care for my patients' disabilities or health conditions.	1 2 3 4 5	1 2 3 4 5
18. Connecting my patients to other services in the community (e.g., Vocational Rehabilitation, Family Support, and Mental Health Services).	1 2 3 4 5	1 2 3 4 5
19. Helping my patients' apply for or keep Supplemental Security Income (SSI)	1 2 3 4 5	1 2 3 4 5

AREA	**B** **How much have you become involved with your patients in this area?**	**C** **Is it within your role to assist in this area?**
20. Helping my patients get health insurance when they become adults.	1 2 3 4 5	1 2 3 4 5
21. Finding health care providers who will care for patients' when they become adults.	Not at All Very Much 1 2 3 4 5	Not at All Very Much 1 2 3 4 5
22. Discussing with my patients how to take care of their health to be successful at work or college.	1 2 3 4 5	1 2 3 4 5
23. Teaching my patients' how to manage their health condition on their own	1 2 3 4 5	1 2 3 4 5

For items 11 through 23, if there were any activities or areas that you feel are within your role but you have not been as involved as you would like, please check the barriers to involvement you have encountered (check all that apply):

☐ I do not have enough time.

☐ I feel I need additional training.

☐ Financial reimbursement does not support my time in these activities.

☐ I need more information or involvement from the families or youth I serve.

☐ Other (please describe): ______________________________

____

____

____

Questions 25 through 27 ask you to tell us what age, in general, your patients' should be when you begin to do discuss certain healthcare decisions.

25. In general, how old should patients be when you begin preparing them to care for their

Disabilities' or health problems on their own? ***(Please fill in the age)***

________________ Years of Age

26. In general, how old should patients be when you begin spending some of the appointment meeting with them alone? ***(Please fill in the age)***

________________ Years of Age

27. In general, how old should patients be when you begin to help them transition from pediatric to adult health care providers? ***(Please fill in the age)***

________________ Years of Age

If you have any ideas or suggestions on how health care providers can assist teenagers and young adults with disabilities or special health needs prepare for successful adulthood, we would like to hear from you! Please write your comments below:

____

____

____

If you would consider joining a local community task force to further plan on transition services for youth and young adults with Spina Bifida please provide a method of contact for a representative to communicate plans with you.

Phone number: ____________________ **Best time to call:** _______________________

Email: ____

THANK YOU FOR FILLING OUT THIS SURVEY!

SPINA BIFIDA SUMMIT PROVIDER SURVEY

POST CONFERENCE

After participating in today's Summit please complete the following:

For each rating, please circle the response that best matches your answer:

1 = Not at all

2 = A Little

3 = Sometimes/Somewhat

4 = Quite a bit

5 =Very Much

AREA	**B** **How much will you become involved with your patients in this area in the future?**
	Not at All Very Much
11. Taking care of my patients' disability or health condition.	1 2 3 4 5
12. Taking care of my patients' general health (e.g., accidents, flu &colds, immunizations, ob/gyn).	1 2 3 4 5
13. Talking to my patients about sexual issues (e.g. sexual activity, sexually transmitted diseases)	1 2 3 4 5
14. Talking to my patients about drugs and alcohol.	1 2 3 4 5
15. Screening my patients for mental health problems (e.g. depression, suicide).	1 2 3 4 5
16. Coordinating my patients' health care with other health care providers my patients' are seeing.	1 2 3 4 5
17. Working with schools to coordinate care for my patients' disabilities or health conditions.	1 2 3 4 5

AREA	**B** **How much will you become involved with your patients in this area in the future?**
18. Connecting my patients to other services in the community (e.g., Vocational Rehabilitation, Family Support, and Mental Health Services).	1 2 3 4 5
19. Helping my patients' apply for or keep Supplemental Security Income (SSI)	1 2 3 4 5
20. Helping my patients get health insurance when they become adults.	1 2 3 4 5
21. Finding health care providers who will care for patients' when they become adults.	Not at All Very Much 1 2 3 4 5
22. Discussing with my patients how to take care of their health to be successful at work or college.	1 2 3 4 5
23. Teaching my patients' how to manage their health condition on their own	1 2 3 4 5

Will the information you learned today change your practice? If yes, please describe one practice change. ____

Would you be interested in participating in a transition task force? Yes   No If yes, please provide contact information: ____

____

Any comments to improve the program: ____

____

____

Any future program suggestions: ____

____

____

THANK YOU FOR FILLING OUT THIS SURVEY!

References

American Academy of Family Physicians; American Academy of Pediatrics; American College of Physicians; American Osteopathic Association. (2010). Joint principles of the patient-centered medical home. *Available at: www.pcpcc.net/content/joint-principles-patient-centered-medical home.* Accessed May 17, 2016.

Bethell, C. D., Read, D., Brockwood, K., American Academy of Pediatrics. (2004). Using existing population-based data sets to measure the American Academy of Pediatrics definition of medical home for all children and children with special health care needs. *Pediatrics,* 113, (5 suppl): 1529-37.

Boudreau, A. A., Goodman, E., Kurowski, D., Perrin, J. M., Cooley, C., Kuhlthau, K. (2014). Care coordination and unmet specialty care among children with special health care needs. *Pediatrics,* Vol. 133, Issue 6, 1046-1053. Doi: 10.1542/peds.2013-2174.

Brei, T.J. (2007). The Future of the Multidisciplinary Clinic. *The Scientific World Journal*, 7, 1752-1756.

Dicianno, B. E., & Wilson, R. (2010). Hospitalizations of adults with spine bifida and congenital spinal cord anomalies. *Archives of Physical Medicine and Rehabilitation, 91*(4), 529-535. Doi: http://dx.doi.org/10.1016/j.apmr.2009.11.023

Geerts, E., Van DeWiel, H., Tamminga, R. (2008). A pilot study on the effects of the transition of paediatric to adult health care in patients with haemophilia and in their parents: patients and parent worries, parental illness related distress and health related quality of life. *Haemophilia*, 14:1007-1013.

Geenen, S. J., Powers, L. E., Sells, W. (2003). Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *Society for Adolescent Medicine*, 32: 225-233.

Fineout-Overholt, E., Melnyk, B.M., Stillwell, S. B., and Williamson, K. M. (2010). Evidenced based practice step by step: Critical appraisal of the evidence: Part 1. *AJN*, Vol. 110, No. 7, 47-52.

Kennedy, A., Sawyer, S.M. (2008). Transition from pediatric to adult services: are we getting it right? *Curr Opinion Pediatrics*, 20: 403-309.

King, I. M. (1992). King's Theory of Goal Attainment. *Nursing Science Quarterly*, 5:1, 19-26.

Lewis, J., Slobodov, G. (2015). Transition from pediatric to adult health care in patients with chronic illnesses: An integrative review. *Urologic Nursing*, 35 (5), 1-7.

Liptak, G. S., Kennedy, J. A., & Dosa, N. P. (2010). Youth with spina bifida and transitions: Health and social participation in a nationally represented sample. *The Journal of Pediatrics, 157*(4), 584-588.e1. Doi: http://dx.doi.org/10.1016/j.jpeds.2010.04.004

Lomas, J. (1993). Retailing research: increasing the role of evidence in clinical services for childbirth. *The Milbank Quarterly*, 71 (3), 439-475.

McPherson, M., Arango, P., Fox, H., Lauver, C., McManus …& Strickland, B. (1998). A new definition of children with special health care needs. *Pediatrics*, 102, 137-140.

Melnyk, B. M., Fineout-Overholt, E., Stillwell, S. B., and Williamson, K.M. (2010). Evidenced based practice step by step: The seven steps of evidenced-based practice. *AJN*, Vol. 110, No. 1, 51-53.

Melnyk, B., Fineout-Overholt, E. (2014) Evidenced based practice in nursing and healthcare: A guide to Best Practice, 3rd Edition. Wolters-Kluwer, Philadelphia, PA.

Mukherjee, S. (2007). Transition to Adulthood in Spine Bifida: Changing Roles and Expectations. *The Scientific World Journal*, 7, 1890-1895.

NINDS. "Spina Bifida Fact Sheet," Publication date June 2013. NIH Publication No. 13-309

Rauen, K., Sawin, K., Bartelt, T., Waring, W., Orr, M. & O'Connor, R. (2013).Transitioning adolescents and young adults with a chronic health condition to adult healthcare - an exemplar program. *Rehabilitation Nursing, 38*(2), 63-72.

Ridosh, M. B. (2011). Transition in young adults with spina bifida: A qualitative study. *Child: Care, Health & Development, 37*(6), 866-874. doi:10.1111/j.1365-2214.2011.01329.x

Sawin KJ, Rauen K, Bartelt T, et al. (2015).Transitioning adolescents and young adults with spina bifida to adult healthcare: Initial findings from a model program. *Rehabilitation Nursing*. 40 (1):3-11.

Schor, E. (2015). Transition: Changing old habits. *Pediatrics,* Vol 135, No. 6, 958-960. Doi: 10.1542/peds.2014-3934.

Strickland, B., McPherson, M., Weissman, G. et al. (2004). Access to the medical home. Results of the National Survey of Children with Special Health Care Needs. *Pediatrics*, 113: 1485-1492.

Strickland, B. B., Jones, J. R., Ghandowe, R. M., Kogan, M. D., Newacheck, D.W. (2011). The medical home: health care access and impact for children and youth in the U.S. *Pediatrics*, Vol. 127, (4): 604-611. Doi: 10.1543/peds.2009-3555.

Spina bifida: key primary care issues (2002). *Australian Family Physicians.* 31 (1), 66-69.

Van Cleave, J., Boudreau, A., McAllister, J., Cooley, C., Maxwell, A. and Kuhithau, K. (2015). Care coordination over time in medical homes for children with special health care needs. *Pediatrics,* Vol 135, No. 6, 1018-1026. Doi: 10.1542/peds.2014-1067.

Wang et al. (2010). Health care transitions among youth with disabilities or special health care needs (SHCN): an ecological approach. *Journal Pediatric Nurse,* 25 (6), 505-550. Doi: 10.1016/j.pedn.2009.07.003.

West, C., Brodie, L., Dicker, J., Steinbeck, K. Development of health support services for adults with spina bifida. *Disability & Rehabilitation*. 2011; 33 (23):2381-2388.

Woodward J, F., Swigonski, N. L., Ciccarelli M, R. Assessing the health, functional characteristics, and health needs of youth attending a noncategorical transition support program. *J Adolesc Health*. 2012; 51 (3):272-278.

Young NL, Sheridan K, Burke TA, Mukherjee S, McCormick A. Health outcomes among youths and adults with spina bifida. *J Pediatr*. 2013; 162 (5):993-998.