



Spina Bifida Association NEO Educational Summit: Building Collaborative Ties to Create Seamless Access from Pediatric to Adult Services

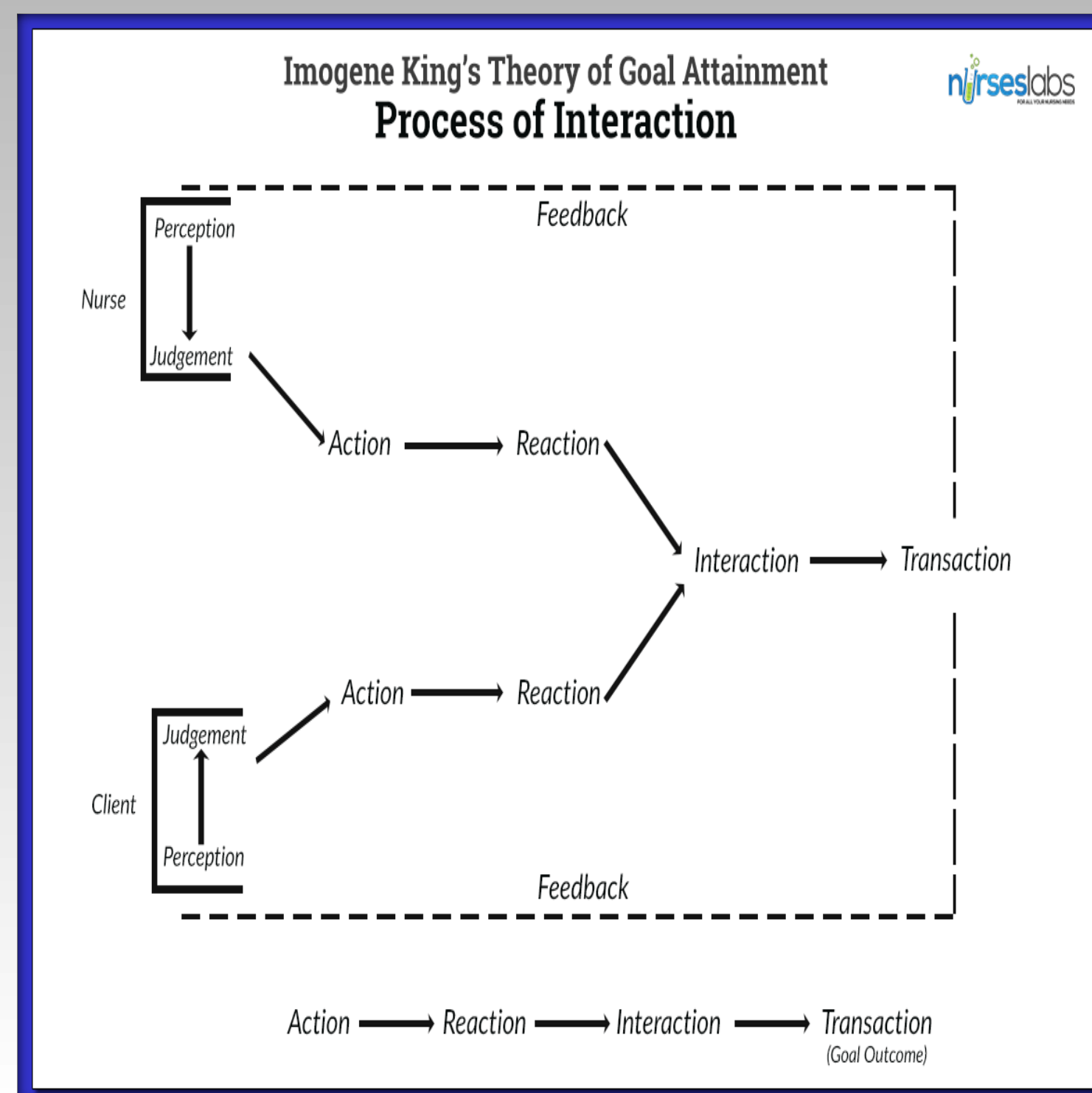
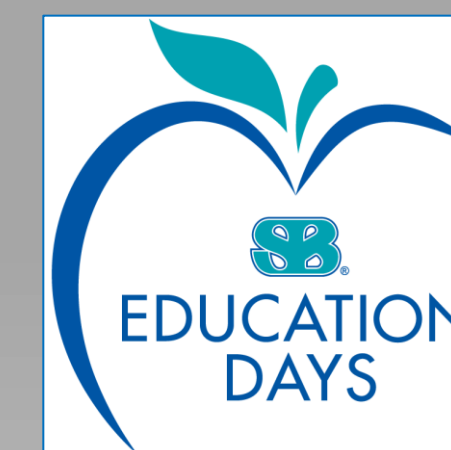
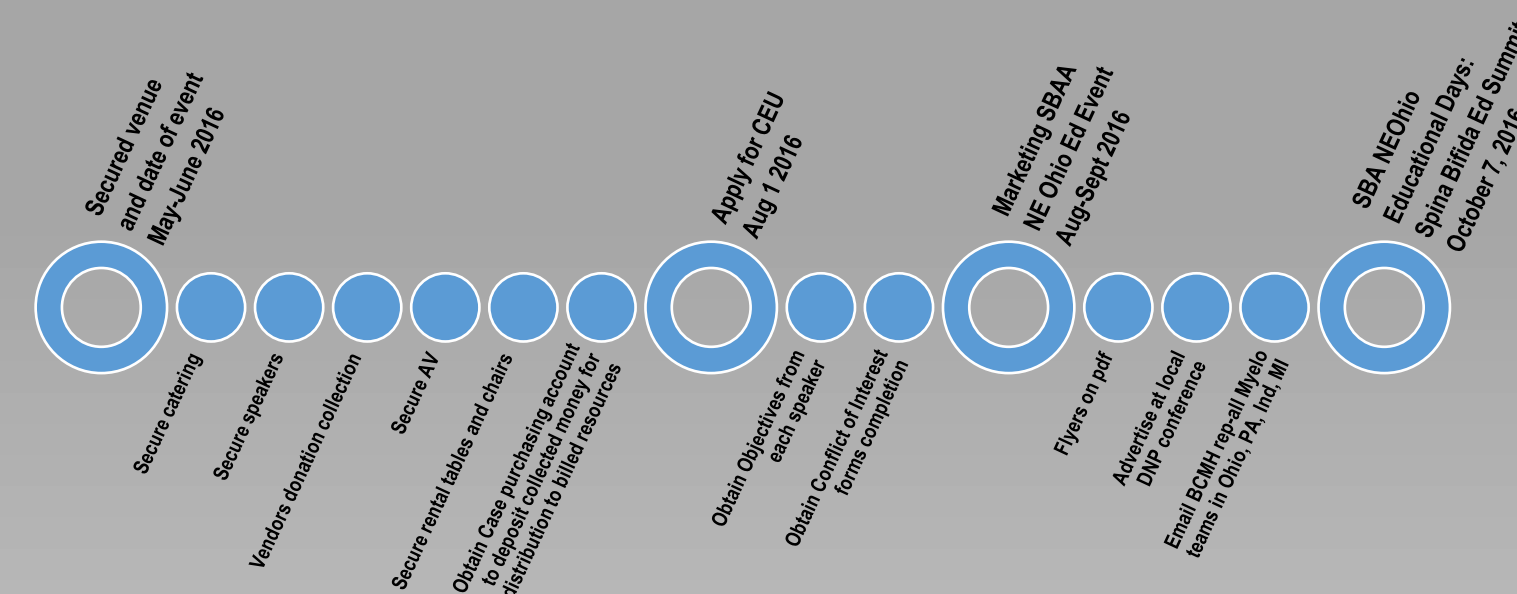


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INTRODUCTION

- Spina Bifida (SB) is a congenital neural tube defect that occurs at conception and is considered a complex multi-system birth defect (NIH, 2013).
 - Prevalence rates (CDC, 2014):
 - Hispanic: 3.80 per 10,000 live births.
 - Non-Hispanic black or African-American: 2.73 per 10,000 live births.
 - Non-Hispanic white: 3.09 per 10,000 live births.
 - Improved prevalence rates due to folic acid fortification
 - The lifespan of children living with SB has continually increased and now exceeds 85% due to improvements in medical and surgical management.
- The effects of SB can vary in severity for an individual and depends on where the level of defect occurs along the neural tube.
 - Many children have congenital hydrocephalus resulting in cognitive and social delays.
 - Others have difficulty with ambulation requiring use of ambulatory aids like braces or forearm crutches.
 - Some children are severely affected - will be wheelchair bound for their lifetimes.
 - Bladder and bowel issues are very common and prevent independent continence.
 - 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.
 - Care for the child and family is usually coordinated within a SB clinic, or program, located at a children's hospital.
 - Increased survival clearly supports the need to provide care across the continuum to include more adult based services.
 - Young adults with SB have unique medical and social needs that are not commonly addressed in a pediatric service.
- Transition from pediatric to adult care present both barriers and challenges to the adult population living with SB, their families and healthcare providers

DNP CAPSTONE TIMELINE OF ACTIVITIES:



MATERIALS & METHODS

- A needs assessment and literature reviews identified engagement was needed.
- Identified 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 was completed as an intervention to foster mutual goal setting and exploration.

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, Cleveland Clinic Foundation, SBAA PAC member
8:15 – 9:15 am	Transition from Teens to Adulthood: Barriers and Approaches to Care • Irene Dietz MD, MetroHealth Medical Center Comp Care Program
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, University of Pittsburgh Medical Center
12:15 – 1:15 pm	Lunch
1:30 – 2:00 pm	Peristeen Bowel Management and Urologic Catheterization: & Reimbursement • Coloplast Representative
2:00 - 2:45 pm	Breakout Sessions * Concurrent Adolescent/Female Adult Sexuality/Building Trust: Building Healthy Relationships (18 and older females only affected by Spina Bifida and or caregivers) o 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) o Hadley Wood, MD * Concurrent Mental Illness Prevalence and Risk Factors Among Transitional Youth with Spina Bifida (For Healthcare Providers only) o Theresa Hovanec Berger, MHNP Beacon Health
3:00 – 3:30 pm	Adolescent/Young Adult Transition Discussion Panel
3:30 – 4:00 pm	Closing Remarks

REGISTER TODAY
www.sbeducationdays.org

RESULTS

- 29 participants attended the Educational Summit
 - The goal was 50 participants so 54% was achieved
 - Majority (79%) were registered nurses or advanced practice registered nurses
 - Pre and post conference surveys were received from 18 (62%) of the 29 participants
 - Wilcoxon signed rank test was used to test significance (alpha = 0.05) between pre and post conference surveys
 - Significant increase between pre and post responses was found for all 12 questions addressing transition practices and beliefs.
 - 1 question that was not significant: taking care of my patients' disability or health condition
 - Fourteen speakers provided content about transition from pediatric to adult programs
 - Participants reported increased awareness and commitment to transition practice.
 - All attendees (100%) reported satisfaction with the program
 - 95% rated speakers on the Likert scale as either a 5 or 4 (excellent or very good).
- ## CONCLUSIONS
- The SBA Educational Summit on transition for youth and young adults living with spina bifida was successful
 - Participants requested another opportunity to attend future transition events.
 - The Educational Summit met the aim to educate participants to commit and contribute to active transition planning and assistance in their practices.

REFERENCES AVAILABLE UPON REQUEST

