

SBA NEO Educational Summit: Building collaborative ties to create seamless access from pediatric to adult services

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Background

- ▶ **Spina Bifida (SB) is a neural tube defect**
- ▶ **Problem population living longer into adulthood**
- ▶ **Need establish transition into adult based services**
- ▶ **Lack of adult clinics/medical homes in Ohio**
- ▶ **Spina Bifida Association of America sponsor NEO Adult Education Day**

Purpose

- ▶ Provide an educational Summit for people living with SB, families, and both pediatric and adult health care professionals.
- ▶ Identification and education of key stakeholders involved in transition services is first needed to promote engagement toward a common goal.
- ▶ Aim to establish a core group of people committed to plan, implement, and evaluate adult transition services for adolescents and young adults living with SB.
- ▶ Does successful transition to adult based care decrease unnecessary ER visits for adolescents and young adults with SB?

Project Learning Outcomes Objectives

- ▶ **Develop leadership skills in linking role of Licensed Independent Provider (LIP) multidisciplinary team member to bridge pediatric to adult based services gap.**
- ▶ **Collaborate with specialty team providers that care for adults with Special Healthcare Needs (SHCN).**
- ▶ **Assist clients/caregivers to access appropriate primary care providers and community resources to develop medical homes into adulthood.**
- ▶ **Evaluate attendance at SB multidisciplinary clinics to improve health outcomes and decrease Emergency Room (ER) visits for preventable care conditions.**

Evidenced Based Interventions

- ▶ Literature Review-Healthy People 2020
- ▶ Analysis of Current State of Affairs
- ▶ Health Care Transition Survey: Provider Version
- ▶ AAP 2015 Module 4: Facilitating the Transition From Pediatric to Adult Care resource
- ▶ SBAA “Preparations”
- ▶ Transition Readiness tools www.gottransition.gov

Methods: Data Collection Tools

- ▶ Demographic Data Sheet
- ▶ Pre-post transition surveys at upcoming Spina Bifida Association Adult Education Day Summit
- ▶ Modified with permission Dr. Geenen survey
- ▶ Post program evaluation for CEU certificate
- ▶ SPSS input for data analysis

Results

- ▶ 29 participants attended the Educational Summit.
- ▶ 14 speakers provided content about transition from pediatric to adult programs, transition obstacles and challenges, mental health assessments, and bowel program innovations.
- ▶ Breakout sessions for teen/young adult on sexuality were also provided.
- ▶ A majority of attendees (21 of 29, or 72%) were registered nurses or advanced practice registered nurses who work with youth, young adults, and families living with Spina bifida.
- ▶ Pre and post conference surveys were received from 18 (62%) of the 29 participants
- ▶ Participants reported increased awareness and commitment to transition practice.
- ▶ Wilcoxon signed rank test was used to test significance ($\alpha = 0.05$) between pre and post conference surveys
- ▶ Significance was found for all 13 questions addressing transition practices and beliefs.
- ▶ All attendees (100%) reported satisfaction with the program and 95% rated speakers on the Likert scale as either a 5 or 4 (excellent or very good.)

Conclusion

- ▶ The SBA Educational Summit on transition for youth and young adults living with Spina bifida was successful and many 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.
- ▶ 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 on the part of patients, families and providers.
- ▶ APRN's are a key component in bridging this transition gap between SB population, caregivers, and professionals.

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