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**Transition**

## Education and employment as young adults living with spina bifida transition to adulthood: A study of the National Spina Bifida Patient Registry, 2009-2019

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**Background:** Spina bifida is a complex chronic condition and adds further challenges during the transition from adolescence to adults. Previous studies have shown that young adults with spina bifida (YASB) experience multiple challenges in achieving educational and employment milestones when transitioning to early adulthood. However, these studies are limited due to small sample sizes and limited information on other potentially relevant clinical variables. This study aimed to describe the education and employment transition experience of YASB and investigate factors associated with employment.

**Methods:** We queried education and employment data from the National Spina Bifida Patient Registry 2009 – 2019. We applied generalized estimating

equation models to analyze sociodemographic and disease-related factors associated with employment. **Results:** 1,909 participants aged 18-26 years contributed 4,379 annual visits. The study sample was 55.5% female and 66.8% non-Hispanic White. At last visit, the median age was 21 years, 52.6% were covered by non-private insurance, 41.9% were non-ambulatory, and 39.0% were continent of both bladder and bowel. A total of 41.8% had at least some post-high school education, and 23.9% were employed. In a multivariable regression model, employment was significantly associated with education level, lower extremity functional level, bowel continence, insurance, and history of non-shunt surgery.

**Conclusions:** This large, national sample of YASB demonstrated low rates of post-secondary education attainment and employment. Specific sociodemographic, medical, and functional factors associated with employment are important for clinicians to consider when facilitating transition for YASB into adulthood. Additional research could help us understand impact of cognitive functioning and social determinants of health on transition success in YASB.

## Project echo: Building capacity for pediatric clinicians to support the transition from pediatric to adult centered care for youth living with spina bifida

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**Background:** In response to the need to improve transition to adult care for individuals with spina bifida (SB), the Centers for Disease Control and Pre-

vention funded the American Academy of Pediatrics (AAP) to develop and implement the *Transition from Pediatric to Adult Centered Care for Youth Living with Spina Bifida ECHO*. The objectives were to understand the medical and developmental issues for youth/young adults with SB, increase healthcare clinician knowledge/self-efficacy in SB healthcare transition (HCT) management, and identify strategies to support family engagement.

**Methods:** From August 2021 to May 2022, participants met biweekly for 12 virtual sessions. The cohort comprised 35 clinicians from 18 institutions across 14 states. Session materials and resources from the preceding transition-centered quality improvement learning collaborative, including best-practice written examples, documentation templates from Got Transition's Six Core Elements of HCT (e.g., Transition Policy document), and English/Spanish-language family education resources, were shared and archived. Participants completed post-session and retrospective pre/post program surveys and had opportunity for a feedback focus group.

**Results:** Post-program survey analysis (Wilcoxon signed-ranks test) ( $n=5$ ) indicated that participation in ECHO resulted in improvements in mean post-ECHO knowledge scores, compared to pre-ECHO scores, on 5 of 12 measures, with large effect size ( $z = -1.732$ , 90% confidence interval [CI],  $p = .083$ ,  $r = -.775$ ). Moderate effect size was noted on the remaining measures. Clinicians reported the ECHO was a valuable use of their time and helped them provide better care for individuals with SB. Focus group participants reported deeper understanding of the importance and practice of shared decision making and increased practical knowledge.

**Conclusions:** ECHO evaluation findings suggest that the AAP SB Transition ECHO positively affected participants' knowledge in key areas and proved to be an effective model for training.

### Quality improvement learning collaborative on healthcare transition: National collaboration strengthened multidisciplinary efforts during the COVID-19 pandemic

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**Background:** Individuals with spina bifida (SB) lack structured supports to transition to adult care. With funding from the US Centers for Disease Control and Prevention, the American Academy of Pediatrics (AAP) facilitated a quality improvement (QI) learning collaborative. The aim of this QI collaborative was to test its feasibility while increasing the implementation of healthcare transition (HCT) practice.

**Methods:** Two cohorts of pediatric-adult clinic dyads met between September 2019 to November 2020 and November 2020 to July 2021. Clinicians attended lectures, QI review, and coaching-calls based on the Plan-Do-Study-Act model. Clinicians were provided resource toolkits with documentation templates and handouts. Clinicians completed quarterly surveys based on the Got Transition @ Six Core Elements to track HCT practice implementation. Measures were adapted from the Current Assessment of Healthcare Transition Activities tool.

**Results:** Nine clinic dyads participated in the first cohort and five in the second. QI activities encompassed 1,203 chart reviews. Although the COVID-19 pandemic differentially affected the cohorts, 85 patients transitioned. In cohort one ( $n=57$  patients) the "Pediatric patients with a scheduled follow-up visit within six months" outcome measure improved from 13% at baseline (Sept 2019) to 65% at the end of the project (Nov 2020). The adult measure, "Transition planning and integration of patients into the adult practice," demonstrated the greatest change with a 54% improvement. In cohort two ( $n=28$  patients) the percent of pediatric patients with a "Care plan" improved slightly from 56% to 58% (July 2021). The adults demonstrated the greatest improvement in "Transfer of care and initial visit" with a 100% improvement.

**Conclusions:** The project documented the feasibility of a transition-centered QI learning collaborative and that such model resulted in increased implementation of recommended HCT practices.

## Barriers and facilitators to self-management, self-advocacy, and community inclusion for adolescents and young adults with spina bifida

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**Background:** Eighty-five percent of children born with spina bifida (SB) survive to adulthood. However, adolescents and young adults (AYA) with SB experience significant challenges in developing independence with self-management/self-advocacy skills and achieving desired community participation and supportive relationships. Our objective was to understand the barriers and facilitators that impact self-management, self-advocacy, and community inclusion and supportive relationships of AYA with SB as they transition to adulthood.

**Methods:** An academic-community research partnership with members from a multidisciplinary SB clinic and a community-based SB organization conducted a mixed methods study with focus groups/informant interviews via Zoom with adolescents with SB (age 14-19), adults with SB, healthcare/community providers, parents/caregivers of transition-age youth and adults with SB. Participant surveys provided contextual and demographic data. Paraphrased statements from our previous study describing the three domains of self-management, self-advocacy, and inclusive communities/relationships were shared with participants to facilitate discussion; they were recorded and transcribed. An iterative coding process by research team members identified preliminary themes.

**Results:** Ten focus groups and thirteen interviews were completed with 39 participants. The importance of planning and goal setting, having/being a mentor, emotional impact of chronic disease, learning from experience, and changing care needs as one ages were common themes across all three domains. Organizational skills, managing bowel and bladder challenges, transportation barriers, and scaffolding to learn new skills were prevalent themes in self-management. The value of life experiences and self-worth, barriers from mental health issues, and benefits of support people were common themes

identified to influence the acquisition of self-advocacy skills. Participants emphasized the importance of an expectation of independence by family, providers, and caregivers and of community inclusion by community members. When discussing overcoming barriers to community inclusion, understanding, and trusting friendships, removal of barriers (e.g., transportation), support from a life coach, community advocate, or other support person, supportive connections or networks, and being empowered to speak up were common themes

**Conclusions:** Setting expectations for independence and inclusion and opportunities for mentorship, targeted goal setting, and learning from life experiences and may improve self-management, self-advocacy, and community inclusion in individuals with SB as they transition to adulthood. After further refining of themes, findings will inform pilot interventions for AYA with SB.

## Health care transition in pediatric neurosurgery: A consensus statement from the American Society of Pediatric Neurosurgeons

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**Background:** The number of children with complex medical conditions surviving to adulthood is increasing. A planned transition to adult care systems is essential to the health maintenance of these patients. Guidance has been developed for general health care transition from adolescence to adulthood.

The goals of the present work are: 1) Define the current state of transitional care in pediatric neurosurgery and 2) develop best-practice guidelines for transitional care from pediatric to adult neurosurgical health care.

**Methods:** Completion of the Current Assessment of Health Care Transition Activities survey was requested of 178 North American pediatric neurosurgeons using a web-based questionnaire in order to capture transitional care practices of American Society of Pediatric Neurosurgery (ASPN) membership. The authors concurrently conducted a literature review on transitional care for young adults with special health care needs and/or neurological conditions from. Selected articles were assembled and reviewed by experts and members of the ASPN Quality, Safety, and Advocacy committee. Best practice recommendations were developed and subjected to peer review by expert external groups.

**Results:** Seventy-six responses to the survey (42%) were received, and 62 respondents (82%) answered all 13 questions. Scores of one (the lowest possible score) were recorded by nearly 60% of respondents on transition policy, 70% on transition tracking, 85% on transition readiness, 40% on transition planning and transfer of care, and 50% on transition completion. Average responses on all core elements were less than two on the four-point scale. Seven best practice recommendations were developed and endorsed by ASPN leadership.

**Conclusions:** The majority of pediatric neurosurgeons have transition practices that do not meet the needs of patients and families, and should be improved. Adoption of a structured approach to transition, local engagement with adult neurosurgical providers, and national partnerships between pediatric and adult neurosurgery organizations are suggested to address gaps in health care transition for patients served by pediatric neurosurgeons.

## Ten-year observations from an adult spina bifida clinic

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**Background:** In 2012 we launched a multi-disciplinary Adult Spina Bifida Clinic (ASBC). Enrollment has steadily grown and currently 287 unique adult patients have been evaluated and treated. Eighty-two percent had open myelomeningocele (MMC) and the remainder had closed or occult dys-

raphism. Several questionnaire-based survey studies have enabled development of clinically derived hypotheses.

**Methods:** Observational cohort study. Variables retrieved and recorded from EMR and subjected to summary statistics and regression analyses.

**Results:** Five key observations summarize our initial experience: 1.) Despite high levels of self-identified permanent disability, a robust program that emphasizes education and a working bowel program can significantly reduce self-identified permanent disability. At outset 106/188 (56.4%) patients in clinic self-identified as permanently disabled. After 5 years 101/283 (35.7%) self-identify as permanently disabled ( $p < .001$ ) 2.) Adults with spinal lipomas carry a high burden of chronic, daily, life-altering pain. Of 33 patients with spinal lipomas 14 (42%) were identified with daily, life altering pain that was identified as the primary issue in their lives. 3.) A high percent of patients has maintained their insurance status that supported pediatric care. 4.) A looming crisis is potentially at hand related to aging parents who are caregivers. 5.) A functioning bowel program is central to capacity to gain and hold employment.

**Conclusions:** The provision of care for adults with SB is in its infancy. A functioning bowel program and education are critical. Organized, robust programs that address these variables may favorably impact disability. Pain is a serious co-morbidity in a high percentage of adult lipoma patients. Strategies to mitigate pain could improve QOL. Many patients that transition to adult care maintain their primary insurance coverage. Finally, the development of long-term care options appears valuable.

## Second iteration of individualized transition plan (ITP) in spina bifida patients: A model for other medically complex conditions

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**Background:** The process of transition planning for patients with spina bifida (SB) in the healthcare setting remains an opportunity for improvement. While prior research has demonstrated that effective transition can improve health outcomes and quality of life,

little is known about the most optimal transition strategies and implementation. The individualized transition plan (ITP) was developed to optimize the readiness of adolescents with SB for adult health care. The ITP focused on maximizing education, bowel continence and self-goals. It has been modified to reflect clinical challenges and observed patient needs.

**Methods:** The ITP in its first form was utilized in clinic from 2016-2020. ITP goals included: 1- to maximize education, 2- to have a working bowel program, 3- completion of a transition readiness assessment questionnaire (TRAQ), 4- an identified self-goal, 5- a goal set by SB coordinator. Challenges were identified: If a patient already had a working bowel program, was not cognitively able to complete the TRAQ or was not expected to live independently, making timely adjustments to the preset goals was challenging to accomplish in the clinical setting. The ITP also did not address important factors related to guardianship, adult provider referrals and emergency planning.

**Results:** A modified ITP was developed with clear instructions for the administrator. Two pathways (independent or caregiver supported) were outlined for patients. Updated ITP goals include: 1) Referrals: an assessment of sub-specialists that will be needed in adulthood. Transition team facilitates open communication between pediatric and adult specialist. 2) Career/Education & Advanced Care Plan: Patients are referred to vocational rehabilitation and other community resources to aid in seeking employment. Families are provided with information regarding guardianship. 3) TRAQ/Zarit Burden Index (ZBI): patient receives specific goal aimed at improving transition readiness or decreasing caregiver burden. 4) Self/Parent Goal: transition team partners with patient/caregiver on a self-goal. 5) Emergency/Sick Plan: a plan is developed that is specific to where the patient is in the transition process.

**Conclusions:** Based on practical experience, the ITP has evolved to focus on five goals: referrals, education, advanced care planning, improving transition readiness, and emergency planning. Though developed for our spina bifida clinic, the ITP concept is applicable to transition of care in any chronic childhood illness.

## The JUMP program: Mentorship in spina bifida transition from pediatric to adult care

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**Background:** The transition from pediatric to adult care is a period with elevated risk of adverse events. The purpose of this study is to describe a mentorship program designed to increase transition readiness, patient autonomy, and improve outcomes across transition to adult healthcare.

**Methods:** We created the Join, Unite, Motivate, and Prepare (JUMP) Program to support individuals with spina bifida by improving readiness for the transition process.

Our mentee target population were patients presenting to the Spina Bifida clinic at Children's of Alabama who were 15 to 19 years of age. Mentors were approved undergraduate/medical students who volunteered to participate. Each mentor received online training in mentorship.

Upon enrollment, each patient set a combination of clinical, self, and parent/guardian goals using the individualized transition plan (ITP). These goals were shared with the mentor, mentee, parent/guardian, and physician to achieve a successful transition process.

To monitor success, the program director routinely meets with each mentor to discuss progress made and areas of growth. These include continuous quantitative and qualitative goal setting and failures that need to be addressed for each updated agenda.

**Results:** 13 mentor-mentee matches were created over a period of 9 months. Steady growth through constant, maintained interaction was achieved.

Noted success in the program has been through mentees gaining employment, applying for scholarships, starting college, and connecting with others who are going through similar circumstances.

Challenges have arisen through failure to follow-up after initial office visit, risk with using virtual platform, and wide array of locations of both mentors and mentees across state of Alabama.

**Conclusions:** Transition from pediatric to adult care for adolescents with spina bifida has proven to be a large hurdle. Easing this process through well-thought out, interactive processes have the potential to improve readiness, increase patient autonomy,

and provide exposure to the adult healthcare community.

### Does a dedicated transition process impact patient experience in an adult spina bifida clinic?

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**Background:** Optimized care for patients with spina bifida (SB) requires services from multiple medical specialties along with social and psychological support. An important fundamental in transitional care is that proper transition centers upon a process that emphasizes progressive autonomy, independence and responsibility for independent medical and social decision making. Preliminary experience in adult care has suggested that structured transition is an important contributor to quality care for adults but data supporting this are limited. Our aim is to assess the extent to which a structured transition program contributed to favorable outcomes in an adult multidisciplinary SB clinic.

**Methods:** We created a 23-question survey for adult SB patients regarding their care experiences surrounding transition to adulthood. IRB approval was obtained. Metrics included standardized indices of daily pain, ADL independence, and satisfaction with multidisciplinary care. From August 2020 to June 2022, the survey was offered via phone and in-person at adult SB clinic visits. Each survey was completed by the patient with help from family member(s).

**Results:** Approximately 230 patients were approached for participation. 108 (47%) surveys were completed. Three incomplete surveys were excluded from analysis. 67 patients completed a transition of care from the Children's of Alabama (COA) SB clinic to the UAB SB clinic. The remaining 38 patients

presented to the UAB clinic from alternative institutions. 72.7% of patients in the COA/UAB group reported pain-free daily life compared to 44.7% of patients in the alternative group. 84.6% of patients in the COA/UAB group rated their multidisciplinary care satisfaction as 8/10 or higher compared to 77.1% in the alternative group. In the COA/UAB group, 65.7% reported ADL independence compared to 81.6% in the alternative group.

**Conclusions:** Successful transitional multidisciplinary SB care (COA/UAB) was associated with higher satisfaction and pain-free daily life compared to patients who received SB care at other institutions or who did not make a direct transition from COA to UAB. A high rate of ADL independence was reported among COA/UAB patients, although this finding wasn't as pronounced comparatively.

### The impact of a health care transition program on post-transfer chronic care management and utilization for young adults with spina bifida

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**Background:** A structured health care transition (HCT) process supports continued access to condition management for youth with spina bifida (SB). While various pediatric HCT clinical models have been implemented to prepare for HCT, their impact on post-transfer outcomes is less well known.

**Methods:** A retrospective chart review was completed of adult SB patients establishing care within a single-center medical home for adults with intellectual and/or developmental disabilities. We compared chronic management outcomes (bowel and bladder regimens and presence of a skin injury at the first adult visit), and health care utilization (outpatient, emergency room, and hospitalization) in the first year post-transfer between young adults with SB who did (HCT group) and did not (non-HCT group) participate in a SB HCT preparation program in the pediatric hospital setting. Associations between outcomes and clinical and demographic factors were also assessed.

**Results:** 162 patients with SB from the pediatric hospital established adult care between 2009 and

2021, and 68 participated in the HCT program. The HCT group was more likely to have a bowel management program ( $p < 0.001$ ) at the time of establishing care. The presence of a skin injury on the initial visit was significantly associated with more ER and hospital visits ( $p = 0.0073$ ). In the first year, the HCT group had more subspecialty visits ( $p = 0.01$ ) compared to the non-HCT group. Race/ethnicity, ambulation status, bowel regimen use, and skin injury were also associated with the number of post-HCT primary care visits. There was no statistically significant difference between groups regarding the bladder management regimen, the presence of a skin injury, rates of emergency room and hospital utilization, and primary care visits post-HCT.

**Conclusions:** Our results indicate that structured HCT programs for individuals with SB may support being on a bowel regimen and engagement in outpatient subspecialty care post transfer.

### Co-development of an illustration representative of people living with spina bifida

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**Background:** The lack of health education resources specific to people with disabilities contributes to disparities in outcomes. Adolescents with spina bifida report poor understanding of their sexual health due to inadequate education, leading to unintended pregnancies and underutilization of preventative care.

**Methods:** As a first step in developing an online sexual health resource for adolescents with physical disabilities, we sought end-user feedback to create illustrated characters for use in educational materials. Two styles of characters were developed by the research team, which included a professional disability artist. Oral and online survey feedback was obtained at the Spina Bifida Association's Clinical Care Conference (Image 1 and 2). A new image was then created (Image 3). The new image and favored image from the first round (Image 2 and 3) were then tested through an online survey advertised on the

Spina Bifida Association's Instagram story feed for the second round of feedback. Open-ended comments were organized by categories and overlapping themes.

**Results:** Feedback was obtained from 139 audience members and 25 survey respondents from the conference and 156 Instagram survey respondents. Themes included depiction of disability, non-disability diversity, other physical appearance, emotional response, and design style. Most commonly responses focused on ensuring characters had a range of accurately depicted mobility aids and the inclusion of characters without mobility aids.

**Conclusions:** This work culminated in the co-development of an illustration that represents how people impacted by spina bifida view themselves and their community (Image 4). We anticipate that using these images in education materials will improve their acceptance and effectiveness.

### Facilitation of healthcare transition for individuals with spina bifida using a provider transition order set

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**Background:** Optimal healthcare transition is a purposeful, planned move of adolescents and young adults with chronic physical and medical conditions from child- to adult-oriented healthcare. Transition for individuals with spina bifida requires coordination between the individual, family, health care providers, school, and supportive services to promote lifelong functioning and maximize potential. Thoughtful planning and coordination can help facilitate a more successful transition with goals to improve patient and family preparedness and satisfaction throughout the process.

**Methods:** A provider transition order set was created through collaboration between providers, rehabilitation therapies, child and family services, and information systems. Background education around transition was provided. An order set reminder prompted automatically for patients ages 14-21 during a Physical Medicine and Rehabilitation (PM&R) clinic visit. Goals of this project were to increase awareness of available resources, empower transition focused discussions, and improve transition planning efforts. Potential orders included physical,



occupational, and speech therapy evaluations, driving evaluation, therapeutic recreation evaluation, psychology/neuropsychology testing referral, social work referral, complex care clinic referral, and referral to adult PM&R and spina bifida clinics. Referrals using the order set were tracked between April 2022 and September 2022. Because social work referrals were most common, these were also tracked between December 2021 and April 2022 prior to the initiation of the order set for comparison.

**Results:** The transition order set reminder automatically prompted for 449 patients seen in clinic by a total of 20 PM&R providers and facilitated 281 referrals for 82 unique patients ages 15-24. The most common age for referrals was 17 years old and included 135 referrals for 34 unique patients. Referrals to social work were highest in this group at 71, compared to 41 referrals in the five months prior to the initiation of the order set.

**Conclusions:** Transition team education and organized planning by way of a provider transition order set can increase awareness and highlight important components of a successful healthcare transition. Ongoing collaboration between providers and support team members will be important to improve processes and outcomes. Future efforts will be made to continue education around healthcare transition and identify additional resources and partnerships vital to the transition process.

### Interventions to increase independence for individuals with spina bifida: A scoping review

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**Background:** The increased life expectancy of youth with spina bifida requires thoughtful programming to assist with transition to adulthood. Furthermore, the medical, neurocognitive, and psychosocial complexity of youth with spina bifida impacts their ability to achieve adult milestones, such as education, employment, independent living, and social

relationships. This project sought to examine current interventions aimed at increasing adult-readiness skills and to identify gaps in the literature to guide future research.

**Methods:** Using the PRISMA framework for scoping reviews, peer reviewed journal databases were searched for articles published between 01/2000 and 12/2020, identifying 1835 unique articles. For full inclusion, articles had to include an intervention to increase a domain of independence for children, teens, or adults with spina bifida (as identified by Spina Bifida Association care guidelines). Review articles, cross sectional studies, and non-English articles were excluded.

**Results:** Thirty studies met full inclusion criteria for the scoping review. Included studies identified interventions across a wide number of target areas (psychosocial, peer support, transition to adulthood programs, technology tracking tools, increasing continence/toileting skills, and goal setting skills). Studies varied with population age and included adult and pediatric samples, with over half focused on pediatric samples. The majority of the studies focused on a spina bifida only recruitment sample, while other studies included a mixed sample of other acquired or congenital spinal cord injury.

**Conclusions:** Although interest in the importance of transition to adulthood programming has increased over the past 20 years, interventions aimed at increasing independence among youth with spina bifida are limited. Indeed, in the current scoping review, only 30 studies uniquely address domains of independent living in individuals with spina bifida. Because of the challenges associated with spina bifida and the documented difficulties in reaching milestones in adulthood, interventions to increase independence skills remain an important area of further research.

### Health literacy among youth with spina bifida as they transition into adult care

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**Background:** Health literacy plays a vital role in transitional care from pediatric to adult care. Low health literacy is often associated with adverse health outcomes (Rague et al., 2021). Kaye (2020) found that out of 145 youth with SB, one-third never

reached shared self-responsibility or independence in self-care with caregivers, depending on someone for most or all of their healthcare needs. Similarly, Chisolm et al. (2015), showed health literacy affects medical compliance, communication with providers, and overall health-related quality of life. The transition to adult care is critical in patients with SB but only half of those affected have adequate health literacy to succeed in the transition of care. Factors that lead to low health literacy are a lack of physical or intellectual capacities in order to comply with follow through of care or capacity building to navigate the complex nature of the American healthcare system. Youth with low health literacy may also have parents or caregivers who also experience low health literacy. The low health literacy in parents or caregivers can lead to low health outcomes, poor health behaviors, and increased dependency of youth with SB on their caregivers for long-term healthcare supports. As youth with SB transition into adult care, the dynamic of roles and expectations change for oneself and that of parents/caregivers. It is important to acknowledge that transition to adult care is a process and will take time. Incorporating youth with SB in their health care decisions and the medical system processes early can help to increase their understanding and the importance of health literacy as they grow older. Youth with SB have been described as passive and socially immature (Holmbeck et al., 2010). This behavior can be changed in the teen years but is more difficult to change as the person with SB grows older. It is important to focus on tasks that require responsibility early on and including youth with SB in their medical care discussions and care. There are going to be health issues that arise in adulthood. With proper care, education and an increase in health literacy, some if not most of these health-related issues can be preventable. The purpose of the current review is to synthesize the existing research on health literacy among youth with Spina Bifida as they transition into adult care.

**Methods:** The purpose of this literature review is to explore and synthesize recent literature integrating empirical and theoretical studies (Lawless & Foster, 2020). For the structure of this paper and review of the literature eight steps were followed (Costa & Zoltowski, 2014): (1) identification of research topic; (2) selection of databases; (3) determination of keywords; (4) determination of articles by search of keywords and inclusion and exclusion criteria; (5) organization of articles; (6) removal and organiza-

tion of data for synthesizing; (7) Through review of articles; (8) Understanding of data. The PRISMA (Preferred Reporting Items for Systematic Review and Meta- Analysis) decision tree (2015) was used to show study selection.

**Databases and Keywords used:** The following databases were searched: PubMed, Medline, Academic Search Complete, and CINAHL. The research was conducted using these combination of the following terms (health literacy\*) OR (health education\*) AND (Spina Bifida\*) AND (youth\*) AND (adolescent\*) in English only.

**Inclusion and exclusion criteria:** The literature was reviewed dating from 2001-2021 in order to obtain the most recent data. The literature was search in October 2021 and the articles were selected based on the following inclusion criteria: (1) article published between 2001 and 2021; (2) addressed the terms “health literacy” in youth and/adolescent with Spina Bifida, ages eleven to twenty-one, and/or “health education”; (3) peer-reviewed; (4) full length free articles. After reviewing the literature, looking at titles and abstracts, the following exclusion criteria was considered: (1) addressing sexual health for men or women; (2) neonates; (3) articles addressing prevention of Spina Bifida.

**Data Management:** The PRISMA decision tree summaries the search results process. Originally, 125 excluding duplicate articles were extracted. The articles were scanned, and exclusion criteria was applied. Seventeen articles remained and full analysis of the articles took place.

**Results Analysis:** The seventeen remaining articles were reviewed to determine how health literacy affects transition into adult care for youth with SB, the role that families play in health literacy and transition from pediatric care to adult care, and health outcomes for successful transition into adult care by youth affected by SB.

**Results:** A search of the databases resulted in a total of 128 publications. In the analysis of the titles, keywords and abstracts, exclusion and inclusion criteria were applied. Sixteen articles were chosen and read in full as shown in the PRISMA tree (Fig. 1). The articles found in the search were excluded for the following reasons: duplicated article (n=3); articles addressing sexual health (n=8); articles addressing neonates (n=10); and articles addressing prevention (n=10). Articles that were included addresses youth defined as ages eleven through twenty-one, health literacy and transitional care from pediatric care to

adult care. Emerging themes through the research were identified as: (1) the significant medical demands of youth with SB and their families, (2) the unique needs of individuals with SB that address social isolation and cognitive deficits, (3) early education on self-care to youth with SB can lead to more independence into adulthood.

**Conclusions:** This integrative literature review of peer reviewed literature on health literacy among youth with SB as they transition into adult care focused on articles published from 2001 to 2021 and reviewed the articles associated with this theme. There was a predominance of articles that addressed physical health, pediatric outcomes after surgical procedures, and healthy lifestyles. A gap in research addressing health literacy as youth transition to adult care was evident. Publications from pediatric journals was where most of the research is published regarding youth with SB. The self-determination model framework was referenced the most in the reviewed articles. The self-determination model addresses three basic human needs of competency, autonomy and relatedness that motivate use as we grow and change (Cherry, 2021). The present integrative literature review showed that low health literacy results in poor health compliance, poor health outcomes and increase dependence on caregivers for youth with SB. Therefore, increasing health literacy for family caregivers and youth with SB would result in better health outcomes as they transition into adult care.

### Use of self-assessment in the transition population to improve independence and clinical outcomes as part of a dedicated transition program

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**Background:** The Spina Bifida Program at Primary Children's Hospital developed a transition clinic in July 2019. The program consists of a monthly clinic in which providers engage in transition discussions following an age-based roadmap. The clinic is designed to shift from a pediatric model of care to an adult, patient-centered model. We set out to determine if the dedicated transition clinic within the

Spina Bifida Program was associated with an improvement in patients' independence.

**Methods:** During annual or semi-annual visits, patients in the Spina Bifida transition clinic complete a self-assessment to evaluate their independence. Answers were de-identified and stratified by patient age. The first step of the project sought to collect baseline data related to how patients' independence changed as they age in the clinic. The second phase will evaluate the impact of the self-assessment and transition discussions on all graduates from the pediatric Spina Bifida Program.

**Results:** Responses to the self-assessment indicated that independence improves with age. In the 12-14 age group, 17% of respondents refilled their medications and 14% knew to make their own appointments. By ages 18-20, 70.59% refilled their medications, and 52.38% knew to make their own appointments. Responses demonstrated older patients engage in their care more frequently than their younger counterparts. In the 18-20 age group, 78.95% thought about questions to ask before a visit, while only 66% in ages 15-17 and 40% in ages 12-14 years reported doing so.

**Conclusions:** We suspect the implementation of the dedicated transition clinic has increased independence in our transition-aged population. This data has helped us focus clinical discussions on topics where there were less degrees of independence improvement with age. In phase two, we plan to determine whether independence scores improve because of the dedicated transition clinic as compared to patients graduating prior to 2019.

### Feasibility and implementation of independence skill screening for youth with spina bifida

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**Background:** Youth with spina bifida navigate a variety of increasing expectations for medical, physical and cognitive independence during adolescence. Readiness for independence can be more challeng-

ing due to the medical condition complexity and executive function challenges. The Spina Bifida Association (SBA) guidelines recommend regular assessment and tailored interventions to assist with adult readiness skills. Systematic screening and feedback with families may offer early identification of needs and linkage to services to help develop independence skills.

**Methods:** Using a quality improvement (QI) methodology, the current project sought to evaluate feasibility of an independence skill readiness questionnaire in our hospital's Myelomeningocele Program. Potential barriers were assessed through two Plan-Do-Study-Act (PDSA) cycles to evaluate online completion of the Kennedy Krieger Scales of Independence (KKIS), Spina Bifida version. Following PDSA cycles, we implemented a roll out of KKIS administration in clinic for youth ages 14-17 years. Project goals were to evaluate pre-clinic completion of the KKIS, overall KKIS completion, and screening results of the KKIS.

**Results:** Since 04/2020, 68 KKIS administrations have been completed. During the QI project, 86% of individuals had an activated MyChart account and 70% had an e-mail in the medical record system. Preferred mode of completion was online before clinic (46%). Clinic iPad allowed an additional 28% of KKIS to be completed during clinic. Of KKIS administrations, approximately 24% of individuals elevated on at least one of the two KKIS subscales. Of these, 16% were referred to an outpatient intervention.

**Conclusions:** Clinic administration of the KKIS is a feasible method of screening independence readiness skills. The KKIS results provide helpful feedback to review with caregivers and patients about independence skills. Screening of independence skills using the KKIS identifies a notable number of individuals who may benefit from linkage to specialty supports and interventions regarding development of adult independence skills.

### **Transition Readiness Assessment Questionnaire Spina Bifida (TRAQ-SB) specific module and its association with clinical outcomes among youth and young adults with spina bifida**

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**Background:** In order to transition to adulthood and independence, youth with spina bifida must assume significant self-management responsibilities including monitoring for shunt malfunction, maintaining intact skin in areas that are insensate, and maintaining proper bowel and bladder function. Validated measures of specific spina bifida self-management skills are lacking and this hampers the ability of clinical personnel to support successful transition for youth with spina bifida.

**Methods:** We developed a self-report measure specific to SB self-management skills consistent with the framework of the Transition Readiness Assessment Questionnaire (TRAQ). To test the predictive validity of the tool we surveyed 90 youth and young adults ages 12-25 with spina bifida attending a multidisciplinary clinic participating in the National Spina Bifida Patient Registry (NSBPR).

**Results:** Adjusted for age, gender, race, insurance status and lesion level, higher scores on the TRAQ-SB (increased self-management) were negatively associated with urinary incontinence in the past month. Only lesion level, and not TRAQ-SB scores, was a significant predictor of stool incontinence and skin breakdown.

**Conclusions:** Higher TRAQ-SB scores are negatively associated with bladder incontinence in youth with spina bifida. While stool continence and skin breakdown were not associated with TRAQ-SB scores, this relation is complex and may be obfuscated by either reporting bias or outcome measurement bias. To further refine the questionnaire and understand this relationship we need to field it prospectively in the SB network with larger samples. The TRAQ-SB questionnaire, however, does have value in the clinical setting to help promote the acquisition of specific self-management skills among youth with spina bifida.

### **“Lost in ambivalence” – The importance of supporting parents in the transition process: A qualitative Study**

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**Background:** When children with spina bifida (SB) become adults, parents face the big step of accompanying their children into adult care. During this transition process, parents must adapt their previous parental role in view of the changing responsibility for their children. The transition thus means a major upheaval and reorientation for both parents and their children, which triggers different feelings such as fear and insecurity.

**Methods:** In the qualitative study ten parents of children with SB were asked before, during and after transition about their experience regarding the process by means of semi-structured interviews. The interviews were analyzed using theoretical coding. Based on these findings further practice development took place in interprofessional collaboration.

**Results:** During the transition process parents experienced an ambivalence between handing over responsibility to their child and protecting them and their health. These ambivalent feelings must be considered in the complex context of school, family and health and dealt with sensitively, but openly and transparently. The feelings remain with the parents even after the child has entered adult care. A flattening of the ambivalences is described by the parents when they see that their child is well cared for and receives external support.

**Conclusions:** Patients and their families are often treated by a large interprofessional team. A structured approach led by a professional who is familiar with the parents can be helpful and provide orientation and security. Different programs or tools might be useful, such as adapted questionnaires or specific counselling. An Advanced Practice Nurse (APN) can play an important role in this, especially when planning and coordinating the transition process for the patient and their family, but also in supporting the youth and their family. In addition, APNs have the understanding and know-how to recognize the difficulties and ambivalent feelings of parents during the detachment process.

### Transitional urology in spina bifida: Are we actually making the transition?

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**Background:** Transitioning pediatric spina bifida (SB) patients to adult care remains challenging for patients, providers, and hospital systems. Despite dedicated hospital-based transition teams, barriers continue to exist in moving care to adult urologic providers (AUP) within our system or the adult care system. Based on models of transition in other subspecialties, we began incorporating an AUP into the pediatric specialty practice to allow for an improved transition to an adult practice in 2017. We evaluated our progress in transitioning these patients to an AUP.

**Methods:** Retrospective review of the EMR of our clinic's SB cohort in our pediatric hospital and adult hospital facilities.

**Results:** We reviewed the EMR from July 1, 2017, through June 30, 2022. In Fiscal years (FY) 2018 to 2022 the division saw 1270 SB patients, 363 of those patients were 13+ years of age and the AUP saw 93 (26%) of those patients and 164 of those patients were 18+ years and the AUP saw 85 (52%) of those patients. Of the patients  $\geq 13$  years old, 48 were female and 45 were male. The ages range from 16.77 to 50.93 years (mean 27.48 years, Median 25.54 years.) Of these patients, 23 (25%) underwent surgical interventions with the AUP. In FY 2018-2022, 47 of 93 patients were seen at the adult hospital. Twelve patients saw an AUP and 8 patients underwent urologic surgery. In total, 42 of 93 patients established care with providers outside of Urology in the adult hospital.

**Conclusions:** Since starting our dedicated transitional program, the majority of our adult SB patients have been transitioned to an AUP. The majority are seen in our pediatric facility with a significantly smaller proportion making full transition to adult facilities. Much work remains to determine the optimal pathway of transitioning SB patients in different health care environments.

### Standardization of healthcare transition for spina bifida: The creation of an EMR toolkit

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**Background:** Young adults with spina bifida risk increased morbidity and mortality if unable to successfully transition to adult medical specialties. An

assessment at an academic children's hospital found that few clinics had pediatric to adult healthcare transition (HCT) processes. An HCT toolkit was developed and integrated into the electronic medical record (EMR). The toolkit includes readiness assessments, preparatory questions and education, a transfer of care summary, patient registry and reporting workbench, and dashboard to track institutional transition metrics. Other elements include a centralized provider intranet site with guidelines and resources, and patient HCT website.

**Methods:** This project utilized the Quality Implementation Framework and consisted of four key phases: 1. assessment and capacity building with a current state analysis, and identification of collaborative partners and champions; 2. implementation planning with the formation of administrative, staff, and technical advisory groups; design, collaborative review, and approval of toolkit, proof-of-concept demonstration, and final project approval; 3. implementation utilizing a Transition Implementation, Adoption, and Policy Workgroup, demonstration to project collaborators, a "Go-live" release to the institution, and training and orientation of the toolkit for staff and administration; 4. improving future application, via collecting feedback and review of toolkit and workflow integration.

**Results:** Successful implementation of a standardized transition process was achieved with the development and integration of a robust HCT EMR toolkit. Review of transition workbench reports shows increasing engagement in HCT activities within the spina bifida clinic and across the institution.

**Conclusions:** The toolkit provides an innovative approach to the problems that have plagued the HCT process for young adults in the spina bifida clinic, by providing coordinated, HCT planning and tracking. Simultaneous utilization by multidisciplinary specialty clinics, a global platform for collaboration, and optimized transition planning for spina bifida make this tool an essential part of continued and future practice.

## Transition to Adulthood: Experience of youth with spina bifida in Japan

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**Background:** Emerging adults with spina bifida have complex health care and developmental care needs. As more children with spina bifida reach adulthood due to improvement in neurosurgical care, transition to adulthood for this population has received increasing attention. However, the experiences during transition for emerging adults with spina bifida in Japan remain unknown. The purpose of this study was to describe the experiences of transition to adulthood for emerging adults with spina bifida in Japan.

**Methods:** Qualitative descriptive design using thematic analysis was chosen to explore the experiences of emerging adults with spina bifida. Eight emerging adults aged between 20 and 29 years living in Japan (37.5% female; 100% living with parents) participated in semi-structured telephone or Skype interviews. The Theory of Emerging Adulthood and the Ecological Model of Secondary Conditions and Adaptation in Spina Bifida influenced the development of the interview guide which addressed transition to adulthood and adult healthcare.

**Results:** Six core themes were identified: (a) struggling, (b) finding the meaning of "being an adult", (c) learning to implement self-management, (d) health care, (e) processes and challenges in establishing and retaining relationship with friends, and (f) broadening scope of experiences.

**Conclusions:** This study contributed to identification of both challenges and positive aspects in experiences of emerging adults with spina bifida in Japan. Ever present were participants' experiences of struggling during transition to adulthood, especially when trying to find a job, establishing relationship with friends, and making transition to adult health care. Participants shared their unique perspectives on the meaning of "being an adult" as a person with spina bifida in Japan. Health and social programs assisting emerging adults with spina bifida in achieving milestones for adulthood and transitioning to adult health care in Japanese social context are needed.

## Understanding young adult and parent/caregiver priorities in facilitating successful transition from pediatric to adult care

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**Background:** The impact of spina bifida on functional and cognitive ability varies. The transition years are generally defined as aged 14-23. For adolescent and young adults living with spina bifida, the transition years require moving from family-centered pediatric providers and services to patient-centered adult providers and services. Navigating the transition years requires systems that support young persons living with spina bifida and their parent/caregiver, regardless of functional and/or cognitive ability.

**Methods:** We will conduct three virtual focus groups, each with 6-8 participants, a facilitator and a note-taker, in early November 2022. Focus group participants are young adults, age 24-31 or the parent/caregiver of young adults, age 24-31, who are living with a complex health condition such as spina bifida and cerebral palsy and have completed or are close to completing the transition from pediatric to adult health systems. Participants are recruited from a specialty health system that provides pediatric and adult care for persons living with these complex health conditions. The goals of our study are defining a transition system 'that works' from the young adult and caregiver perspective, understanding what young adults and caregivers know now but did not know when they started transition, and identifying 'transition champions.'

**Results:** The three focus groups are delineated by young adult ability and include: 1) Young adults with moderate to high functional and/or cognitive ability; 2) Parents/caregivers of young adults with moderate to high functional and/or cognitive ability; and 3) Parents/caregivers of young adults with limited functional and/or cognitive ability. Thematic content analysis of focus group transcripts will be completed by February 1, 2023.

**Conclusions** The voice and perspective of young adults living with spina bifida and cerebral palsy and varying degrees of functional and cognitive ability, and their caregivers, must be prioritized when developing processes to support pediatric to adult health system transition.

## Telemedicine and spina bifida transition: A pilot randomized trial

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**Background:** Transition of care is the planned movement of adolescents and young adults from pediatric to adult health care. Many studies have demonstrated the importance of an organized transition process. The purpose of this study is to determine the efficacy of a telemedicine intervention for improving transition readiness among adolescents with spina bifida.

**Methods:** The present study is a randomized, controlled trial, including children 14 years of age and older with myelomeningocele from a multidisciplinary spina bifida clinic. Subjects were randomized to standard care or to an intervention, consisting of video telemedicine contacts at 3-, 6-, and 9-months from the clinic visit. The primary outcome measure was change in Transition Readiness Assessment Questionnaire (TRAQ) score from baseline to 1-year follow up.

**Results:** Twenty-four patients were enrolled in the study and underwent randomization. Mean age at enrollment was 15.8 years. Ten patients (40%) were female, and the majority were white, non-Hispanic (67%). One patient in the telemedicine group completed two of the three planned telemedicine sessions. No other participant completed any telemedicine counselling sessions. The study was stopped early for lack of participation in the intervention.

There was no significant change in the TRAQ score between enrollment and 1-year follow up ( $D=0.36$ ,  $p=0.46$ ). However, there were significant improvements in sub scores for Managing Medications, Appointment Keeping, and Managing Daily Activities.

**Conclusions:** Telemedicine video follow up with adolescents with myelomeningocele is unlikely to significantly improve their readiness for TOC. A hybrid approach, using telemedicine in addition to mentoring may prove to be beneficial.