SPINA BIFIDA ASSOCIATION

Guidelines for the Care of People with Spina Bifida

Transition

Workgroup Members: Ellen Fremion, MD (Chair); Shannon Bevans, MSW; Melissa Kaufman, MD; Ann Modrcin, MD; Shubhra Mukherjee, MD; Pamela Murphy, MD; Denise Rosser, RN; Katherine Smith, PhD, RN

We thank the work of the 2018 workgroup members: Ellen Fremion, MD (Chair); Melissa Kaufman, MD; Julianne Lane, RN; Sue Leibold, RN, MS; Ann Modrcin, MD; Sue Mukherjee, MD; and Katherine Smith, PhD, RN.

Introduction

The primary goal of health care transition is to maximize lifelong functioning through the provision of high-quality, developmentally appropriate health care that continues uninterrupted as the individual moves from adolescence to adulthood.[1] Collaboration and coordination between the individual, family, pediatric and adult health care providers, allied health services, and school systems are essential to navigate the complexities of transition to adult care and life.[2-4] Fostering the gradual, developmentally appropriate acquisition of independent skills through goal setting and coaching enables adolescents and young adults with Spina Bifida (SB) to optimize their independence and participation in adult roles and activities during transition.[5-8] While transition focuses on adolescent and young adult age groups, the trajectory to maximize adult function and independence is fostered throughout the lifespan by setting expectations for adult independence and the eventual transition of care.[3,9]

It is important to note that young adults with SB not only face the challenges of changing health care systems and responsibilities but may also experience increased health risks during transition. Many young adults with SB have increased hospitalizations for chronic condition exacerbations, such as urinary tract infections, shunt complications, and skin ulcers, and more difficulty accessing health care services than their age-matched peers.[10,11] Also concerning, young adults with SB are less likely to achieve emerging adult milestones such as leaving home, attending college, finding employment, developing romantic relationships, and having multiple friendships compared to their peers without SB.[12] Executive function, socioeconomic status, intrinsic motivation, and parental fostering of independence are significant predictors of successful transition to adulthood.[13] Hence, patient-centered, comprehensive transition care is needed to address the chronic health condition, funding, care coordination, self-management, and social challenges that adolescents and young adults with SB face.[3,5,7,10,14]

SPINA BIFIDA ASSOCIATION

Guidelines for the Care of People with Spina Bifida

Survival to adulthood for individuals with SB now exceeds 85%, but the degree of adult independence in the population varies.[15] In general, individuals with higher lesions (i.e., above L2) and hydrocephalus are more dependent on others for bowel and bladder management, mobility, self-care, transfers, and activities of daily living.[16,17] Additionally, adolescents with SB may experience a two- to five-year delay in developing autonomy skills compared with their typically developing peers and may overestimate their abilities.[18-20] By age 30, approximately one-third of individuals with SB are independent, one-third need supervision and occasional help, and one-third routinely need assistance for daily care needs.[21] Thus, lifelong assessment and gradual, iterative interventions to maximize chronic condition management, family function, socialization, cognitive function and school performance, mental health, and self-management/self-care are foundational to their optimal participation, function, and quality of life in adulthood.[3,5,6,22-24] (Self-Management and Independence Guidelines, Family Functioning Guidelines)

The Health Care Transition Process:

Preparation Transition planning with the individual and their family is a lifelong process, but particular attention to preparation should begin between the ages of 12-14.[6,25] Additionally, transition preparation involves supporting the individual in the gradual, developmentally appropriate assumption of increased independence and responsibility for self-care and condition management through coaching in the home, school, and clinic settings.[5]

Transfer of care refers to the hand-off of care plans and responsibilities from pediatric to adult providers as the individual establishes care in the adult setting. Usually transfer occurs between the ages of 18-21, but timing can be variable based on care needs and health care settings.[6,7,26]

Transition completion refers to the establishment of the individual in the adult health care setting, with adult care providers, and with needed community supports to optimize their adult life.[25]

Elements for Comprehensive Transition to Adult Care Planning

1. Designate clinic staff or refer to a designated transition program to support planning, care coordination and transition to adult-oriented care.[2,3,7,27]
2. Begin transition planning at ages 12-14, which includes[28]:
   a. discussing a transition policy that explains the transition process and decision-making support, etc.
   b. creating a medical summary (e.g. medical conditions and management plans, past medical/surgical history, and care team) that can be modified throughout transition

   c. understanding and preparing for adult insurance plans and home and community-based waiver support eligibility and coverage changes
   d. preparing for long-term care support needs (e.g., nursing/provider services, adaptive equipment/supplies, etc.), and education/employment goals and support needs.
3. Assess and support self-management development for health care navigation and chronic condition management using a validated tool such as the Transition Readiness Assessment Questionnaire-SB (TRAQ-SB).[29,30] (Self-Management and Independence Guidelines)
4. Consider the adolescent's views and preferences regarding transition plans.
5. Designate time alone with the adolescent for at least part of their visit when developmentally appropriate.
6. Ensure flexibility regarding transfer timing based on the individual's cognitive development, physical abilities, social and financial situation, and health status.
7. Provide chronic condition management and age-appropriate preventative care throughout transition.
8. Identify adult providers to assume care prior to the transition and strive for regular collaboration between pediatric/adult providers and patient/family stakeholders to improve the transition process.[6,26,31,32]

SPINA BIFIDA ASSOCIATION

Guidelines for the Care of People with Spina Bifida

Implementing a Structured Transition Preparation Approach in the Pediatric SB Clinic Setting

Implementing a comprehensive transition program can be a daunting task. Below are some stepwise approaches and timelines that have been used in SB clinics.[6,7]

Year 1	Year 1-2	Year 3-4	Continue…
• Meet with transition stakeholders to discuss process and develop a transition policy. Stakeholders should include pediatric/adult providers, patients, and families.	• Implement a transition policy and a medical summary discussion with adolescents ages 12-14 and up. • Implement a hand-off process between pediatric and adult providers. • Implement a way to track patients between discharge from pediatrics and establishing with adult care.	• Implement a transition self-management assessment such as the TRAQ-SB with adolescents. Review the assessment and provide goal-setting support to improve independence. • Implement a strategy to track and monitor patients throughout the transition process (electronic health care record tools can be used).	• Continue to review the transition process and outcomes with stakeholders to make improvements.

Implementing transition support for SB in the adult clinic setting

The multidisciplinary SB clinic model is often not feasible in adult settings. However, there are a variety of SB adult care models that aid in transfer to adult care support depending on the health care setting including physical medicine and rehabilitation, primary care medical homes with internal medicine or combined internal medicine-pediatric or family practice physicians, and urology clinics.[3,7,33-41] Regardless of the clinic setting, it is important that adult clinics ensure that young adults with SB are receiving chronic care management, preventative care, care coordination, assistance in navigating adult services, and ongoing self-management support.[11,36,42-45] (Health Promotion and Preventive Health Care Services)

SPINA BIFIDA ASSOCIATION

Guidelines for the Care of People with Spina Bifida

Outcomes

Primary

1. Maximize health and participation in emerging adult milestones throughout the transition process for individuals with SB.

Secondary

1. Provide patient-centered, comprehensive transition care that includes transition planning and care coordination beginning by age 14; self-management coaching; decision-making support; education and employment resources; and independent-living support.

Tertiary

1. Promote access to uninterrupted, developmentally appropriate SB condition management and preventative care throughout transition – specifically, ages 14-21.

0-11 months

Clinical Questions

1. How can a child's probable trajectory regarding future adult function and independence be identified?
2. What are barriers and facilitators to participating in emerging adult milestones for children with SB?
3. What are the essential transition planning elements to promote uninterrupted access to care once children with SB need adult care?

Guidelines

1. Provide families with a realistic, long-term orientation that includes a probable trajectory for adult function and expectations to promote life-long optimal independence according to the child's abilities.[3,15,16,18,21,45,46]
2. Provide information for families regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.[47]
3. Consider regular evaluation of social determinants of health and immigration status (when applicable). Offer resources and increased navigation support if needs are identified as barriers can impact the individual's long term functional trajectory and access to care.[34,48]
4. Discuss plans regarding where individuals with SB can access comprehensive care throughout the lifespan including the transition to adult care.[3,49]

1-2 years 11 months

Clinical Questions

1. How can a child's probable trajectory regarding future adult function and independence be identified?

2. What are barriers and facilitators to participating in emerging adult milestones for children with SB?
3. What are the essential transition planning elements to promote uninterrupted access to care once children with SB need adult care?

Guidelines

1. Provide families with a realistic, long-term orientation that includes a probable trajectory for adult function and expectations to promote life-long optimal independence according to the child's abilities.[3,5,15,16,18,21,45,46].
2. Provide information for families regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.[47]
3. Consider regular evaluation of social determinants of health and immigration status (when applicable). Offer resources and increased navigation support if needs are identified as barriers can impact the individual's long-term functional trajectory and access to care.[34,48]
4. Discuss plans regarding where individuals with SB can access comprehensive care throughout the lifespan including the transition to adult care.[3,49]

3-5 years 11 months

Clinical Questions

1. How can a child's probable trajectory regarding future adult function and independence be identified?
2. What are barriers and facilitators to participating in emerging adult milestones for children with SB?
3. What are the essential transition planning elements to promote uninterrupted access to care once children with SB need adult care?

Guidelines

1. Provide families with a realistic, long-term orientation that includes a probable trajectory for adult function and expectations to promote life-long optimal independence according to the child's abilities.[3,5,15,16,18,21,45,46]
2. Optimize bowel and bladder continence beginning in school-aged children as continence is a major factor in promoting life-long social participation, quality of life, and education and employment opportunities.[24,34,50]
3. Provide information for families regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.[47]
4. Consider regular evaluation of social determinants of health and immigration status (when applicable). Offer resources and increased navigation support if needs are identified as barriers can impact the individual's long-term functional trajectory and access to care.[34,48]

5. Discuss plans regarding where individuals with SB can access comprehensive care throughout the lifespan including the transition to adult care.[3,49]

6-12 years 11 months

Clinical Questions

1. How can a child's probable trajectory regarding future adult function and independence be identified?
2. What are barriers and facilitators to participating in emerging adult milestones for children with SB?
3. What are the essential transition planning elements to promote uninterrupted access to care once children with SB need adult care?

Guidelines

1. Provide families with a realistic, long-term orientation that includes a probable trajectory for adult function and expectations to promote life-long optimal independence according to the child's abilities.[3,5,15,16,18,21,45,46]
2. Optimize bowel and bladder continence and independent management beginning in school-aged children as continence is a major factor in promoting life-long social participation, quality of life, and education and employment opportunities.[24,34,50]
3. Promote participation in self-advocacy opportunities such as individualized education plan (IEP) meetings.[8] Consider neurocognitive assessment to identify cognitive, adaptive, or learning support needs if knowledge or skill gaps are identified. (Self-Management and Independence Guidelines, Neuropsychology Guidelines)
4. Provide information for families regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.[47]
5. Consider regular evaluation of social determinants of health and immigration status (when applicable). Offer resources and increased navigation support if needs are identified as barriers can impact the individual's long term functional trajectory and access to care.[34,48]
6. Discuss plans regarding where individuals with SB can access comprehensive care throughout the lifespan including the transition to adult care.[3,49]
7. Review the clinic's transition policy with patients and families between ages 12-14.[25]

13-17 years 11 months

Clinical Questions

1. How can a child's probable trajectory regarding future independence be identified?
2. What are barriers and facilitators to participating in emerging adult milestones for children with SB?

3. What are child-centered perceptions of a successful transition experience?
4. What are the systems level barriers to successful transition and strategies that have effectively mitigated them?
5. What are the key transition readiness parameters for patients with SB that can be measured over time?
6. What are the preventative and chronic condition management considerations in the transition age group, ages 14-21?
7. What are the essential transition planning elements to promote uninterrupted access to care once children with SB need adult care?

Guidelines

1. Consider having a designated transition clinic or care coordinator to support transition planning and coordination acknowledging that young adults may need ongoing support throughout hand-off and transfer to adult care.[2-4,6,7,26,51]
2. Provide families with a realistic, long-term orientation that includes a probable trajectory for adult function and expectations to promote life-long optimal independence according to the child's abilities.[3,15,16,18,21,45,46]
3. Promote participation in self-advocacy opportunities such as IEP meetings.[8] Consider neurocognitive assessment to identify cognitive, adaptive, or learning support needs if knowledge or skill gaps are identified. (Self-Management and Independence Guidelines, Neuropsychology Guidelines)
4. Consider regular evaluation of social determinants of health and immigration status (when applicable). Offer resources and increased navigation support if needs are identified as barriers can impact the individual's long-term functional trajectory and access to care.[34,48]
5. Discuss transition planning with adolescent and family throughout adolescence ensuring that the adolescent's and family's views and preferences are considered in transition planning.[14,26,43,47,52-56] Transition planning should include:
    a. Expectations of when the transfer to adult care will occur based on the individual's health condition, insurance/funding, cognitive development, and personal/family needs.[3,7,26,34]
    b. Expectations of who will provide care throughout the transition process. Often multidisciplinary clinics are not available for adults thus a primary care medical home or physiatrist practice may be best to provide comprehensive SB management for adults. Urologists often play an important role in facilitating transition to adult-centered care as well.[3,7,33-41]
    c. Long-term financial, insurance, and supportive living (housing and transportation) plans, based on the individual's current needs and probable trajectory of adult function. Information regarding the Social Security

Administration's Disability Determination Services before age 18, as applicable.

d. Information regarding the adolescent's education and employment needs, such as vocational rehabilitation services, school transition planning as part of the IEP, and adaptive vocational needs.[14,57]
e. Preparation for decision-making supports and modalities that maximize the individual's ability to participate in decisions for themselves once they are age 18, such as a medical power of attorney, supportive decision-making, or guardianship. Referral to medical legal partnerships may be needed.

6. Create medical summary including past medical and surgical history, current care plans, medications, allergies, vaccines, and current providers.
7. Regularly assess self-management independence throughout transition using a validated tool such as the TRAQ-SB. Discuss the results with the adolescent and family and set realistic goals to improve independence. Emphasize that self-management development is a gradual, iterative process.[5-7,20,30,51,58-60] (Self-Management and Independence Guidelines)
8. Optimize bowel and bladder continence and independent management as continence is a major factor in promoting life-long social participation, quality of life, and education and employment opportunities.[24,34,50,59,61]
9. Designate time alone with the adolescent for at least part of their visit, if developmentally appropriate.[31]
10. Ensure patient-centered and developmentally appropriate preventative and chronic condition management services are provided throughout transition. Topics to particularly address in this age group include: bowel/bladder management, skin health, sexual health and function, mental health, healthy weight, and adaptive equipment/supplies to maximize independent function.[11,36,42-45] (Health Promotion and Preventive Health Care Services Guidelines)
11. Patients and families should know the signs, symptoms and action steps to manage these common SB-related complications: shunt malfunction, urinary tract infection, constipation, and skin ulcers.[10,62] These management plans should be included along with a medical summary to hand-off to adult providers. (Neurosurgery Guidelines, Bowel Function and Care Guidelines, Urology Guidelines, and Integument (Skin) Guidelines)
12. Prepare a hand-off packet that includes the medical summary, action plans, supply/equipment, and other important care coordination information to hand off to identify adult providers. Adult providers should include a primary care physician, neurosurgeon (if shunt or other neurosurgery history), urology if neurogenic bladder, and physiatrist if ongoing mobility management needs. See example of Spina Bifida Clinic Transition Discharge Worksheet below.

SPINA BIFIDA ASSOCIATION

Guidelines for the Care of People with Spina Bifida

18+ years

Clinical Questions

1. What are barriers and facilitators to participating in emerging adult milestones for individuals with SB?
2. What are the preventative and chronic condition management considerations in the transition age group?
3. What are the essential transition planning elements to promote uninterrupted access to care once children with SB need adult care?
4. What are the best strategies to find and engage adult providers?

Guidelines

1. Provide families with a realistic, long-term orientation that includes a probable trajectory for adult function and expectations to promote life-long optimal independence according to the child's abilities.[3,15,16,18,21,45,46]
2. Consider regular evaluation of social determinants of health and immigration status (when applicable). Offer resources and increased navigation support if needs are identified as barriers can impact the individual's long-term functional trajectory and access to care.[34,48]
3. Optimize bowel and bladder continence and independent management as continence is a major factor in promoting life-long social participation, quality of life, and education and employment opportunities.[6,24,34,50,61,63,64]
4. Regularly assess self-management independence throughout transition using a validated tool such as the TRAQ-SB (validated up to age 25). Discuss the results with the adolescent and family and set realistic goals to improve independence. Emphasize that self-management development is a gradual, iterative process.[5-7,20,30,51,58-60] (Self-Management and Independence Guidelines)
5. Promote ongoing collaboration between pediatric/adult care providers and patients/families to improve the transition process and promote best care practices.[3] Often multidisciplinary clinics are not available for adults; thus, a primary care medical home or physiatrist practice may be best to provide comprehensive SB management for adults. Urologists often play an important role in facilitating transition to adult-centered care as well. Also important is identifying an adult neurosurgeon for ventricular shunt concerns.[3,7,41,33-40]
6. Continue to assist with transition coordination as applicable including: [2,4,26,43,53-55,65,66]:
    a. Assistance in identifying adult providers who accept the patient's insurance and can assume his/her care.
    b. Counseling regarding long-term financial, insurance, and supportive living plans (housing, transportation, etc.) based on the individual's current needs and probable trajectory of adult function.

   c. Information for education/employment transition support as applicable to the individual's need such as vocational rehabilitation services, school transition planning, as part of the Individualized Educational Plan, and adaptive vocational needs.
   d. Decision-making supports and modalities that maximize the individual's ability to participate in decisions for themselves, such as a medical power of attorney, supportive decision-making, or guardianship. Referral to medical legal partnerships may be needed.
   e. Adult disability determination information, if applicable.
   f. Updating a medical summary including past medical and surgical history, current care plans, medications, allergies, vaccines, and current providers.
7. Ensure patient-centered and developmentally appropriate preventative and chronic condition management services are provided throughout transition. Topics to particularly address in this age group include: bowel/bladder management, skin health, sexual health and function, mental health, healthy weight, and adaptive equipment/supplies to maximize independent function.[11,36,42-45] (Health Promotion and Preventive Health Care Services Guidelines)

Research Gaps

1. There is a need for studies that explore comprehensive care and best practices for children with SB ages 13+ that address demographic and functional variables that influence transition, preventative care and condition management, strategies to improve access to quality health care throughout transition, and evaluation of effective self-management intervention programs.[12,66-68]
2. Educational programs are needed to improve health care professional's awareness and knowledge of the medical and social issues related to the transition from child to adult life and health care for people living with SB.
3. Studies are needed to identify the risks and facilitators of secondary education and workforce and social participation for adults 18+ with SB, in order to inform transition counseling and intervention.[68-70]
4. Studies to examine internet and technology applications for education and transition should be further explored.[70]
5. Studies are needed to determine what barriers/facilitators adult health care providers experience in caring for adults with SB, and how they can best support health care services for adults with SB.
6. There is a need to identify models of care for adults living with SB that consider the specific needs of the individual, such as proximity to appropriate specialty and primary care services, transportation accessibility, personal preference, and social determinants about the service delivery desired.[5,48]

Transition Tools

TRAQ-SB	Wood, et al. Transition Readiness Assessment Questionnaire Spina Bifida (TRAQ-SB) specific module and its association with clinical outcomes among youth and young adults with Spina Bifida[30]
General Transition Tools	https://www.gottransition.org/
Spina Bifida Clinic Transition Discharge Worksheet	https://www.spinabifidaassociation.org/resource/transition-dischargeworksheet/
Pocket card: Signs of Shunt Malfunction in Infants and Toddlers (side A); in Children and Adults (side B).	https://www.spinabifidaassociation.org/wp-content/uploads/SIGNS-OF-SHUNT-MALFUNCTION-IN-INFANTS_TODDLERS.pdf

References

1. American Academy of Pediatrics, American Academy of Family Physicians AC of P-AS of IM. Consensus statement on health care transitions for young adults. *Pediatrics*. 2002;110(Supplement 3):1304–1306.
2. Seeley A, Lindeke L. Developing a transition care coordination program for youth with Spina Bifida. *J Pediatr Heal Care*. 2017;31(6):627–633. https://doi.org/10.1016/j.pedhc.2017.04.015
3. Hopson B, Rocque BG, Joseph DB, Mclain ABJ, Davis RD, Wilson TS, et al. The development of a lifetime care model in comprehensive Spina Bifida care. *J Pediatr Rehabil Med*. 2018;11(4):323–334.
4. Lindsay S, Cruickshank H, Mcpherson AC, Maxwell J. Implementation of an inter-agency transition model for youth with Spina Bifida. *Child Care Health Dev*. 2016;42(2):203–212.
5. Holmbeck GN, Kritikos TK, Stern A, Ridosh M, Friedman CV. The transition to adult health care in youth with Spina Bifida: theory, measurement, and interventions. *J Nurs Scholarsh*. 2021;53.2:1–10.
6. Hopson B, Alford EN, Zimmerman K, Blount JP, Rocque BG. Development of an evidence-based individualized transition plan for Spina Bifida. *Neurosurg Focus*. 2019;47(4):7–12.
7. Fremion E, Morrison-Jacobus M, Castillo J, Castillo H, Ostermaier K. A chronic care model for Spina Bifida transition. *J Pediatr Rehabil Med*. 2017;10(3–4):243–247.
8. Betz CL, Hudson SM, Lee JJ, Smith KA, Van Speybroeck A. An exploratory study of adolescents and emerging adults with Spina Bifida knowledge of their individual education program: implications for health care transition planning. *J Pediatr Rehabil Med*. 2019;12(4):393–403.
9. Mukherjee S, Pasulka J. Care for adults with Spina Bifida: Current state and future directions. *Top Spinal Cord Inj Rehabil*. 2017;23(2):155–167.
10. Wilson R, Lewis SA, Dicianno BE. Targeted preventive care may be needed for adults with congenital spine anomalies. *PM R*. 2011;3(8):730–738. Accessed August 8, 2019. http://doi.wiley.com/10.1016/j.pmrj.2011.05.021
11. Young NL, Anselmo LA, Burke TA, McCormick A, Mukherjee S. Youth and young adults with Spina Bifida: their utilization of physician and hospital services. *Arch Phys Med Rehabil*. 2014;95:466–71.
12. Liptak GS, Kennedy JA, Dosa NP. Youth with Spina Bifida and transitions: health and social participation in a nationally represented sample. *J Pediatr*. 2010;157(4):584–588, 588.e1.
13. Liptak GS, Garver K, Dosa NP. Spina Bifida grown up. *J Dev Behav Pediatr*. 2013;34:206–215.
14. Lindsay S, Cruickshank H, McPherson AC, Maxwell J. Implementation of an inter-agency transition model for youth with Spina Bifida. *Child Care Health Dev*. 2016 Mar;42(2):203–212.
15. Dillon CM, Davis BE, Duguay S, Seidel KD, Shurtleff DB. Longevity of patients born with myelomeningocele. *Eur J Pediatr Surg*. 2000;10:33–34.

16. Verhoef M, Barf HA, Post MWM, van Asbeck FWA, Gooskens RHJM, Prevo AJH. Functional independence among young adults with Spina Bifida, in relation to hydrocephalus and level of lesion. *Dev Med Child Neurol*. 2006;48:114–119.
17. Hetherington R, Dennis M, Barnes M, Drake J, Gentili F. Functional outcome in young adults with Spina Bifida and hydrocephalus. *Child's Nerv Syst*. 2006;22:117–124.
18. Davis BE, Shurtleff DB, Walker WO, Seidel KD, Duguay S. Acquisition of autonomy skills in adolescents with myelomeningocele. *Dev Med Child Neurol*. 2006;48(4):253–258.
19. Psihogios AM, Holmbeck GN. Discrepancies in mother and child perceptions of Spina Bifida medical responsibilities during the transition to adolescence: associations with family conflict and medical adherence. *J Pediatr Psychol*. 2013;38(8):859–870.
20. Strömfors L, Wilhelmsson S, Falk L, Höst GE. Experiences among children and adolescents of living with Spina Bifida and their visions of the future. *Disabil Rehabil*. 2017;39(3):261–271.
21. Oakeshott P, Hunt GM. Long-term outcome in open Spina Bifida. *Br J Gen Pract*. 2003;53:632–636.
22. Thibadeau JK, Alriksson-Schmidt AI, Zabel TA. The national Spina Bifida program transition initiative: the people, the plan, and the process. *Pediatr Clin North Am*. 2010;57(4):903–910.
23. Sawin KJ, Buran CF, Brei TJ, Fastenau PS. Correlates of functional status, self-management, and developmental competence outcomes in adolescents with Spina Bifida. *SCI Nurs*. 2003;20:72–85.
24. Rocque BG, Bishop ER, Scogin MA, Hopson BD, Arynchyna AA, Boddiford CJ, et al. Assessing health-related quality of life in children with Spina Bifida. *J Neurosurg Pediatr*. 2015 Feb;15(2):144–149.
25. Got Transition. The National Alliance to Advance Adolescent Health. Accessed April 2, 2019. https://www.gottransition.org/
26. Binks JA, Barden WS, Burke TA, Young NL. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and Spina Bifida. *Arch Phys Med Rehabil*. 2007;88(8):1064–1073.
27. Lindsay S, Cruickshank H, McPherson A, Maxwell J. Implementation of an interagency transition model for youth with Spina Bifida. *Child Care Health Dev*. 2015;42:203–212.
28. Lemly DC, Weitzman ER, O'Hare K, O'Hare K. Advancing healthcare transitions in the medical home. *Curr Opin Pediatr*. 2013;25(4):439–446.
29. Johnson K, Rocque B, Hopson B, Barnes K, Omoike OE, Wood D. The reliability and validity of a newly developed Spina Bifida-specific Transition Readiness Assessment Questionnaire: Transition Readiness Assessment Questionnaire-supplement (TRAQ-SB). *J Pediatr Rehabil Med*. 2019;12(4):415–422.
30. Wood D, Rocque B, Hopson B, Barnes K, Johnson KR. Transition Readiness Assessment Questionnaire Spina Bifida (TRAQ-SB) specific module and its association with clinical outcomes among youth and young adults with Spina Bifida. *J Pediatr Rehabil Med*. 2019;12(4):405–413.
31. Suris J-C, Akre C. Key elements for, and indicators of, a successful transition: an international delphi study. *J Adolesc Heal*. 2015;56(6):612–618.

32. National Alliance to Advance Adolescent Health. Got Transition. Published 2014. Accessed May 22, 2019. http://www.gottransition.org/providers/index.cfm
33. Szymanski KM, Cain MP, Hardacker TJ, Misseri R. How successful is the transition to adult urology care in Spina Bifida? A single center 7-year experience. *J Pediatr Urol*. 2017 Feb;13(1):40.e1-40.e6.
34. Shepard C, Doerge E, Eickmeyer A, Kraft K, Wan J, Stoffel JT. Ambulatory care utilization among patients with Spina Bifida: change in care from childhood to adulthood. *J Urol*. 2018;199:1050–1055.
35. Dicianno BE. 21st century challenges to the provision of health care to adults with Spina Bifida : a rehabilitation approach. *Arch Phys Med Rehabil*. 2014;95(9):1601–1602.
36. Kelly M, Thibadeau J, Struwe S, Ramen L, Ouyang L, Routh JC. Evaluation of Spina Bifida transitional care practices in the United States. *J Pediatr Rehabil Med*. 2017;10:275–281.
37. Skokan AJ, Kovell RC. Advances and challenges in transitional urology: caring for adolescents and young adults with lifelong complex genitourinary conditions. *Curr Urol Rep*. 2018 Apr 7;19(4):26.
38. Hettel D, Tran C, Szymanski K, Misseri R, Wood H. Lost in transition: patient-identified barriers to adult urological Spina Bifida care. *J Pediatr Urol*. 2018;14(6):535.e1-535.e4.
39. Wajchendler A, Anderson P, Koyle MA. The transition process of Spina Bifida patients to adult-centred care: an assessment of the Canadian urology landscape. *Can Urol Assoc J*. 2017;11(1–2):S88–91.
40. Aguilera AM, Wood DL, Keeley C, James HE, Aldana PR. Young adults with Spina Bifida transitioned to a medical home: a survey of medical care in Jacksonville, Florida. *J Neurosurg Pediatr*. 2016;17(2):203–207.
41. De Kort LMO. Transition from childhood to adolescence: steps to be taken. *Curr Opin Urol*. 2020;30(4):491–495.
42. Kinsman SL, Levey E, Ruffing V, Stone J, Warren L. Beyond multidisciplinary care: a new conceptual model for Spina Bifida services. *Eur J Pediatr Surg*. 2000;10(Suppl I):35–38.
43. Le JT, Mukherjee S. Transition to adult care for patients with Spina Bifida. *Phys Med Rehabil Clin N Am*. 2015;26:29–38.
44. van Staa AL, Jedeloo S, van Meeteren J, Latour JM. Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child Care Health Dev*. 2011;37(6):821–832.
45. Patel SK, Staarmann B, Heilman A, Mains A, Woodward J, Bierbrauer KS. Growing up with Spina Bifida: bridging the gaps in the transition of care from childhood to adulthood. *Neurosurg Focus*. 2019;47(4):1–8.
46. Roebroeck ME, Jahnsen R, Carona C, Kent RM, Chamberlain MA. Adult outcomes and lifespan issues for people with childhood-onset physical disability. *Dev Med Child Neurol*. 2009;51(8):670–678.
47. Lotstein DS, Inkelas M, Hays RD, Halfon N, Brook R. Access to care for youth with special health care needs in the transition to adulthood. *J Adolesc Heal*. 2008;43(1):23–29.

48. Castillo J, Brei TJ. Immigration and transition: changing demographics forecast the emerging trends in Spina Bifida care. *J Pediatr Rehabil Med*. 2019;12(4):337–338.
49. Kinsman SL, Levey E, Ruffing V, Stone J, Warren L. Beyond multidisciplinary care: a new conceptual model for Spina Bifida services. *Eur J Pediatr Surg*. 2000;10 Suppl 1:35–38.
50. Wiener JS, Suson KD, Castillo J, Routh JC, Tanaka S, Liu T, et al. Bowel management and continence in adults with Spina Bifida: results from the National Spina Bifida Patient Registry 2009-15. *J Pediatr Rehabil Med*. 2017;10:335–343.
51. Choi EK, Bae E, Jang M. Transition programs for adolescents and young adults with Spina Bifida: a mixed-methods systematic review. *J Adv Nurs*. 2021;77(2):608–621.
52. Betz CL, Smith KA, Van Speybroeck A, Hernandez FV, Jacobs RA. Movin' on up: an innovative nurse-led interdisciplinary health care transition program. *J Pediatr Heal Care*. 2015;30(4):1–16.
53. Kaufmann Rauen K, Sawin KJ, Bartelt T, Waring WP, Orr M, Corey O'Connor R. Transitioning adolescents and young adults with a chronic health condition to adult healthcare - an exemplar program. *Rehabil Nurs*. Jan 2013;38(2):63–72.
54. Cox A, Breau L, Connor L, McNeely PD, Anderson PA, MacLellan DL. Transition of care to an adult Spina Bifida clinic: patient perspectives and medical outcomes. *J Urol*. 2011 Oct;186(4 Suppl):1590–1594.
55. Fiorentino L, Datta D, Gentle S, Hall DM, Harpin V, Phillips D, et al. Transition from school to adult life for physically disabled young people. *Arch Dis Child*. 1998;79:306–311.
56. Mirkin K, Casey JT, Mukherjee S, Kielb SJ. Risk of bladder cancer in patients with Spina Bifida: case reports and review of the literature. *J Pediatr Rehabil Med*. 2013;6(3):155–162.
57. Lindsay S, McPherson AC, Maxwell J. Perspectives of school-work transitions among youth with Spina Bifida, their parents and health care providers. *Disabil Rehabil*. 2017;39:641–652.
58. Haarbauer-Krupa J, Alexander NM, Mee L, Johnson A, Wise J, Arora Gupta N, et al. Readiness for transition and health care satisfaction in adolescents with complex medical conditions. *Child Care Health Dev*. 2019;45(3):463–471.
59. Betz CL. Self-management and health care transition: Trials, tribulations and triumphs. *J Pediatr Rehabil Med*. 2017;10(3–4):177–183.
60. Campbell, F., Biggs, K., Aldiss, S. K., O'Neill, P. M., Clowes, M., McDonagh, J., ... & Gibson, F. (2016). Transition of care for adolescents from paediatric services to adult health services. Cochrane Database of Systematic Reviews, (4).
61. Faleiros F, Warschausky S, Käppler C, Schutt W, Cintra MM, Rabeh SAN, et al. Bladder self-management in the transition to adulthood with Spina Bifida in 3 countries: a comparative study. *J Wound, Ostomy Cont Nurs*. 2019;46(4):321–326.
62. Dicianno BE, Wilson R. Hospitalizations of adults with Spina Bifida and congenital spinal cord anomalies. *Arch Phys Med Rehabil*. 2010;91:529–535.
63. Gatti C, Del Rossi C, Ferrari A, Casolari E, Casadio G, Scire G. Predictors of successful sexual partnering of adults with Spina Bifida. *J Urol*. 2015;182(4 Suppl):1911–1916.

Published October 2009. Accessed January 27, 2015. http://www.sciencedirect.com/science/article/pii/S0022534709003930
64. Lam Van Ba O, Soustelle L, Wagner L, Siegler N, Boukaram M, Naoum K Ben, et al. Impact on quality of life and sexual satisfaction of continent cystostomy with enterocystoplasty in an adult neurologic population. *Neurourol Urodyn*. 2018;37(4):1405–1412.
65. Lindsay, S., McPherson, A. C., & Maxwell, J. (2017). Perspectives of school-work transitions among youth with spina bifida, their parents and health care providers. Disability and rehabilitation, 39(7), 641-652.
66. Mukherjee S. Transition to adulthood in Spina Bifida: changing roles and expectations. *ScientificWorldJournal*. 2007;7:1890–1895.
67. Sawyer SM, Blair S, Bowes G. Chronic illness in adolescents: transfer or transition to adult services. *J Paediatr Child Health*. 1997;33:88–90.
68. Betz CL, Smith K, Macias K. Testing the transition preparation training program: a randomized controlled trial. *Int J Child Adolesc health*. 2010;3(4):595–607.
69. Sawyer SM, Macnee S. Transition to adult health care for adolescents with Spina Bifida: research issues. *Dev Disabil Res Rev*. 2010;16(1):60–65.
70. Betz CL, Smith KA, Macias K, Bui K. Exploration of internet use: profile and preferences of transition-aged adolescents with Spina Bifida. *Pediatr Nurs*. Jan;40(4):173–178.