

# Transition

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## Introduction

The primary goal of transition from pediatric to adult health care is to maximize lifelong functioning through the provision of quality, developmentally-appropriate health care that continues uninterrupted as the individual moves from adolescence to adulthood.<sup>1</sup> Coordination between the individual, family, health care providers, school, and allied health services throughout the transition process enables young adults with Spina Bifida to optimize their ability to eventually assume adult roles and activities.

Health care transition is a process that includes:

1. Preparation for engaging in adult health care and adult responsibilities through planning and coaching during pediatric years, school, and home settings.
2. Handoff of care responsibilities from pediatric to adult providers and from parents to young adults as they are developmentally able.
3. Transfer of care to adult providers and health care settings between the ages of 18-21.<sup>2</sup>

Adolescents and young adults with Spina Bifida have increased hospitalizations for chronic condition exacerbations, such as urinary tract infections and skin breakdown, and more difficulty accessing health care services than their age-matched peers.<sup>3</sup> Furthermore, they are less likely to achieve emerging adult milestones such as leaving home, attending college, finding employment, developing romantic relationships, and having multiple friendships. Executive function, socioeconomic status, intrinsic motivation, and parental fostering of independence are significant predictors of successful transition to adulthood.<sup>4</sup> 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 Spina Bifida face when transferring to adult care and life. (Neuropsychology Guidelines, Self-Management and Independence Guidelines)

The following key elements have been identified as essential for transition programs for adolescents with chronic conditions:

1. Designate a transition program to support care coordination and transition to adult-oriented care;
2. Ensure flexibility regarding transfer timing based on the individual's cognitive development, physical abilities, social and financial situation, and health status;
3. Begin transition planning at ages,<sup>12-14</sup> including creating a medical summary, identifying insurance coverage plans, and designating care providers throughout the transition process;
4. Support self-management development for health care navigation and chronic condition management (Neuropsychology Guidelines, Self-Management and Independence Guidelines);
5. Consider the adolescent's views and preferences regarding transition plans;
6. Designate time alone with the adolescent for at least part of their visit, if developmentally appropriate;

7. Identify adult providers to assume care prior to the transition; and
8. Provide chronic condition management and age-appropriate preventive care throughout transition.<sup>1,5-6</sup> (Health Promotion Guidelines)

While transition focuses on adolescent age groups, the trajectory to maximize adult function and independence is fostered throughout the lifespan by setting expectations for adult independence and making the transition to adult care. While survival to adulthood for individuals with Spina Bifida now exceeds 85%, the degree of adult independence in the population varies.<sup>7</sup> 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.<sup>8-9</sup> Individualized goals and interventions should be emphasized for adolescents with Spina Bifida because they tend to experience a two- to five-year delay in developing autonomy skills compared with their typically-developing peers.<sup>10</sup> By age 30, approximately one-third of individuals with Spina Bifida are independent, one-third need supervision and occasional help, and one-third routinely need assistance for daily care needs.<sup>11</sup> Thus, lifelong assessment and interventions to maximize chronic condition management, family function, socialization, cognitive function and school performance, mental health, and self-management/self-care are foundational to participation, function, and quality of life in adulthood.<sup>9,12-15</sup> (Self-Management and Independence Guidelines).

Transition resources and assessment tools can be found at [www.gottransition.org](http://www.gottransition.org).

## **Outcomes**

### **Primary**

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

### **Secondary**

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

### **Tertiary**

1. Promote access to uninterrupted, developmentally-appropriate Spina Bifida condition management and preventative care throughout transition, specifically ages.<sup>14-21</sup>

## **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 Spina Bifida?
3. What are the essential transition planning elements to promote uninterrupted access to care once children with Spina Bifida need adult care?

### **Guidelines**

1. Provide families with a realistic, long-term orientation that includes a probable trajectory for adult function and expectations for optimal independence according to the child's abilities.<sup>7-11,16</sup>
2. Provide information for families regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.<sup>17</sup>

3. Set expectations as to where individuals with Spina Bifida can access comprehensive care throughout the lifespan, including transition care.<sup>18</sup>

## **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 Spina Bifida?
3. What are the essential transition planning elements to promote uninterrupted access to care once children with Spina Bifida need adult care?

### **Guidelines**

1. Provide updates for families regarding a probable trajectory for adult function and expectations for optimal independence according to the child's abilities and chronic condition status.<sup>7-11,16</sup>
2. Provide updates for families on information regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.<sup>17</sup>
3. Review expectations as to where individuals with Spina Bifida can access comprehensive care throughout the lifespan, including transition care.<sup>18</sup>

## **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 Spina Bifida?
3. What are the essential transition planning elements to promote uninterrupted access to care once children with Spina Bifida need adult care?

### **Guidelines**

1. Provide updates for families regarding a probable trajectory for adult function and expectations for optimal independence according to the child's abilities and chronic condition status.<sup>7-11,16</sup>
2. Provide updates for families on information regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.<sup>17</sup>
3. Review expectations as to where individuals with Spina Bifida can access comprehensive care throughout the lifespan including chronic condition management, preventative care, and transition care.<sup>18</sup>

## **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 Spina Bifida?
3. What are the essential transition planning elements to promote uninterrupted access to care once children with Spina Bifida need adult care?

### **Guidelines**

1. Provide updates for families regarding a probable trajectory for adult function and expectations for optimal independence according to the individual's abilities and chronic condition status.<sup>7-11,16</sup>
2. Consider unique neuropsychological issues in transition and self-management. (Neuropsychology Guidelines, Self-Management and Independence Guidelines)
3. Provide updates for families on information regarding long-term financial, insurance, and supportive living planning based on the child's probable trajectory into adult function.<sup>17</sup>
4. Review expectations where individuals with Spina Bifida can access comprehensive care throughout the lifespan including chronic condition management, preventative care, and transition care.<sup>18</sup>
5. Review the clinic's transition policy with patients and families at age 12.<sup>19</sup>

## **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 Spina Bifida?
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 Spina Bifida 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 Spina Bifida need adult care?

### **Guidelines**

1. Provide updates for children and families regarding a probable trajectory for adult function and expectations for optimal independence according to the individual's abilities and chronic condition status.<sup>7-11,16</sup>
2. Consider neurocognitive assessment to identify cognitive, adaptive, or learning support needs if knowledge or skill gaps are identified. (Neuropsychology Guidelines, Self-Management and Independence Guidelines)
3. Discuss transition planning with children and families including:<sup>5,17,20-27</sup>
  - 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.
  - b. Expectations of who will provide care throughout the transition process.
  - c. Counselling regarding long-term financial, insurance, and supportive living (housing and transportation) plans, based on the individual's current needs and probable trajectory of adult function.
  - d. Information regarding the child's education and employment needs, such as vocational rehabilitation services, school transition planning as part of the Individualized Educational Plan [INSERT LINK], and adaptive vocational needs.
  - 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 for neurocognitive testing and to medical legal partnerships may be needed.
- f. Information regarding the Social Security Administration's Disability Determination Services before age 18, as applicable.
  - g. Creation of a medical summary including past medical and surgical history, current care plans, medications, allergies, vaccines, and current providers.
  - h. Self-management support. Consider using transition and self-management assessment tools to direct goals and interventions.<sup>19</sup> (Self-Management and Independence Guidelines)
4. Ensure that the patient's views and preferences are included in transition planning.<sup>6</sup>
  5. Designate time alone with the child for at least part of their visit, if developmentally appropriate.<sup>6</sup>
  6. Consider having a designated transition clinic or care coordinator to support transition planning and coordination.<sup>5</sup>
  7. Ensure patient-centered and developmentally appropriate preventive and chronic condition management services are provided throughout transition. (Health Promotion Guidelines) Evaluate management plans and assess for necessary adaptive equipment and supplies to maximize independent function.<sup>18,22-23</sup>

## 18+ years

### Clinical Questions

1. What are barriers and facilitators to participating in emerging adult milestones for individuals with Spina Bifida?
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 Spina Bifida need adult care?
4. What are the best strategies to find and engage adult providers?

### Guidelines

1. Provide updates for adults and families regarding a probable trajectory for adult function and expectation for optimal independence according to the individual's abilities and chronic condition status.<sup>7-11,16</sup>
2. Consider unique neuropsychological issues in transition and self-management. (Neuropsychology Guidelines, Self-Management and Independence Guidelines)
3. Continue to assist with transition coordination as applicable including:<sup>5,13,20-25,28</sup>
  - a. Assistance in identifying adult providers who accept the patient's insurance and can assume his/her care.
  - b. Counselling 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 [INSERT LINK], 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. Creation of a medical summary including past medical and surgical history, current care plans, medications, allergies, vaccines, and current providers.
  - g. Self-management support. (Self-Management and Independence Guidelines) Consider using transition and self-management assessment tools to direct goals and interventions.<sup>19</sup>
4. Ensure that patient-centered and developmentally appropriate preventive and chronic condition management services are provided throughout transition. Evaluate management plans and assess for necessary adaptive equipment and supplies to maximize independent function.<sup>18,22-23</sup>

## Research Gaps

1. There is a need for studies that explore comprehensive care and best practices for children with Spina Bifida ages 13+ that address demographic and functional variables that influence transition, preventive care and condition management, strategies to improve access to quality health care throughout transition, and evaluation of effective self-management intervention programs.<sup>28-31</sup>
2. Educational programs are needed to improve health care professionals' 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 Spina Bifida.
3. Studies are needed to identify the risks and facilitators of secondary education and workforce and social participation for adults 18+ with Spina Bifida, in order to inform transition counseling and intervention.<sup>29,31</sup>
4. Studies are needed to examine internet and technology applications for education and transition should be further explored.<sup>32</sup>
5. Studies are needed to determine what barriers/facilitators adult health care providers experience in caring for adults with Spina Bifida, and how they can best support health care services for adults with Spina Bifida.
6. Studies are needed to determine the best assessments to measure transition readiness for adolescents with Spina Bifida.
7. There is a need to identify models of care for adults living with Spina Bifida that consider the specific needs of the individual, such as proximity to appropriate specialty and primary care services, transportation accessibility, and personal preference about the service delivery desired.

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