

The National Spina Bifida Program Transition Initiative: The People, the Plan, and the Process

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- Employment

Spina bifida (SB) is a multidimensional condition thought to impact different life-domains across the course of development. Children born three to four decades ago who were affected by chronic childhood conditions, such as SB and cerebral palsy, generally did not live to adulthood.¹ Survival rates for conditions such as these have increased dramatically in industrialized countries since that time² and are no longer considered to result in premature death by default. Nevertheless, growing up with SB or cerebral palsy poses multiple challenges that children without a chronic and complex disabling condition do not experience. Thus, the manner in which SB-related variables influence the transition of youth into adulthood has increasingly become an area of public health interest.

Preparing for life as an adult for any young person with such conditions involves a broad range of concerns, inevitable stumbling blocks, as well as opportunities for creative adaptation. Current understanding of the condition-related impact of SB

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upon transition processes includes several promising areas of knowledge, but also includes significant research gaps and domains that have been understudied, leaving in many instances decisions to be made based on personal expert opinions. However, research has shown that, in addition to the perhaps obvious medical complications that can occur with complex childhood conditions compared with adolescents without physical disabilities, 11- to 16-year-old adolescents with physical disabilities reported more difficulty with decision making, more difficulty making and communicating with friends, that they were less likely to have plans to attend college, and more likely to be unable to express what they would be doing at age sixteen.³ Moreover, challenges were also reported in achieving independent living, vocational independence, and community mobility, and in participation in social activities.³ Although the value that is placed on having a job, living independently, and having hobbies and friends is subjective and, to some degree, culture-specific, they are generally important cornerstones in people's lives.

The Centers for Disease Control and Prevention (CDC) has a long and successful history in the discovery of causative factors of SB and in the prevention of births that are affected by SB.⁴ However, it was not until 2003 that a more coordinated CDC effort was initiated to include a focus on persons who are born and living with SB. The National Spina Bifida Program (NSBP) was developed as a congressionally mandated program and placed at the National Center for Birth Defects and Developmental Disabilities at CDC. The goals of this program are to: facilitate independence, enhance participation in society, increase access to effective health care, and to increase the number of persons living healthy lives with minimal associated health conditions. To achieve these goals, surveillance, intramural and extramural research, close collaboration with SB advocacy organizations such as the Spina Bifida Association (SBA), as well as other mechanisms and partnerships are used.

Many believe that to realize the desired level of independence and participation by adults with SB, intentional preparation for this achievement needs to begin at an early age.⁵ However, although it is mandated that aging out of the school system be preceded by "transition" planning, this planning generally occurs when a child reaches the age of 14 to 15 years. The plan typically encompasses what he or she may be doing upon leaving high school—work, further education, or some type of training. Although the condition-related impact of SB is better understood during early periods of child development, it is considerably less well understood during adolescence and young adulthood and there is little research or guidance on how to manage the transition process. Even in well-designed research studies, there is often little linkage between findings and eventual outcomes that might be useful for guiding interventions to improve the outcomes of the adult transition process in SB. The American Academy of Pediatrics has expended much effort to describe the need for and the difficulties associated with the transfer to a health care system that is family-centered, continuous, comprehensive, coordinated, compassionate, and culturally competent for children with special health care needs as they become too old to be cared for in the pediatric system of care.⁶ The term "transition" has been used to refer to this transfer of medical care effort as well. However, the issues of transition are much broader and long-standing than either of these definitions and require the interplay of medical, educational, and social systems that are often working independently and not set up to support the achievement of independence or the early and ongoing developmental work that may be necessary for a successful transition into young adulthood for persons living with chronic childhood conditions. The creation of a resource to guide the preparation for adult participation (ie, life-course transition) was consequently identified as a high priority area by the NSBP. The availability of a resource

of this kind will help individuals with SB as well as their parents, teachers, doctors, and other professionals anticipate common SB-related developmental challenges as well as obtain information regarding known intervention or accommodation approaches.

THE PROCESS OF THE NSBP TRANSITION INITIATIVE

The concept of delineating the problems and developing a plan to be used to facilitate the life-course transition process for persons with SB, and possibly other chronic childhood conditions, was developed by NSBP professionals. The first step involved organizing a two-day Transition Summit hosted by CDC. Persons living with SB and family members of persons living with SB, as well as professionals from different disciplines with recognized expertise in SB and SB research (including developmental pediatrics, nursing, psychology, occupational therapy, and rehabilitation medicine) were invited to participate in the Summit. Professionals representing SBA and CDC also participated. The group was charged with specific tasks. Initially, the group members were asked to state the needs of persons with SB (and other chronic childhood conditions) that must be met in order that they may transition successfully from a child-oriented system of care and services to one focused on the needs of an independent and participating adult. The discussion was then directed to describe the barriers that prevent developmentally appropriate transitions throughout the life course in medical and nonmedical areas; to describe interventions or programs with demonstrated success in addressing the identified barriers to successful and timely transitions; and to describe the expected outcomes of effective transition programs or resources. Toward the end of the Transition Summit, a conversation was held to identify the next steps needed to put available and appropriate transition-related resources into the hands of persons who may need them. To frame this work, the NSBP's draft "Life-Course Model" (discussed in detail later) was presented as a way to organize the discussion about resources and interventions. The discussion regarding interventions encompassed several specific domains that included: Health Care, Access and Use; Health Promotion; Sexuality and Reproductive Concerns; Self-Advocacy or Self-Care Management; Education or Job Training; Relationships; Socialization or Social Skills; Depression and Mental Health (including during major disasters); Transportation; Mobility; Family Interventions; and Preventing Secondary Conditions. The Transition Summit discussions resulted in the articulation of a number of key principles to guide the development of interventions, as well as the identification of interventions specific to particular age groups. A summary of these key principles is presented in **Box 1**.

Following the Transition Summit, NSBP elicited a one-year commitment from each of the Summit participants who were willing and able to continue working on the transition initiative. The group in its entirety (20) consented to the one-year commitment. A timeline representing the overall progress of the work is outlined in **Fig. 1**.

The Life-Course Model for Spina Bifida

The life problems experienced by a person and the impact of those problems are unique to each individual and his or her specific situation and condition. Recommendations to buffer or solve the problems encountered would, of course, include an assessment of each person's situation, desires, and life circumstances. Nevertheless, there are certain key domains that, without consideration throughout the life course, may result in a less than satisfactory progression to independence, participation, and health. The consistent mantra throughout this work has been that to successfully prepare a young adult for a healthy life that includes participation and self-sufficiency.

Box 1

Key concepts from the transition summit

General

- Transition begins early—identify developmental issues at birth and across the life course.
- Monitor developmental progress systematically in different stages or aspects of life.
- Individualize transition interventions as appropriate and based on developmental assessment.

Adolescents

- Begin planning for transition before child becomes an adolescent.
- Education and guidance for adolescents is essential. Information should be provided often and until the adolescent models behavior that is reflective of the education.
- At times, male or female differences and concerns may need to be addressed in same-gender groups.
- Mentor teens with SB by adults with SB.
- Create opportunities for participation in team sports and group activities.
- Create and use peer groups.

Young Adults

- Empower young adults to be self-advocates
- Link young adults to offices of disability at post-secondary schools
- Promote volunteerism and building and sustaining relationships

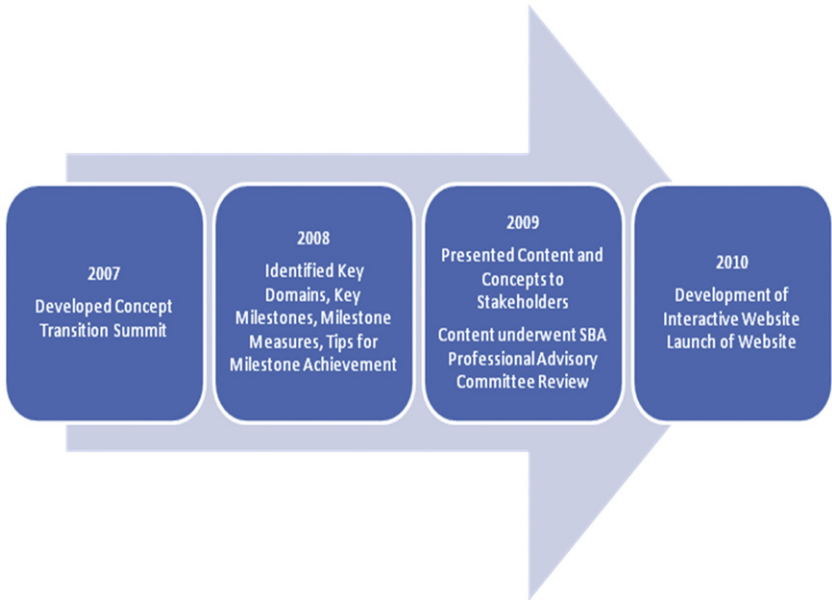


Fig. 1. Timeline of the overall work progress.

Intentional preparation needs to begin at an early age. Therefore, the Life-Course Model was laid out developmentally, beginning with the preschool years and continuing through school-age, adolescence, and young adulthood. It is acknowledged that an individual's development does not end at young adulthood. However, it became necessary to put parameters on the work because it quickly became extensive, and there were concerns that it would become overwhelming and unwieldy for the work groups and for the final user.

The Life-Course Model was designed to address three broad functional domains: Health and Condition Self Management; Social and Personal Relationships; and Education or Income Support (Fig. 2).

The first of these broad functional dimensions, Health and Condition Self Management, included discrete functional domains related to mobility, skin integrity, sexuality, obesity prevention, bowel or bladder management, and condition self-management. The second broad functional domain area was Social and Personal Relationships, which included content specific to discrete functional domains including the personal development of the individual with SB, as well as his or her relationship with parents, siblings, friends, and romantic or intimate partners. The third and final broad functional domain was Education or Income Support, which included a focus upon discrete areas such as cognitive development, mastery of different academic content, functional academics, prevocational skill development, and the development of responsibility-taking behaviors. Discrete functional domains were identified within each of these broad functional areas, and these discrete areas were further subdivided by age to examine smaller transitional steps occurring within each discrete functional domain during the preschool, school-age, adolescent, and young adult time periods. Segmentation of discrete functional domains according to broad age ranges permitted a greater appreciation of the transition processes occurring across the development of youth with SB. For instance, examining the development of condition self-management skills according to the noted age ranges helped elucidate a series of transitional steps that would be useful for focusing research and intervention efforts.

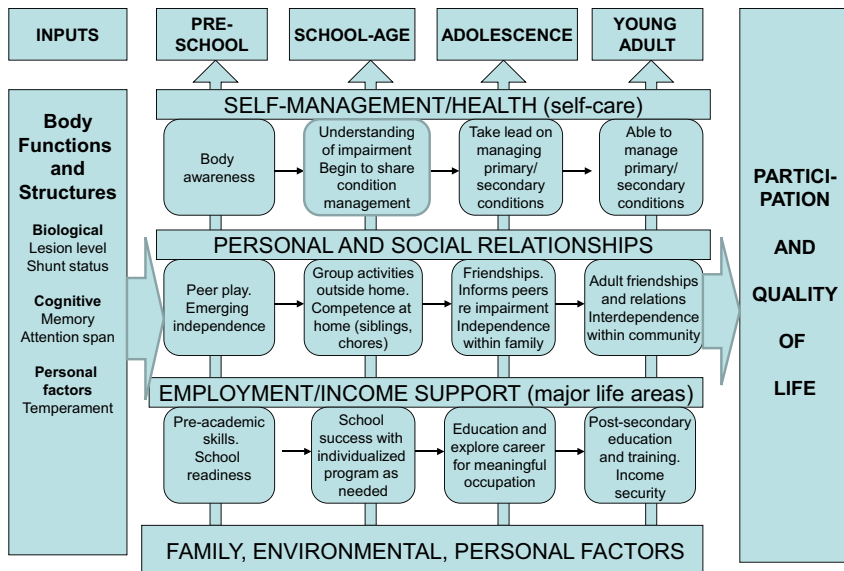


Fig. 2. The Life-Course Model for spina bifida.

Examples include: beginning awareness of SB during preschool, engagement in health promotion and illness prevention during the school-age years, gradual reduction in need for external self care supervision and prompting during adolescence, and eventual independence in self-management and self-care competencies during young adulthood. In the end, examining transition of youth with SB via both the age dimension and the functional dimension proved useful for identifying distinct and parallel developmental processes thought to underlie the gradual transition of youth with SB into the roles and responsibilities of adulthood.

The Life-Course Model also incorporates unique factors that each person with SB or other chronic condition brings to the table. These factors were delineated as biologic factors, personal factors, and cognitive skills. Common to these factors is that they are not very, if at all, modifiable. Other factors certainly have the potential to moderate outcomes, such as family, environment, and culture. These factors may or may not be modifiable, but they are likely to impact how the other factors interact. Although the vital role of these potential moderating factors was acknowledged in the model, they were not explored or developed in any detail.

The Life-Course Model proved helpful in organizing the different topics that the working groups (discussed in more detail later) identified as the issues most relevant to facilitate the timely and successful path through the developmental stages and it has continued to be useful to summarize the completed work. It cannot, and is not intended to be, an all encompassing transition model.

There are clear similarities between the International Classification of Functioning Disability and Health (ICF)⁷ and the Life-Course Model although the terminology and the purpose differ. Whereas the ICF is a detailed classification system for the description of health and health-related states, the Life-Course Model was designed to specifically target the process and actions needed for multiple life stages and life-course transition for persons with SB. Nevertheless, what are referred to as “inputs” in the Life-Course Model are comparable to, for example, “body functions and structure” and “personal factors” in the ICF. Both models also acknowledge the importance of environmental factors as well as participation in life and society. With participation and quality of life as the long-term goals, the work groups populated the different cells in the Life-Course Model by domain and age group, with concepts that were considered to represent key developmental milestones, measures and indicators of milestone achievement, tips to accomplish the key milestone, and associated references.

TRANSITION WORKING GROUPS

After the Transition Summit and as a result of the themes that emerged during the Summit that were important to the successful transition of persons affected by SB, five working groups were created (**Fig. 3**).

Each group consisted of four to five people and a volunteer leader. The leader, in conjunction with professionals from CDC, organized the work and facilitated the progress. The groups worked via conference calls from November, 2007, until June, 2008, reviewing the literature and determining their approach to develop a Life-Course Model of transition. In addition, the group leaders held a separate conference call monthly to discuss progress and differences in approach. During this time the groups recommended the final product be developed into an interactive Web site that could be used by parents of children born with SB, persons with SB, and professionals working with persons affected by SB. Although the focus was clearly on SB, many in the working groups recognized the overlap of this work with the process of transition

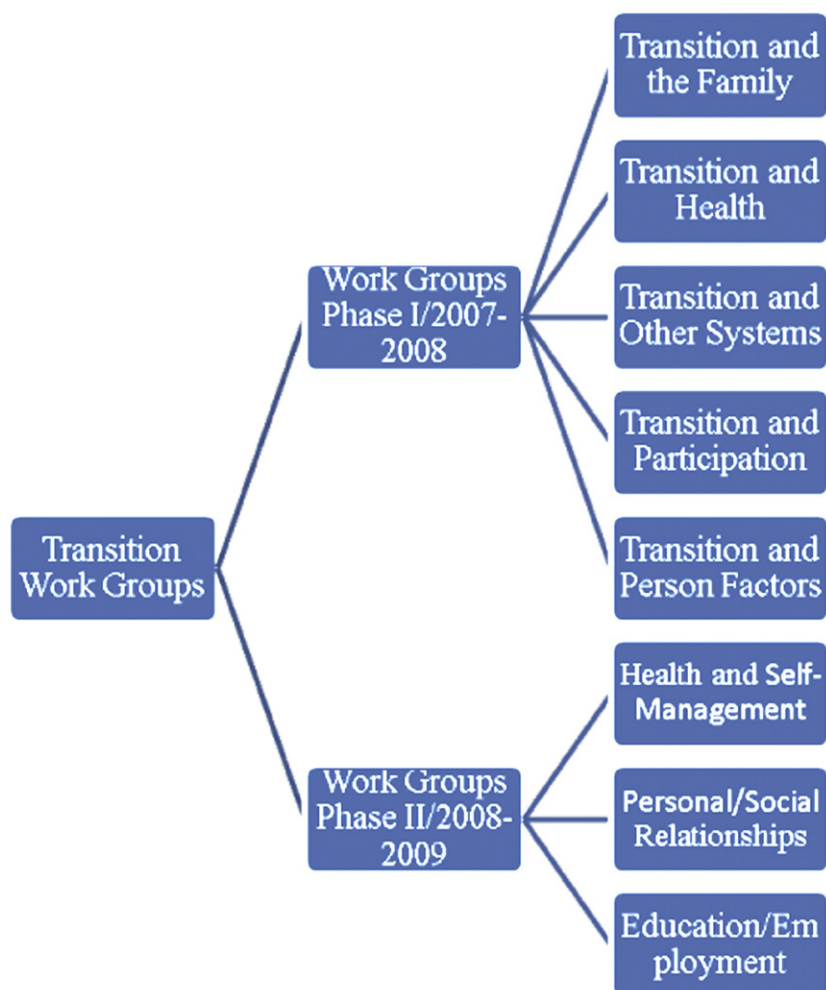


Fig. 3. Transition work groups.

for children with other chronic childhood conditions. Therefore, the literature reviews that were undertaken were not limited to SB. The groups had a second face-to-face meeting in Tucson, Arizona, at the annual national SBA meeting at which time they shared the status of the work on their topics. After the meeting, the five groups were restructured into three groups that would encompass the aspects included in the initial domains: Health or Condition Self Management; Social and Personal Relationships; and Education or Income Support (see [Fig. 3](#)). These groups worked from November, 2008, until June, 2009, at which time, during the SBA Annual Meeting, the three domains were highlighted in specific presentations to receive feedback from clinicians, persons with SB, and their families regarding the relevance and the content of the model and the domains. The sessions were well received; comments were recorded and incorporated into a final version of the Life-Course Model. The work was also vetted with attendants at the First World Congress on Spina Bifida in Orlando, Florida, in March of 2009.

The final version of the document underwent a review by a subcommittee of the SBA Professional Advisory Committee. Comments received were considered and incorporated as appropriate and the Spina Bifida Life-Course Model was finalized. This content is being incorporated by SBA into a Web-version for access by clinicians, persons with SB, and their families, and will be available via the SBA Web site late in 2010. A key recommendation of the working groups is that the information not be presented so as to be too voluminous at one time. Therefore, users may access the content by domain (Health or Self Management, Personal or Social Relationships, Education or Income Support) or by age (preschool, school-age, adolescent, young adult), and navigate through the site viewing as much or as little content as desired. Incorporated into the Web application is the opportunity for the reader to answer questions regarding the developmental progress of a person in the different domains so as to gauge roughly the progress made toward the achievement of a specific developmental milestone. It should be noted, however, that the Web site is organized to efficiently summarize information that may be applicable to a person. It is not a standardized self-assessment and should not be regarded as such. It is intended to be complementary to, and not replace, the work and advice of health care professionals in the lives of persons affected by SB. Individuals who access the Web site will have the opportunity to share personal success stories and helpful tips and interventions that may be used to assist others to make progress toward achieving the particular milestones. The site will be reviewed on at least an annual basis for the verification of the links included as well as to provide an opportunity for information review and update.

This article outlines and summarizes the rationale and the work process that was undertaken to address the issues of transitioning throughout the life course for persons growing up with SB. Although this work focused specifically on transition for children and adolescents with SB, there is substantial overlap with other chronic childhood complex conditions.

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