

# The Life Course Model Web Site: An Online Transition- Focused Resource for the Spina Bifida Community

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## KEYWORDS

• Spina bifida • Transition • Adulthood • Development

Spina bifida (SB) is a multi-dimensional disorder thought to impact different life domains across the course of development. The manner in which SB-related variables influence the transition of youth into adulthood has increasingly become an area of public health interest, particularly given medical advances that have made survival into adulthood the general rule rather than the exception.<sup>1</sup> Current understanding of the disease-related impact of SB upon these transition processes includes several promising areas of knowledge, but also includes significant research gaps and domains that have been understudied (see the article by Kathleen Sawin elsewhere in this issue for further exploration of this topic). The disease-related impact of SB is best understood in domains such as education,<sup>2,3</sup> and is far less understood in

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domains such as employment and independent living in adulthood. Similarly, disease-related impact of SB is better understood during early periods of child development,<sup>4</sup> and is considerably less well understood during adolescence and young adulthood. Moreover, even in well designed studies, there is often little linkage between research findings and eventual outcomes that might be useful for guiding interventions to improve the outcomes of the adult transition process in SB.

This combination of islands of fruitful transition-related research mixed with significant research gaps/understudied areas has increased the difficulty associated with developing integrated lifespan resources for individuals with SB. The Life Course Model Web site project was initiated in 2007 by the Centers for Disease Control and Prevention and the Spina Bifida Association to accumulate SB-related transition-related information and organize it into a useful and accessible resource (see the article by Thibadeau and colleagues elsewhere in this issue for further exploration of this topic). Specifically, this effort was intended to help individuals with SB as well as their parents, teachers, doctors, and other professionals anticipate common SB-related developmental challenges and to obtain information regarding known intervention and accommodation approaches. The overall design is intended to facilitate an individualized exploration of information specific to the different functional transitions presented to youth with SB as they develop, and then to provide associated intervention tips and resources from the available research and the large body of experience of parents and clinicians in the field.

#### **STRUCTURE OF THE LIFE COURSE MODEL WEB SITE**

The specialized transition-related information included in the Life Course Model Web site is organized around the Life Course Model described by Mark E. Swanson in this issue. This model includes four general age ranges; preschool, school-age, adolescence, and young adulthood. Each of these age ranges was noted to contain important transitions in multiple functional life domains. For instance, important academic transitions are experienced by most individuals with SB in each of the noted age ranges, including the beginning of formal schooling, the transition of the individual into the increased academic expectations of third and fourth grade, the transition of the individual into middle school/high school, and the process involved in making plans following high school. Other transition processes can be traced along this time dimension, such as the series of transitions that occur within the parent/child relationship (eg, the development of parent/child attachment in childhood, a gradual shift of responsibilities from parent to child in adolescence, and the eventual development of parent/child interdependence in young adulthood).

In addition to the age clusters described, the logic model that provides the underlying structure to the Life Course Model Web site also includes several broad functional domains that represent another dimension of the model. The first of these broad functional dimensions, self-management/health, includes discrete functional domains related to mobility, skin integrity, sexuality, obesity prevention, bowel/bladder management, and condition self-management. The second broad functional domain area is personal and social relationships; this area includes 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/intimate partners. The third and final broad functional domain of the Life Course Model Web site is employment and income support; this area includes 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 are identified within each of these broad functional areas, and these discrete areas are 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.

The Life Course Model Web site allows exploration of the noted SB-related transition information according to both age dimension and the functional dimension, thereby demonstrating the distinct and parallel developmental processes thought to underlie the gradual transition of youth with SB into the roles and responsibilities of adulthood. Specifically, the Web site format allows an exploration of a distinct functional domain (eg, relationship with siblings) sequentially by age (ie, longitudinally), allowing one to see the conceptual manner in which this distinct functional domain develops across the lifespan (eg, managing early sibling conflicts during the school-aged years may facilitate the development of mutual sibling support during young adulthood). The flexibility of the Web-based format also allows for exploration of the functional domain by individual age ranges (ie, cross-sectional), allowing one to see the manner in which distinct functional domain elements might overlap, develop in tandem, or mutually facilitate growth at different periods of time (eg, maximizing mobility during preschool may help prevent obesity during preschool).

The Life Course Model Web site is intended to allow navigation of the transition content in a number of different ways based upon the user's individual concerns, learning styles, or interests. To organize content areas, specific indicators of milestone achievement are included by age and functional domain. These indicators of developmental progress allow the user to quickly assess the developmental gains of his or her child with SB within the context of the transition model. For instance, a parent of a preschooler can quickly access indicators of success transitional achievement during the preschool years, and use this information to gauge a child's progress or needs. In turn, the same parent of a preschooler with SB can review indicators of discrete functional development during childhood and adolescence, perhaps in anticipation of upcoming transitional challenges and developmental steps. To facilitate access to these indicators of milestone achievement, the indicators of milestone achievement are worded in question format, which facilitates the possibility of an online developmental survey that can help direct parents, teachers, clinicians, and others to indicators and content that may be of particular interest based upon their survey responses.

In addition to the milestones and indicators described previously, the Life Course Model Web site presents various practical tips, intervention strategies, and assessment techniques that are associated with the indicators/milestones in the transition process. There are currently few (if any) evidenced-based practices that have been developed for addressing the academic, personal/social, or health care and self-management needs of youth with SB. As such, most tips and intervention strategies are generated out of either promising practices or reports of effectiveness based upon parent or clinician anecdotal report. The Web-based platform allows all of these tips and intervention strategies to be available for review at any point at which a parent, clinician, or person with SB encounters a discrete functional content area for which he or she wants intervention advice. In this respect, the tips and interventions are nested within the broader transition related content, and the interested user can access this information via a simple mouse click. Furthermore, link-out options permit direct electronic routing of the user to additional Internet-based resources such as scientific abstracts, source documents, additional explanations of concepts, or additional resources in areas of interest or concern.

In short, the Web site model allows the user to navigate horizontally among the indicators of milestone achievement in different functional domain areas and during

various periods of development, but also allows the user to drill down into the Web site for helpful tips and strategies for addressing indicator-related areas of concern. The following examples are presented to illustrate this drill down process. These examples were selected to illustrate the age range included in the Life Course Model Web site (preschool, school age, adolescence, young adulthood), provide examples of the functional domains, and demonstrate the organization of the content included.

#### **EXAMPLE OF WEB SITE USE: PRESCHOOL, SOCIAL DEVELOPMENT**

The distal outcomes of SB in young adulthood are increasingly believed to be shaped in part by earlier developmental transition processes, and the transition content of the Life Course Model Web site extends down to the preschool years to reflect this early influence. The preschool years are a particularly salient period in which play and friendship skills develop, and preschoolers with SB often have the added barrier of physical/mobility-related issues that disrupt aspects of preschool peer interactions.

A parent, teacher, or day care provider could find considerable information about the social development of preschoolers with SB on the Life Course Model Web site, including several indicators that could help determine if a youngster is meeting key social milestones such as the transition from parallel to interactive play. The transition to interactive play is a key component to social competence and acceptance, and can be an area of difficulty for preschoolers with SB. To help assess this, the Web site user is cued to answer several preschool-related questions, such as

- Does your child appear comfortable in small play groups?
- Does your child share some toys with peers?
- Does your child seem to understand the feelings of other children?

Answering yes to these questions provides age-related feedback and assurance regarding milestone achievement, and answering no highlights a potential area for additional assessment or intervention.

If concerned about this social milestone, a parent or educational provider could easily drill down in the Web site content at this point and access intervention-related information to help create opportunities for further social interaction. For instance, intervention strategies might include providing the child with SB access to a play group, and providing other parents or teachers with information about SB to assure them that safe interactive play with preschoolers with SB is both possible and necessary. Similarly, tips and interventions at this level include guidance to help potential peers understand and demystify SB by bringing SB-related items to the playgroup (eg, wheelchairs), talking about the items with children in the play group, and letting the other preschoolers ride in them. Both of these intervention approaches are designed to help provide the preschooler with SB access to social settings by helping parents, teachers, and other children better understand the condition. In this instance, the interventions are targeted toward helping to reduce the fear or uncertainty experienced by others regarding SB, and allow them to comfortably interact with children with SB. Assuring other parents and other children that SB is nothing to be afraid of will then set the stage for more opportunities for interactive play.

#### **EXAMPLE OF WEB SITE USE: SCHOOL AGE, OBESITY PREVENTION**

Many of the health outcomes of SB evolve over time, with early medical status, procedures, and preventative care occurring during childhood thought to shape the health outcomes in youth adulthood. The Life Course Model Web site includes many

indicators of health-related milestone achievement that can help families and medical teams gauge the extent to which a child with SB is developing in a way that will support positive health outcomes in the future. One particularly salient area of health-related concern for youth with SB during childhood is obesity prevention, as intervention efforts to prevent obesity can help prevent many other conditions (pressure sores) with downstream implications for health status in young adulthood. Within the Life Course Model Web site, a primary developmental milestone for children with SB involves maintaining appropriate weight for height and age. The Life Course Model Web site provides information and links to help professionals assess this developmental milestone and monitor weight and body mass index. Moreover, the Life Course Model site provides multiple questions to help the provider, parent, or nurse determine if the child is showing other indicators of healthy weight management for age.

For instance, involvement in physical activity is an important secondary indicator of obesity prevention efforts, and the preparation site queries the parent or health care provider on issues such as exercise (Does your child participate in adapted physical education at school?) and sports involvement (Is your child a member of a community adapted sports team?). If the respondent answers no to the first of these questions, he or she can drill down in the Web site to find multiple resources regarding adapted physical education, including resources for adapted physical education teachers, guidance regarding the use of paraeducators for physical education class, and suggestions for assessing the child's present level of performance and developing appropriate child-specific adaptive physical education (APE) goals.

Similarly, if the parent, teacher, or health professional answered no to questions about the child's involvement with an adapted sports team, he or she would have the option of drilling down in the Web site to additional resources and suggestions regarding this type of activity. These resources include a rationale for athletic involvement (eg, self-confidence, self-reliance, independence, problem-solving abilities, and leadership skills), sports readiness assessment sheets for various wheelchair sports, links for searching (by state) for adapted sports programs and camps, and links to fan sites for paraathletes. In this manner, indicators of obesity prevention are brought to the attention of parents, educators, and medical professionals, and these individuals can help steer children with SB into adapted physical education or adapted sports programs.

#### **EXAMPLE OF WEB SITE USE: ADOLESCENCE, CONDITION MANAGEMENT/SELF-CARE**

In individuals with SB, condition self-management involves the individual's knowledge base concerning SB and his or her ability to engage in activities related to personal safety, medication management, and complication prevention. This is an important area of transition concentration, as responsibility for condition management progressively shifts from the parent to the individual with SB over time. Adolescence is a particularly salient period of time in this transition, as condition management is thought to become the primary responsibility of the adolescent with SB, and the parent progressively moves into a supportive (rather than primary) role.

The adolescent transition milestones of the Life Course Model Web site reflect this shift (eg, the adolescent is independent in self care or care management with or without supervision and prompting), and the questions presented to the user provide further indication as to whether this transition is occurring. For instance, indicator questions query whether the adolescent can initiate making a medical appointment, asks basic questions of health care providers, reports pain episodes including headaches, monitors status of supplies and medications before they run out, and takes medicines without prompting or cues.

If the answer to any of these questions is no, the user of the Web site further delves into the available resources, tips, and interventions linked to each of the indicator questions described previously. For example, links to products designed to help improve management of medication and medical appointments are provided, including links to resources such as equipment order flow sheets and talking with your doctor video clips. If an adolescent with SB is struggling to assume more responsibility for medication and other self-care responsibilities, the Life Course Model Web site provides links to multiple transition assessment tools, guides to SB, and health care transition workbooks.

### **EXAMPLE OF WEB SITE USE: YOUNG ADULthood, ACTIVITIES OF DAILY LIVING**

One of the most challenging of transitions faced by individuals with SB is the move from a supported home environment into a living setting with far fewer prompts, cues, or reminders to complete essential aspects of independent living. Transitioning in this manner requires independent initiation, completion of activities of daily living, and taking responsibility for household matters. In addition to condition management and medically related self-care, movement into a less restrictive/supportive setting presents the challenge of organizing the routine aspects of daily life. The Life Course Model Web site can be a useful resource for anticipating the challenges the young adult with SB will face when transitioning out of the family home setting, or assessing his or her progress once he or she has taken on more responsibility for the activities of daily living.

To help assess how well the young adult with SB is taking responsibility for independent living skills, the Life Course Model Web site provides several cueing questions. These questions focus upon topics such as making and keeping appointments, preparing meals, doing housework, and managing finances. In the event that the Web site user indicates that any or all of these topics are areas of concern, he or she can identify specific assessment methods that can further delineate specific areas of independent living strengths and weaknesses. Moreover, there are multiple tips and intervention strategies listed that are frequently found useful by individuals with SB when taking on more responsibilities, including guidance for using technologies such as timers and alarms, pill box organizers, smartphones, on-line reminder services, voice recorders, and talking key chains. Additionally, recommendations of specific accommodative devices are provided, including different reminder systems engineered for individuals with cognitive disabilities.

### **SUMMARY**

The transition of youth with SB into adulthood is an exciting opportunity to branch out, explore and participate in community, and reach higher levels of independence. The Life Course Model Web site is a resource designed to help in this process, both by confirming the progress made by individuals with SB as well as highlighting possible areas of needed accommodation or intervention. Effective Web-based presentation of this type of content is typically dynamic in nature, and is developed via multiple iterations based upon feedback regarding usability and the intuitive nature of the interface. The Web site developed out of the Life Course Model content will require periodic reworking of both format and content to deliver the most up-to-date transition-related information to parents, clinicians, teachers, and individuals with SB. It is the hope of the multidisciplinary team of individuals behind the Life Course Model Web site that the content, format, and usability features of the site will provide a new level of accessibility to knowledge, resources, and guidance related to youth with SB, and that this

information will help reduce the disease-related impact of SB upon youth as they move into the roles and responsibilities of adulthood.

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