A Family Perspective: How this Product can Inform and Empower Families of Youth with Spina Bifida

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Spina bifida (SB) is a common congenital birth defect that has a significant multisystemic effect on the physical, neurocognitive, psychological, and social functioning of affected individuals. It is also well known that the clinical symptoms of SB place considerable physical, psychological, and social demands on the family members involved.[1–4] Despite the pervasive effect that this condition has on family members

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and affected individuals, there are few family-based interventions for this at-risk population. A recent review of the literature on family interventions failed to identify any evidence-based interventions that focused on improving the psychosocial functioning of families of youth with SB.[5] Thus, the Web-based product that is the focus of this special issue is a welcome offering for families who currently lack such a resource.

Although Web-based products for families of youth with SB have not been available until now, there are family-oriented products for populations other than SB, including chronic pain, traumatic brain injury, cancer, and encopresis.[6] Research that examines the usefulness of such sites has revealed that parents and affected youth find these Web resources to be useful as they work on personal goals[7] and that their knowledge of their condition increases with increased use.[8,9] However, in some cases use has been lower than expected, perhaps because recruitment for the studies was timed inappropriately (ie, too close to diagnosis) or because the modules were too time intensive. Family use is higher if hands-on training is provided.[10]

This article focuses on how this new Web site, to be housed at the Spina Bifida Association of America (SBA) and based on the Life Course Model discussed throughout this issue, can help family members build on the strengths of individuals with SB and address areas of difficulty. Moreover, and consistent with the developmental orientation of the Life Course Model, we adopt a developmental perspective in this paper. That is, we maintain that the Life Course Model Web site is useful at all stages of development, with the information provided for families at one stage of development building on the information provided for those at earlier stages of development.

First, a brief overview is provided of relevant theories that supported the development of the Life Course Model, on which the Web site is based. Next, the literature on the adjustment of families of individuals with SB is reviewed as well as the literature on the psychosocial adjustment of affected youth. Specifically, an overview is provided of areas of difficulty for which families are most likely to seek help when using this product. We also expect that families will use the product to build on areas of existing strength. How families may benefit from engagement with the 3 content areas covered by this Web site is also discussed, namely: (1) child health and the transfer of medical management from parent to child (health/self-management), (2) the development of social relationships (social relationships), and (3) the achievement of milestones during emerging adulthood, including achievements in the areas of education and employment (education, employment, and income support).

INCORPORATION OF FAMILY-CENTERED CARE AND THE CHRONIC CARE PRINCIPLES INTO THE LIFE COURSE MODEL

The article by Swanson in this issue provides details on the conceptual thinking that incorporated principles of normal child development and the international classification of functioning, health and disability (ICF) into a framework, termed the Life Course Model. Concisely, the Life Course Model assumes: (1) for optimal development in different domains, children need to attain a sequence of milestones, which are common to all children; (2) the ICF contributes the functional domains of importance and the principle that function is an outcome of the interaction between underlying impairment (eg, cognitive deficit, leg weakness) and the surrounding environment (family, school, community).

The Life Course Model is also anchored in 2 interlocking models of health care delivery, family-centered care (FCC) and the chronic care model (CCM), both of which underscore the central importance of partnering with families to enhance medical and psychosocial outcomes for children with special health care needs, including those with SB. FCC has deep roots in the pediatric literature, particularly in research and clinical care for children with special health care needs and their families. The key elements of FCC include (1) encouraging parental involvement in decision-making; (2) fostering empowerment and self-management capacity in families; (3) attending to the needs of all members of the family unit; and (4) providing culturally respectful services.[11–13] FCC also emphasizes tailoring services to each family's identified strengths, priorities, and needs.[14,15]

This Life Course Model is consistent with the fundamental principles of FCC through its emphasis on equipping key stakeholders (including individuals with SB and their parents) with scientific data, assessment tools, and community resource information in 3 content domains: health/self-management, social relationships, and education/income support. The complementary sources of information presented on the Life Course Model Web site ideally maximize parents' capacity for informed decisions about their child's health care and position them to advocate for their child's and family's needs across the lifespan.

Establishment of the Life Course Model and construction of the Web site were similarly guided by aspects of the CCM, which suggests that productive interactions in health settings develop from "informed, activated patients and prepared, proactive practice teams."[16(p3)] Development of the CCM was sparked by increased recognition of the shortcomings of the health system in attending to psychosocial demands associated with chronic health conditions, namely the physical, social, and psychological stressors experienced by both the affected individual and surrounding family.[17] To address this apparent gap in clinical care, the CCM provides evidence-based guidelines for improving health services at multiple levels of the health system (community, organization, practice, and patient levels). Specifically, the model purports that ideal patient-provider interactions, reduced health care costs, enhanced patient satisfaction, and optimal health outcomes result from proper health care organization and delivery system design, systematic use of clinical information systems, health care provider decision support, patient and caregiver self-management support, and community linkages and resources.[18,19] Another aspect of CCM is the shared management model, in which professionals and families intentionally shift care responsibility across the life course, with the individual assuming full responsibility in adulthood.[20]

The Life Course Model Web site addresses multiple dimensions of the CCM, namely (1) provider decision support, (2) patient and caregiver self-management support, and (3) community linkages and resources. Health care providers may access the Web site to learn teaching tips as they strive to partner with individuals with SB and their families on topics of interest. Content on health/self-management, social relationships, and education/income support is presented from a lifespan perspective, which likely addresses immediate as well as long-term concerns identified by parents and individuals with SB. In the following sections, the extant literature on the adjustment of family members who have a child with SB and the psychosocial adjustment of youth with SB is reviewed, highlighting areas of difficulty that are addressed by the Life Course Model Web site. Next, how families may benefit from the Web site is outlined, including how this novel resource might maximize individual and family self-management.

REVIEW OF PAST RESEARCH ON FAMILY FUNCTIONING IN SB

Family relationships are particularly salient and influential social relationships for youth with SB, given that children with SB tend to be more socially isolated from their peers than are typically developing children.[2] Further, we are interested in family relationships because SB affects not only the child but also the parents and other family members. Given the pervasive effect of this condition, we were also interested in discussing the level of psychosocial adjustment in such individuals across multiple adjustment domains (eg, internalizing symptoms, externalizing symptoms, self-concept).

Family Functioning

Holmbeck and colleagues[5] published a review of research that examined the effect of SB on family functioning.[1,3,4,21] In general, the findings of past work support a disruption-resilience view of family functioning.[22] That is, SB seems to disrupt some aspects of family and parent functioning for many families, but such families also tend to show considerable resilience across other adjustment domains. A significant number of families in which there are children who have SB report difficulties in maintaining clear roles and responsibilities in the family system (23% in the clinically problematic range[21]). With respect to risk factors, Holmbeck and colleagues[23] found that families of youth with SB who were also from lower socioeconomic status (SES) backgrounds were particularly at risk for lower levels of family cohesion, supporting a cumulative risk view of such families (ie, SB status and lower SES have additive effects on family functioning). Given this situation, it is particularly important to market this Web site to families from low-income backgrounds and to address issues related to the availability of computer resources in this subpopulation.

Families of youth with SB do not seem to change with the development of their offspring in the same manner as is found with typically developing youth. For example, with respect to family conflicts, Coakley and colleagues[24] found that, unlike their typically developing peers, families of youth with SB did not show normative increases in family conflict as a function of pubertal development. These investigators speculated that families of youth with SB may be less responsive to developmental change. In support of this attenuated response to development hypothesis, Jandasek and colleagues[25] conducted longitudinal growth analyses in the age period of 9 to 15 years and found that family conflict intensity increased during this early adolescent age range in families of typically developing youth but not in families of children with SB. Further, parents of youth with SB are less likely to discuss issues of sexuality with their offspring than are parents of typically developing youth.[26] Therefore, this Web site aims to serve as a resource to help parents be more responsive to maturational changes in their child with SB.

Adjustment of Parents and Parenting Behaviors

Despite the low levels of family dysfunction at the family systems level, it seems that a sizable minority of parents of children with SB exhibit clinical levels of global psychological distress (eg, anxiety, depressive symptoms, somatic complaints[27,28]). Although most studies that report on parental functioning have focused on maternal functioning, one study of fathers of children with SB indicated that fathers exhibited higher levels of global distress compared with fathers from comparison families.[27] In a recent meta-analysis of 15 studies, Vermaes and colleagues[29] found medium to large effect sizes for the effect of SB on mother and father's psychological adjustment, with larger effects sizes for mothers ($d = .73$) than for fathers ($d = .54$).

Across several studies, parents of children with SB tend to experience more stress in their roles as parents than do comparison parents.[27,30,31] Typically, such parents feel less satisfied and competent as parents, feel more isolated, are less adaptable to change, and hold less optimistic views about the future than comparison parents.[27,32–34] Parents who are single, socially isolated, older, or from an ethnic minority or a low SES background are particularly at risk for such outcomes.[23,35–38]

With respect to parenting behaviors, it has been found that increases in parental responsiveness are associated with increases in adaptive coping strategies in youth with SB (eg, problem-focused coping[39]). However, parents of children with SB tend to exhibit higher levels of intrusiveness, psychological control, and authoritarian parenting (ie, parenting that undermines the autonomy development of their offspring[31,34,40–42]) and these behaviors tend to be linked with less desirable child outcomes. Specifically, higher levels of intrusiveness (sometimes referred to as overprotectiveness) tend to be associated with lower levels of decision-making autonomy, which are in turn related to higher levels of psychosocial difficulties.[34,40] Thus, parents may find this product useful in learning how to avoid certain forms of parenting that may not be beneficial to their child, which seem to be more common in families of children with SB.

Adjustment of Siblings

Few studies have examined the functioning of siblings of children with SB. Findings have been contradictory: an early study using teacher reporting found a 4-fold greater likelihood of adjustment problems for siblings relative to a comparison sample,[43] whereas a later study of siblings of youth with SB reported no differences in self-concept compared with siblings of typically developing youth.[44] Qualitative research has identified both positive and negative outcomes related to having a sibling with SB. For example, siblings report significant levels of concern for the health of their sibling with SB, emotional upset in relation to their sibling's experience with discrimination, teasing, and bullying, and sadness related to the lack of opportunities to engage in physical activities with their sibling with SB.[45,46] Siblings have also identified some positive effects, such as increased empathy for their sibling and a greater appreciation for their own physical abilities.[45,46]

The behavioral and psychological functioning of siblings has been found to be significantly associated with SES, family cohesion, perceptions of social support, and their knowledge of and attitudes toward the illness.[47–49] For siblings of children with SB, more positive attitudes toward SB, greater family satisfaction, lower levels of sibling conflict, and increased social support from classmates significantly predicted higher levels of self-concept and prosocial behavior, and lower rates of behavior problems.[50] In this study by Bellin and colleagues,[50] family satisfaction was the only significant predictor across all 3 sibling adjustment outcome measures, suggesting that family variables may be particularly salient for sibling adjustment. Therefore, parents of youth with SB may also use this Web site tool to learn of ways to protect their typically developing offspring from psychosocial difficulties.

REVIEW OF PAST RESEARCH ON PSYCHOSOCIAL FUNCTIONING IN SB

Research on Children and Adolescents

Previous studies have shown that youth with SB are at risk for exhibiting higher levels of internalizing symptoms (eg, depression, anxiety) and lower levels of self-concept than comparison children.[2,21,51,52] Those with hydrocephalus often exhibit difficulties in certain areas of cognitive functioning and school performance (eg, arithmetical, nonverbal cognitive skills[53];). Such children are also more likely to exhibit attention and concentration difficulties in school settings and tend to score at the low end of the average range of intelligence.[53–55]

To date, more work has been done in evaluating children with SB in the areas just noted than has been conducted in the area of social adjustment. This lack of attention is surprising given that this area of psychosocial functioning is problematic for most children with SB.[2,26] Youth with SB, compared with typically developing youth and those with other chronic conditions, tend to be socially immature and passive, to have fewer friends, to be less likely to have social contacts outside school, and to date less during adolescence,[2,26,56] and these difficulties seem to be maintained over time.[54]

The degree to which an adolescent exhibits decision-making autonomy in both medical and nonmedical areas is another highly salient developmentally oriented variable for these youth and their families.[57,58] Typically developing adolescents view more issues as falling within their own decision-making jurisdiction than they did during childhood and they are also increasingly likely to question the legitimacy of parental authority.[59–61] Holmbeck and colleagues'[2] findings on youth with SB run contrary to this typical developmental trend. Specifically, findings revealed that children and adolescents with SB (and especially boys and those with lower levels of intelligence) tend to be more dependent on adults for guidance, less likely to exhibit behavioral autonomy at home, less likely to exhibit intrinsic motivation at school, and less likely to express their own viewpoints during observed family interactions.[40,58,61] Variation in intrinsic motivation (ie, interest in learning and mastery, curiosity, preference for challenge) proved to be the most robust predictor of psychosocial adaptation (ie, scholastic success, social acceptance, and positive self-worth) in a study by Coakley and colleagues.[62]

Research on Emerging Adults

Emerging adulthood is a critical period in the life of older adolescents with SB[63] (First World Congress on SB Research and Care, March 2009, Orlando, FL, USA[64,65]). In general, many young adults with SB are capable of high levels of independent functioning across multiple domains but most have not been successful in fully engaging in the larger community of typically developing emerging adults.[66] In this section, we review findings related to many of the major milestones of emerging adulthood (ie, psychosocial adjustment, educational achievement, and employment and vocational outcomes).

Regarding psychosocial adjustment, emerging adults with SB, like their younger counterparts, are at risk for depressive symptoms and anxiety.[67,68] Regarding educational outcomes, emerging adults with SB are less likely to go to college (41%–49% of individuals with SB go to college vs 66% of typically developing youth[69–71]). With respect to vocational outcomes, recent studies report rates of full- or part-time employment ranging from 36% to 41% (MH Bellin and colleagues. Gender differences in self-management, community integration, and quality of life in transition-age individuals with spina bifida, unpublished manuscript, 2010),[71–73] which are significantly lower than those found in typically developing youth (ie, roughly 75%[70,71,74]) and in those with other chronic conditions (eg, asthma, cancer; 68% to 78%[72,75]).

Little is known about factors that predict whether or not an emerging adult with SB is able to go to college and become employed. Studies that have been conducted on individuals with SB have tended to focus only on demographic or medical severity predictors. For example, Liptak and colleagues[72] found that communication problems, difficulties with managing responsibilities, lower levels of parental education, and higher rates of parental unemployment were associated with poorer social, vocational, and educational transitions. Bellin and colleagues (Gender differences in self-management, community integration, and quality of life in transition-age individuals with spina bifida, unpublished manuscript, 2010) found that young adult men with SB were more likely to work than women, but that women were more likely to live independently. With respect to medical severity, Hetherington and colleagues[76] found that spinal lesion level and number of shunt revisions were related to employment outcome (with higher lesion levels and more shunt revisions being related to worse occupational outcome; Barf and colleagues[77] found similar results in the Netherlands.

In the absence of data, many have speculated about why young adults with SB are less likely to be successful in negotiating these emerging adulthood milestones. For example, some have described the complexities in managing real world responsibilities with a chronic physical condition, including transportation difficulties and issues related to accessibility.[68,77] Other explanations for these developmental delays focus on financial concerns (including lack of health insurance[78]), lack of job training and vocational rehabilitation services, restricted experiences with self-management,[79] employment discrimination, stigmas related to physical appearance, and a lack of autonomy-related socialization in early childhood.[68,80,81] Many of these issues are addressed with the Life Course Model Web site resource and such content is likely useful for families.

HOW THE LIFE COURSE MODEL WEB SITE INFORMS AND EMPOWERS FAMILIES

This section focuses on the 3 major domains of the Web site: health and self-management, social relationships, and education/employment. The content within each domain is based on the theories discussed earlier and the research findings just reviewed in the areas of family functioning, psychosocial adjustment, and the development of independent functioning. Each of the Web site domains is designed to provide families with readily accessible guidance in raising and caring for children with SB. The Web site (see article by Zabel in this issue) presents strategies that families can use to foster developmental achievements within each domain as children progress from childhood into emerging adulthood and beyond. At the site, searches can be performed either by topic (health/condition self-management, social/personal relationships, education/employment) or by age (preschool, school-age, adolescence, or young adulthood) and searches can be saved or printed for easy reference. The abilities of individuals with SB vary greatly, and cognitive and emotional developmental level rather than a specific age is important to consider when using the Web site. In addition to using this Web site, formal evaluations by psychologists, social workers, occupational therapists, vocational therapists, and other professionals can aid families in determining appropriate interventions.

HEALTH AND SELF-MANAGEMENT: HELPING YOUTH TO BECOME SELF-RELIANT

The primary goal of the health/self-management domain is to help youth become self-reliant in managing their SB. To achieve this goal, the health/self-management section of the Web site contains evidence-based information and resources on SB and anticipatory guidance for families to assist them in managing their children's SB.

The Web site content of this domain is designed to facilitate families' understanding and competencies in managing the long-term health care and special needs of their children. The health information, anticipatory guidance, and resources available on the Web site serve to inform families on the application of evidence-based strategies for their children that aim to foster an optimal state of health, prevent the occurrence of complications and secondary conditions resulting in adverse health consequences, promote the development of a positive body image, and cultivate the development of self-management skills that culminates ultimately in youth who become more self-reliant in managing their SB.

Six areas of specific health concerns for children with SB are covered, including mobility, skin integrity, sexuality, obesity prevention, bowel and bladder management, and condition management. Each of the 6 health areas of the health/self-management domain begins with the identification of developmental milestones, which represent appropriate expectations for the identified health need that is aligned with the child's developmental stage. For example, during the preschool period, developmental milestones regarding sexuality begin with body awareness and naming body parts. During the school-age and adolescent periods, the developmental milestones build on the initial foundation of sexuality learned during the preschool period toward achieving an understanding of themselves as sexual beings. By adulthood, the key milestones are the development of an intact sexual identity and an understanding of sexual relationships.

In terms of condition management, a preschooler's expected milestone achievement of SB knowledge is shown by the following 4 basic skills: (1) knows the name of SB and its functional effects on mobility and bowel and bladder management; (2) knows that SB is a long-term condition and is the reason for their functional limitations; (3) identifies medication by appearance; and (4) assists parent in ordering supplies and medications. The delineation of developmentally appropriate milestones in each of the 6 areas of health/self-management serves to inform parents concerning appropriate expectations for each developmental age.

Each key milestone is accompanied by descriptions of behaviors that the child/young person/young adult should show if they have achieved this milestone. For example, in the area of sexuality, the preschool child is expected to know the difference between good and bad touching, engage in gender-based imaginary role-playing, and be able to name the anatomic body parts on a doll. The descriptions of behaviors that indicate achievement of milestones in health/self-management provide families with concrete examples to evaluate their children's progress in meeting the developmental milestones. The extent to which the child achieves or fails to achieve developmental milestones in any of the 6 areas of the health/self-management domain creates opportunities for the family to consult with the specialized team and/or primary care pediatrician as part of the child's developmental surveillance during regularly scheduled specialty or primary care appointments.

The Web site offers specific ideas for interventions, resources, and referrals for each of the health/self-management areas. For example, recommendations to improve skin integrity for the school-age child include wearing seamless socks to reduce pressure on the feet, ensuring that the child does not walk in bare feet, washing and checking feet daily, and trimming toenails regularly. Further, these suggestions are coupled with a list of resources and referrals for families, including professionals who may be consulted, a specialty shoe retailer, and other Web sites for skin-care assistance.

The information in the health/self-management domain was developed to address families' concerns and uncertainties as to what are developmentally appropriate and reasonable expectations for their children. This Web site provides parents with evidence-based health information, guidance, and resources to inform and empower families to assist their child with SB in managing the condition.

SOCIAL RELATIONSHIPS: DEVELOPING A SOCIAL NETWORK

As noted earlier, individuals with SB have been reported to be less satisfied with partnership relations[82] when compared with peers who do not have SB, and to report low levels of social activities with peers.[66] Although factors that indicate greater severity or involvement of the condition, such as the presence of hydrocephalus, higher level of lesion, or the use of a wheelchair, have been correlated with less participation in society, even persons who are community ambulators have been found to score low on social integration measures.[68]

In light of these findings and the intuitive significance of relationships and participation in society, this domain of the Web site outlines developmental milestones from young childhood to young adulthood that are considered to increase the chances of developing fulfilling personal and social relationships throughout the life course. The development of relationships with parents, siblings, friends, and intimate/romantic partners was targeted during preschool, school-age, adolescence, and the young adulthood years, respectively. In addition, tips and interventions that may be helpful in the achievement of a particular age-specific milestone are offered to enhance preexisting strengths and address areas of concern.

As an example of how one might use this Web site, suppose that a mother of a preschool-aged child with SB is interested in learning more about how to help her child develop friendships. She can log on to the site, navigate to the preschool age category and, from there, navigate to the relationships domain. She is prompted to consider how her own child is developing in the area of making and keeping friends. Young children are not expected to have a flourishing social network but the information provided gives developmentally appropriate pointers regarding some of the milestones that parents can consider in the area of developing friendships. The Web site is intended as a resource and to complement, but not replace, professional opinion or assessment.

If the mother decides to learn more about how her child can develop more positive relations with his/her parents, she finds that a close attachment between child and parent is highlighted as a developmental milestone. In the corresponding tips and intervention section, information is available on secure attachment as well as some parenting strategies likely to increase the chances of achieving a secure attachment. A parent of a school-aged child with SB who is concerned with sibling relations might be prompted to look for warm relationships between siblings. This milestone references the initial development of empathy and the management of conflict. In addition, the need for the sibling of the child with SB to meet their own developmental needs is stressed. Examples of corresponding tips include points on bullying, problem solving, and conflict resolution, as well as the importance of focusing on the siblings' experiences and achievements. Relationships with friends are especially important during adolescence; thus, developmental milestones in this section emphasize the importance of having close, same- age/gender friends and that the adolescent participate in group activities with friends. If those milestones are met, there may be no need to delve into the tips available. However, if the milestones are not met, concrete information is available on strategies that can be used to increase the chances of making friends and participating in group activities.

Whereas the parents of a child with SB are the most likely family members to use the Web site during the younger developmental stages, the individual with SB may be the most likely candidate to search the adolescent or young adult sections pertaining to social relationships. For a young adult, relationships with intimate and romantic partners may be of interest. Milestones discussed include, for example, the preservation of self-esteem and self-confidence, the ongoing development of social coping strategies, and the development of assertiveness and social initiative. Some of the tips include strategies for engaging in social opportunities, steps to increase the likelihood of successful social interactions, and maintaining contact with a large group of friends even if the young person is already dating.

EDUCATION, EMPLOYMENT, AND INCOME SUPPORT: ACHIEVING THE MILESTONES OF EMERGING ADULTHOOD

Parenting involves preparing one's child to become an independent adult. As reviewed in previous sections, for parents of children with SB, this task is complicated by the medical, psychosocial, and neurocognitive difficulties associated with SB, such as a complex medical regimen, difficulties with ambulation and mobility, and problems with executive functions. Preparing one's child to achieve the developmental milestones of emerging adulthood begins as early as the preschool years, although the target skills and milestones vary as a function of the child's developmental level. Facilitating cognitive development and developmentally appropriate responsibility taking at an early age can set one's child on a trajectory for success in later years. The aim of this domain of the Web site is to allow parents to identify strengths and areas for improvement regarding education and employment based on their child's developmental level, and to build their child's competencies to promote future milestone achievement. The Web site resources may be particularly useful during times of transition, such as academic transitions (eg, from elementary school to middle school or high school) and vocational transitions (eg, preparing a teenager or young adult for their first job).

Preschool

Although preschool is a long way from emerging adulthood, early cognitive development helps set the foundation for later academic and vocational success. The Web site provides questions for parents to assess their child's achievement of important cognitive developmental milestones at this age, such as early object use, problem-solving skills, symbolic play, and visual perception. Developmentally appropriate responsibility-taking skills can also be evaluated, such as participating in feeding and dressing oneself and cleaning up after oneself. The assessment questions are not meant to be a substitute for a formal cognitive or developmental evaluation; however, these questions can be useful in identifying areas of strength and weakness and may indicate the need for a professional evaluation. The Web site also provides some general information and Web links regarding how to seek early intervention services, assessment tools often used by professionals, and important laws, such as the Individuals with Disabilities Education Act (IDEA). Furthermore, there are practical suggestions for parents to facilitate the development of specific skills or enhance strengths that children already show. For example, to encourage the development of decision-making skills, parents can provide children with age-appropriate choices, such as wearing a green or blue shirt, or drinking milk or juice. The Web site also provides references for further reading and links to helpful resources, including lists of developmentally appropriate toys.

School Age

The focus of the school-age years is on academic engagement and success, and increased participation in self-care and household chores. Assessment at this developmental stage examines academic success in fundamental subjects such as reading and mathematics, as well as whether the child is exhibiting core processing deficits associated with meningomyelocele, including executive function, memory, and attention problems. These deficits can negatively affect academic performance and the ability to follow through with responsibilities. Time-management skills also become increasingly important during the school-age years. The Web site suggests that parents seek a neuropsychological assessment for their child so that interventions, if needed, can be individually tailored to meet their child's needs. The Web site provides several practical suggestions for improving specific areas of weakness, such as functional mathematical skills, memory problems, and organizational skills. Parents may want to share some of the references and tools provided by the Web site with their child's teachers to assist the child in using such strategies in the school environment. Furthermore, the Web site informs parents that children are entitled to a free and appropriate public education and encourages parents to advocate for the most appropriate services for their child. The Web site also contains recommendations that parents set age-appropriate expectations for household responsibilities, such as regular chores, participating in self-care, caring for personal devices (eg, braces, wheelchair), getting ready for school, and managing an allowance. Recommendations regarding setting up routines and making environmental modifications, such as placing items needed to complete chores within reach, are provided to help parents assist their children in successfully increasing their responsibilities at home.

Adolescence

The Web site focuses on preparing adolescents for the transition into emerging and young adulthood, shifting from general cognitive development to vocational development. It is recommended that parents work with school personnel to develop a specific transition plan as part of their adolescent's Individualized Education Plan. An additional milestone of this age is to begin to explore meaningful and realistic career options. Parents can provide opportunities for exposure to various careers and postsecondary educational options, as well as help adolescents continue to develop the interpersonal and organizational skills that influence success in the workplace. Families can help teenagers identify areas of strength that can become a vocational pursuit and reward the teenager's efforts toward building skills in the chosen area. Although there is great variability among individuals, adolescence is generally characterized by increased responsibility for oneself and one's actions. Parents can help foster an adolescent's autonomy by teaching skills to care for oneself and one's personal belongings, including increased independence in medical self-management and hygiene. In addition, the Web site focuses on increasing responsibility outside the home through increased community engagement, navigation of the community through driving or public transportation, and volunteer or paid job experiences. The practical suggestions offered by the Web site may be helpful for both parents and teens.

Emerging Adulthood

All of the sections discussed thus far are geared toward helping a child achieve the milestones of emerging adulthood, including participating in postsecondary education or training for employment, beginning a career, obtaining financial security, sustaining health benefits, living independently, and balancing employment/personal life responsibilities. The information on the Web site aims to teach both young adults and their families to evaluate their success in achieving milestones and build skills to do so. The Web site gradually shifts the focus from the parent understanding their child's strengths and weaknesses to the young adult with SB increasing their self-awareness of individual strengths and weaknesses. Some assessment tools are referred to that may aid parents and adults in determining appropriate living situations. Parents are encouraged to assist their adult child in developing skills of self-evaluation, self-questioning, and self-checking, rather than problem solving for the adult. Parents may direct their adult children to this Web site for resources on how to solve some of the problems they encounter or use the Web site together to help the adult evaluate current strengths and choose an area of weakness for targeted behavior change.

SUMMARY

In this article, we have discussed how this developmentally oriented Life Course Model Web site can be useful for parents of youth with SB and for the youth themselves as they move toward the emerging adulthood stage of development. As with any intervention, the concern is that families who most need such support are also those who are the least likely to use this valuable resource. Thus, it is critical for the developers of the Life Course Model Web site to provide outreach to the most at-risk populations and to those who have limited access to computer resources. Because the Web site is developmentally oriented, parents and youth are able to make use of this site beginning in early childhood and across the various stages of child development, and young adults can make use of this tool as they transition to early adulthood. As has been done with similar Web-based resources developed for youth with other chronic health conditions,[6] evaluation should be conducted on the feasibility and usefulness of this resource for families and individuals affected by SB.

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