

Using the Spina Bifida Life Course Model in Clinical Practice: An Interdisciplinary Approach

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Spina bifida is a result of the incomplete development of the spinal cord and often results in paralysis, sensory deficits, and neurogenic bowel and bladder. Hydrocephalus is common and may result in cognitive impairments. Other neurologic issues such as Arnold Chiari Type II malformations, tethered cord syndrome, and syringomyelia may cause additional functional impairments. Additional issues may include orthopedic deformities, wounds, and renal complications. Management of the individual with spina bifida requires a comprehensive and multidisciplinary approach involving clinicians from many specialty areas such as physiatry, neurosurgery, neurology, urology, orthopedics, physical and occupational therapy, rehabilitation counseling, neuropsychology, and social services, as well as intensive nursing care.¹ Collaboration of care between these specialty areas provides a comprehensive and interdisciplinary approach to care for the child and family. Multidisciplinary collaboration may extend beyond the clinic or hospital setting as a child grows, enters school, expands his social circles, and transitions into his community as a teen or adult. Additional collaborative services at key transitional points in the child's development may involve school, vocational rehabilitation, and community outreach agencies.

In children with complex conditions like spina bifida, the usual developmental milestones may not be realized without specific attention and support. However, the multiple and medically demanding issues associated with spina bifida may preclude the necessary and time-sensitive assessment of developmental milestone achievement. A Life Course Model for patients, families, caregivers, teachers, and clinicians was developed with support by the National Spina Bifida Program, National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, to facilitate a developmental approach to assessment and intervention along this life trajectory. This Life Course Model was then molded into a web-based tool that provides information about key developmental milestones for particular age groups, validated assessments that can be performed by clinicians or teachers to determine if milestones have been reached, useful suggestions for intervening in creative ways at each step, and evidence-based references. The Life Course Model is described in more detail in an accompanying by Mark Swanson article in this issue. However, a key concept is that the model describes life roles and milestones for the individual in childhood, school age, teen years, and adulthood. This model prepares the person for adult participation in roles related to the following domains: (1) self-management/health, (2) personal and social relationships, and (3) education/employment support. In creating the Life Course Model, clinicians and researchers from across the United States took a "reverse engineering" approach in identifying the developmental milestones one would need to master to successfully transition to adulthood.

In this article, the authors introduce the viewpoints of several key clinicians who are involved in the care of individuals with spina bifida and how the Life Course Model can assist them in the process of assessment, intervention, collaboration with other clinicians, and follow-up. A case study is used to demonstrate the experience of comprehensive and collaborative management in transitioning a child and his family from infancy to adulthood. This Life Course Model will be useful for all clinicians involved in the care of people with spina bifida, but may be a particularly valuable tool for any clinician who works outside a multidisciplinary setting or who may care for people with spina bifida on an infrequent basis.

In the Life Course Model the milestones, assessments, and interventions are different in each age period. Over the life span, the clinicians taking the more active roles in the transition process may change. In many clinics a nurse acts as a case manager, coordinating care among the various disciplines. In other instances a clinician may find that he or she must assist the individual and family even if care

coordination is not his or her primary role. Regardless of who may be involved, the care coordination should always include emphasis on teamwork, loose boundaries around clinical roles, interventions that focus on promoting independence and preserving function, and support for caregivers.²

PHYSICIAN

The Life Course Model provides physicians with assessment tools that may help determine if patients are meeting age-appropriate developmental milestones in various areas. The model also provides many innovative, low-cost strategies not only in the treatment of many medical conditions common in spina bifida, but also for creative ways to educate patients and caregivers and to enhance compliance with self-care regimens. The model can be useful not only for the physician in the community who may lack the resources of large, multidisciplinary settings but also for the physician who is well versed in the care of those with spina bifida.

Many of the common diagnoses resulting in hospitalization and death in individuals with spina bifida are potentially preventable conditions.³ Using the Life Course Model at each visit may help a physician to identify specific target areas where preventative care can be improved and to assess whether interventions provided at the last visit have made an objective or measurable difference. Physicians can also use the model during transitional visits, in which a young person is transitioning from a pediatric clinic either to an adult clinic or into the adult health care arena, because the model provides information on many of the medical and personal issues faced by a young person with spina bifida.

While there are many types of physicians who treat individuals with spina bifida, including those in primary care, pediatrics, and medical specialties, the care of the individual with spina bifida often requires teamwork among many providers. The Life Course Model can be used not only to foster collaborations between physicians and other clinicians such as therapists, neuropsychologists, nurses, or rehabilitation counselors, it can also prompt physicians as to when to consult a physician colleague. The ultimate goal of the model is to restore and preserve health and independent functioning using a team-based approach.

Breaches in skin integrity are one of the most important medical problems that can cause significant morbidity and mortality.³ The Life Course Model provides physicians with tips on treating and preventing wounds, and education materials for patients and families on skin care. Tools are provided that may help the physician address some of the many causes of skin breakdown including nutritional status, pressure, shear, and moisture. Prompts are provided to remind physicians to evaluate for sensory deficits and how they may pose a threat to skin health.

Successful management of other issues such as neurogenic bowel and bladder also requires that the patient and caregivers work as a team with physicians. Besides medical or surgical interventions to manage incontinence and constipation, the physician plays a key role as an educator. The Life Course Model provides tools that may help the patient understand the importance of a bowel or bladder program, and gives tips on strategies for improving compliance and promoting continence.

Secondary musculoskeletal and neurologic disorders can have a significant impact on mobility. Some specialists such as physiatrists, neurosurgeons, developmental pediatricians, or orthopedists may routinely assess functional mobility and its relationship to developmental milestones at each visit. The Life Course Model, however, can guide other physicians in determining whether patients are meeting milestones, and provide suggestions on when referrals to other physician specialists or therapists

are necessary, or when an assessment by a team of clinicians experienced in the prescription of orthoses or assistive technology is needed.

The Life Course Model also provides physicians with tools to promote health and wellness and to treat or prevent obesity, which has become a significant health concern.⁴ Because not all individuals have access to nutritional support services, the physician may be one of the few sources of required information on diet and adaptive exercise. The model provides fun and creative suggestions for home exercise plans, dieting, and sports participation while taking into account such barriers as cost, transportation, motivation, or physical inaccessibility that many individuals face.

Physicians can also be a source of information for educational goals and gainful employment. The model provides physicians with information on when and how to make a referral for Vocational Rehabilitation, career counseling, or job shadowing services. Referrals to Vocational Rehabilitation programs may be necessary to secure funding for assistive technologies such as computer access devices, mobility equipment like wheelchairs, or adaptive driving evaluations and vehicle modifications. When educational or employment barriers are identified with help from the Life Course Model, the physician can offer guidance on which reasonable accommodations may be required. Of course, because a major barrier for education and employment is incontinence, managing the bowel and bladder can make a significant impact on outcomes in these areas. Physicians can also act as sounding boards for parents to develop realistic and medically appropriate goals for children and their teachers. This process may involve providing referrals to physical or occupational therapy or speech language pathology, Early Intervention (EI) services, or advocacy organizations including the Spina Bifida Association and its local chapters. The model provides suggestions for when this may be appropriate.

Given the high rate of acceptance of technology in this population,⁵ physicians may also want to consider taking advantage of alternative technologies that may be available such as web-based or telerehabilitation systems. The model encourages the use of technology as a way to communicate and establish relationships with patients and other providers.

The physician can be involved in helping individuals with spina bifida and their families develop personal and social relationships in a healthy and age-appropriate way. The physician's role may involve identifying stressful issues within the family and support system, diagnosing anxiety or depression, screening for social skills at specific ages, and making referrals to teen clinics. Rarely do individuals with spina bifida obtain sexual education from physicians.⁶ Most young adults desire more information on both fertility and sexuality.⁷ The Life Course Model provides physicians with ways to assess and discuss sexuality and fertility for individuals of all ages.

Physicians wear the hats of educators and clinicians, but their roles as researchers also cannot be understated. Although much is known about the medical and rehabilitation management of spina bifida,¹ guidelines for evidence-based practice in many areas are still lacking, particularly in young adults. The Life Course Model can guide the academician in identifying those areas where research could advance the field substantially.

NURSE

Often in an advanced practice nursing role, the nurse has long been identified as instrumental for the patient and family in the transition process.⁸ The coordinator's role is multifaceted⁹ and the following roles may be needed: (1) expert nurse and coordinator of multidiscipline management, (2) patient and family advocate, (3) resource

consultant, and (4) researcher. As the role of the spina bifida coordinator may vary in different multidisciplinary teams depending on educational background, job description, additional work responsibilities, team members, and size of clinic, the components of the nurse coordinator's clinical role in working with individuals with spina bifida and their families are now described.

The expert nurse and coordinator often works closely with the medical director of the spina bifida multidisciplinary team in managing the care of the patients during and between team visits. Using the nursing process of assessment, planning, implementing, and evaluating,¹⁰ a plan of care is established with specialized medical professionals and allied health professionals at each visit. Recommendations made during a visit must be summarized and an ongoing plan of care established. This plan of care is vital to growth and development as the individual with spina bifida transitions from childhood to adulthood, expanding to his or her full potential. Between follow-up visits the plan of care may require diagnostic tests, referrals to physician specialists or therapists, follow-ups with primary care, or consults with a dietician, neuropsychologist, or social worker. The nurse coordinator is many times the professional responsible for consolidating a written or verbal report from all multidiscipline specialties evaluating the individual with spina bifida in a clinical setting, making sure the individual and family has a copy of the recommendations, and discussing and clarifying direction for the individual with spina bifida and their family between visits. The nurse coordinator works as a liaison to link the various personnel involved in the care plan and those in community outreach to assist the individual and family in obtaining the care recommended by the multidisciplinary team. The nurse coordinator assists with communication to the various care providers, providing clarification, modification, and feedback among professionals.

The expert nurse and coordinator also acts as a first-line professional in triage when an individual with spina bifida or caregiver calls with a concern or problem between clinic visits. The nurse, as a clinician with expertise and knowledge about spina bifida, may be able to resolve many triage concerns. Unexpected crises and unplanned events can easily result in delays and regression in meeting transitional goals. The nurse coordinator, as a clinician, provides prompt follow-up and response from the spina bifida multidisciplinary team and assists in redirecting the individual and family with spina bifida back to the transitional goals established, or initiates modification of those goals if needed. The Life Course Model can be valuable in allowing the nurse coordinator to follow and assess a patient's developmental milestones, and allowing intervention by rapidly triaging problems and activating needed interventions and consultations. The nurse coordinator and other team members can use the Life Course Model to ensure all team members are working toward the patient's and caregivers' necessary and agreed-upon goals.

People with spina bifida and their caregivers may lack information about self-advocacy. The expert nurse and coordinator, acting as an advocate, can provide this education. For example, parents often need to learn to work with their child's school to ensure access to all services that are deemed necessary for the child to thrive and succeed in school. This collaboration may include learning needs of the child, finding a private place for the child to catheterize, or finding access to adaptive playground equipment or an elevator for a child who uses a wheelchair. The nurse provides leadership and support in this process. The nurse often takes the lead in teaching individuals and families that cognitive impairments and learning disabilities can interfere with the development and accomplishment of personal care skills and functional independence.¹¹ The Life Course Model provides not only the nurse coordinator but also the patient and families with valuable tools and suggestions for advocacy and understanding patients' rights.

Nurses act as resource consultants because they are on the front line of care in the lives of individuals with spina bifida and their families.¹¹ Nurses keep a current knowledge of resources that are available for individuals with spina bifida. Informational Web resources such as the Spina Bifida Association of America (SBAA), or state, regional, and community resources are identified and offered to families on a wide variety of topics. If information is not known, the nurse is often able to investigate and find resources. Coordinating follow-up care involves making parents aware of resources and support networks for families on the local, regional, and national level.⁹ The Life Course Model provides the nurse with an extensive list of ideas and resources.

Nurses are also scientists and play the role of researchers. Because nurses are intimately involved in the lives of their patients and families, they are well suited to identifying areas of necessary research, promoting academic work that is clinically relevant, and translating research findings into evidence-based practice. The Life Course Model can serve as a research tool to allow clinician-researchers to identify key research priorities.

OCCUPATIONAL THERAPIST

Occupational therapists (OTs) view the person, the environment, and the interaction between persons and their environments in a holistic manner. Persons continually adapt to the environments in which they live, work, and play while influencing the environment. There is a dynamic interaction created through the individual's life-long learning, development, and maturation. Likewise, the environment is also continually evolving and changing, at times in response to the individual's needs and actions as well as in response to external variables. The developmental frame of reference was originally identified by Lela Llorens, an occupational therapist. The model is built on social, psychological, and physical aspects of life tasks and relationships.¹² Llorens¹³ focused on 2 perspectives: (1) the specific period of life (horizontal development) and (2) the course of time (longitudinal development). The Life Course Model is similarly structured according to developmental milestones that we strive to achieve at various phases of life.

OTs work with persons who have spina bifida in a variety of settings. EI services for children from birth to age 3 years typically occur in the home or daycare setting. Developmentally, this is a period in our lives in which the greatest amount of change occurs in the shortest amount of time. OTs working in EI may not be considering what skills will make their patient a successful employee or spouse, but often focus on assisting them in achieving more immediate developmental milestones. When developmental delay is present and certain skills are not readily emerging, it can eventually cause an incongruity, with some areas of development being advanced and others lagging. Once we reach later stages of development these incongruities become more apparent as several skill areas are often required to complete activities and fulfill more complex roles. Furthermore, an EI OT may only have 1 or 2 patients on their caseload with a diagnosis of spina bifida. Although the EI OT may be experienced and skilled at his or her profession as a clinician, the diversity of diagnoses in patient caseload is broad and time is further limited by travel to the various locations where patients are seen for treatment. The Life Course Model helps to ensure that no areas are overlooked and that assessments and interventions are readily available for the therapist's and family's access.

This tool continues to assist OTs who work in school-based settings. School-based OTs treat students from ages 3 to 21 years. Again, pediatric OTs who work in public or private settings may have just 1 or 2 students registered for treatment on their

caseloads. The process for identifying needs and ongoing goals in the school setting occurs through the development and updates of the students' Individual Education Plan (IEP). Despite having only 1 or 2 students on a caseload who have spina bifida, rehabilitation professionals working in school settings tend to have more experience than other members of the IEP team, including teachers and social workers. Use of the Life Course Model as part of the IEP process helps to ensure that no areas of intervention that can be implemented to further support and enhance the skills of the student are overlooked. Beginning at age 14 years, students in the IEP process should be integrating goals and objectives that prepare the student for transition following high school graduation, whether this includes postsecondary education, employment, or other activities relevant for successful participation as an adult. This is a critical time for the young person to be participating in opportunities that will enable him or her to transition to successful adult roles and include planning for postsecondary education, employment, and independent living.

Once a person with spina bifida has reached adulthood, the most common treatment settings include acute inpatient, skilled nursing facilities, or home health. Often the duration of OT treatment as adult is typically much briefer than in earlier years. However, the Life Course Model is still relevant, and the resources provided can be an invaluable source of information for busy clinicians as they assist in discharge planning, develop home programs, and participate in the education of persons with spina bifida and caregivers.

Finally, OTs are also often members of the team of professionals who work at both pediatric and adult spina bifida clinics. This setting is perhaps that in which the model can best be implemented because of the long-term (often life-long) nature of treatment by a team of professionals dedicated to the care, rehabilitation, and support of persons with spina bifida.

REHABILITATION COUNSELOR

Regardless of the role that the rehabilitation counselor plays in service provision, having a single resource to provide developmental milestones, as well as the means of assessing and addressing progress toward these milestones, will serve to improve the quality and specialization of the services provided, especially because many rehabilitation counselors do not have a specialized knowledge of spina bifida.

Rehabilitation counselors perform 4 primary functions when working with individuals with spina bifida and their families. When working with individuals with spina bifida, rehabilitation counselors act as counselors and case managers. When working with families of or organizations providing services to individuals with spina bifida, rehabilitation counselors serve as consultants and advocates.¹⁴ More specifically, depending on the setting in which the rehabilitation counselor provides services, tasks may include diagnosis, assessment, development planning and follow-through, placement and follow-up services, postemployment services, and general service provision.¹⁵ The comprehensive Life Course Model proposed here provides a resource framework across the life span that can be used by rehabilitation counselors, particularly given their multifaceted roles and the variety of settings across which they might work.

When the rehabilitation counselor acts as a counselor, he or she provides therapeutic and psychoeducational services; this can include working with individuals, groups, or families.¹⁴ In this regard, the Life Course Model provides information for understanding and assessing the relationships and social interactions of individuals with spina bifida. In addition, information regarding the developmental milestones

and the degree to which they have been met, as well as the information on assessment and intervention for these milestones provided by the Life Course Model, will assist in the development of appropriate goals and goal planning.

The rehabilitation counselor also acts as a case manager, and may use the multidisciplinary components and developmental tracking provided by the Life Course Model. A case manager “organizes, coordinates, and sustains a network of formal and informal supports and activities designed to optimize the well-being and functioning of people with multiple needs.”¹⁴ The Life Course Model provides the organizational structure and basis for coordinating services, assessing needs, and communicating with individuals and their families. The division of needs assessment in the model into areas of health, relationships, and education/income support, along with associated landmarks and tools for assessment and intervention, provides a valuable tool for case management.

The rehabilitation counselor also acts as a consultant. In much the same way that the Life Course Model serves rehabilitation counselors in their role as case managers, it provides a framework and basis for communication in their role as consultants. Consultation may occur with individuals, families, groups, organizations, or communities, and may address communication, decision making, coping skills, remediation services, job-enrichment programs, or reducing the impact of functional disability.¹⁴ Situations in which consultation occurs vary across the life span and across settings and service providers. The ability to communicate across these various settings and with individuals, families, and professionals using a common language and a common framework assists in streamlining the process of consultation and the move from consultation to action and intervention.

The best advocate knows the strengths, abilities, and needs of the individuals they serve. When the rehabilitation counselor is an advocate, his or her ultimate goal is to change “environments for growth and development.”¹⁴ The Life Course Model provides information about the individual’s needs, strengths, abilities, and environments, and serves as a tool for growth and change.

Rehabilitation counselors most often work with individuals with spina bifida in vocational rehabilitation. The vocational barriers and needs of individuals with spina bifida span the health, social, and educational domains, and have been found to include bladder control, ambulation, pressure sores, poor job retention, lack of assistance in job searching and placement, poor health insurance, discrimination, lack of career preparation, and lack of involvement in planning the rehabilitation process.^{16–18} The Life Course Model may best serve rehabilitation counselors in vocational rehabilitation by improving the intervention and prevention of many of these barriers earlier in the life span. It also provides rehabilitation counselors with the ability to track, assess, and recommend interventions with the ultimate goal of improving employment outcomes.

In all the roles assumed by rehabilitation counselors, the ability to gather information, communicate with individuals, families, and organizations using a common language, and the access to resources for assessment and intervention only serves to enhance service provision. The Life Course Model, therefore, will improve service provision and allow for more individualized and client-centered counseling, case management, consultation, and advocacy.

NEUROPSYCHOLOGIST

Neuropsychological assessment and consultation is a useful means of identifying the strengths or weaknesses of individuals with spina bifida, identifying intervention/accommodation needs, and monitoring the stability of mental status in this potentially unstable neurologic condition. Repeated neuropsychological assessment is often

performed across the early life span of individuals with spina bifida, for several reasons. First, neuropsychological assessment can assist in the early identification of spina bifida–related learning difficulties that create distinct challenges for educational teams at different points in the educational process (eg, early delays demonstrated in preschool math abilities, reading comprehension difficulties displayed in later elementary school, organizational problems shown in middle school and high school). Second, neuropsychological assessment can be sensitive to the cognitive impact of hydrocephalus, both as a potential indicator of shunt failure and as a method of quantifying cognitive changes associated with past hydrocephalic episodes.¹⁹ Third, neuropsychological assessment is useful for identifying cognitive, behavioral, and emotional variables that can interfere in the ability of individuals with spina bifida to meet increases in self-management expectations (eg, medical self-care, activities of daily living) as they occur across the early life span.²⁰

The Life Course Model is a useful resource in each of these assessment scenarios, as it provides an additional developmental context for individuals with spina bifida at different stages of development. Under the first assessment scenario (assessment targeted toward identification of spina bifida–related learning difficulties), the information contained in the Life Course Model provides the assessing neuropsychologist with specific information regarding learning disability in spina bifida, frequently used tests to identify these disabilities, and a variety of suggested interventions culled from research literature, anecdotal reports, or clinician expertise. While neuropsychologists are trained in many of the cognitive and learning problems identified in youth with developmental disabilities, the Life Course Model resource provides additional information specific to spina bifida for assessment-related purposes.

Under the second assessment scenario (quantifying cognitive changes associated with hydrocephalic episodes), the Life Course Model provides information that would be helpful for interpreting reported symptoms, particularly those that might occur with considerable regularity in youth with spina bifida. For instance, considerable information is provided in the Life Course Model regarding initiation deficits that are often noted in youth with spina bifida. When youths with spina bifida are placed in new situations in which additional self-initiative is necessary, they can often appear to have “regressed” or “declined” in functioning because more problems are being reported than noted in similar situations in the past (eg, increased report of poor homework completion when the youth with spina bifida is promoted into high school where additional organizational skills and individual initiative are required). The developmental context provided by the Life Course Model provides additional information to help the neuropsychologist determine if a true change in functioning has occurred (suggestive of shunt failure), or if these “changes” can be linked to new environmental challenges instead.

The Life Course Model is useful for neuropsychologists testing youth with spina bifida under the third testing scenario (ie, identifying cognitive, behavioral, and emotional variables that can interfere in the ability to meet self-management expectations). Neuropsychologists are adept at quantifying cognitive strengths and weaknesses, including areas such as working memory, prospective memory, and organizational skills that may have considerable relevance to the self-management of a condition such as spina bifida. The Life Course Model provides the neuropsychologist with a comprehensive overview of the various self-management skills and self-care competencies that eventually become the responsibility of adolescents and young adults with spina bifida (eg, self-catheterization, obesity prevention, skin care). By providing neuropsychologists with this specialized information, the neuropsychologist can identify functional areas in which the youth may be at risk (eg, skin

breakdown due to failure to initiate pressure relief exercises) given his or her specific areas of neuropsychological weakness, rather than simply identifying general areas of neurocognitive deficit (eg, poor initiation).

Finally, the Life Course Model provides the neuropsychologist with an interpersonal context in which to understand the youth with spina bifida. Areas such as friendship, parent/child interaction, relationship with siblings, and development of intimate/romantic relationships are all core components of social functioning and identity development. The specialized information available within the Life Course Model provides neuropsychologists with valuable information regarding how those around the youth can respond to his or her pattern of strengths or weaknesses, and help facilitate healthy interpersonal development.

LONGITUDINAL CASE STUDY

Birth to 3 Years

Julio has been participating in EI services based on his Individualized Family Service Plan (IFSP), and sees his OT weekly. His OT, based on the recommended assessment tools in the Life Course Model, administers the Wee-FIM and determines that Julio has deficits in early object usage. In addition, discussion with his family reveals that they have concerns about Julio's physical safety when opportunities arise for him to interact with nondisabled peers, which has limited any such interaction. After reviewing recommendations for possible interventions and determining what was most appropriate for Julio's situation, his OT discusses the importance of Julio engaging in parallel play activities within the community. He begins participating in a swim program appropriate for his age group and attended by young children and their parents. His OT also provides information to Julio's parents regarding developmentally appropriate toys that encourage understanding of cause and effect relationships. The nurse coordinator discusses these events with Julio's OT and refers Julio's parents to a local support group found via the Web site resources. Julio's parents then began interacting with other families who have children with spina bifida. His primary care physician provides anticipatory guidance, well child care, acute care for illness, immunizations, growth, and nutrition follow-up, as well as input into development of the IFSP.

Years 3 to 5

Julio has been attending a local Head Start program designed to accommodate children with developmental disabilities. Julio has been using a walker and often is unable to quickly engage in floor-time play with his peers due to difficulty in transferring from stand to sit position and clutter of the environment (eg, peers on the floor, toys). While working on ambulation goals with his physical therapist (PT), the PT consults the Life Course Model Web site. While thinking more about his ambulation goals, she finds ways to organize the play space differently to allow for clear walkways. Also, the Head Start program develops several play areas enabling Julio to interact with his peers in a standing position. At the next clinic visit, the nurse coordinator discusses Julio's mobility with his family, using a list of mobility milestones she obtained from the Web site. She communicates Julio's achievements and goals to the team of clinicians scheduled to see him. His primary care physician continues health supervision and anticipatory guidance, monitors growth and nutrition, provides immunizations, and communicates with the Early Childhood Special Education program (Part B), which works with the Head Start program to provide developmentally appropriate intervention services, based on Julio's IEP.

School Years

Up until the fourth grade, Julio has been successful academically. However, his math teacher has noticed he is now struggling to keep up with the rest of the students. His IEP does not specifically address any type of learning disability. Julio's parents, on receiving notice from his math teacher about his struggles, access the Life Course Model Web site and recognize that this is a milestone their son may not yet have achieved. Concerned, they complete the Nonverbal Learning Disabilities (NLD), a Parent Rating Scale recommended by the Web site. Based on the results from this scale, his parents request further evaluation by a neuropsychologist to determine if Julio has an NLD. Based on the results from this assessment, Julio's IEP is adapted to reflect the new information. Julio's parents also provide feedback to Julio's teachers based on what they learned from the Web site. His primary care physician continues to provide health supervision, anticipatory guidance, and monitors the IEP.

Teen

Julio is now 15 years old and has been in high school. The school administers a typical interest inventory for students to begin thinking about future careers. Julio's guidance/rehabilitation counselor is concerned, as Julio still expresses a desire only to pursue a career as a professional rap star. He is unwilling to consider other options and believes that his goal is realistic. Julio's counselor consults the Life Course Model Web site for further inventories to assess Julio's strengths and abilities. She chooses the Work-Adjustment Inventory to assess Julio's work temperament and the Jacobs Pre-Vocational Assessment (JPVA) to assess his specific work-related skills. Based on the results from these assessments, Julio's counselor helps him find a volunteer opportunity in the community in line with his interests and abilities. In addition, she encourages Julio to explore rapping as a hobby and to perform in a local or school variety show. His counselor also sets up a peer mentor through the local SBAA chapter and encourages Julio's parents to provide him with opportunities to interact with other adults to discuss potential career paths. His primary care physician continues to provide health care supervision on adolescent issues such as sexuality, risky behavior, and substance abuse, as well as monitoring the transition plan of the IEP.

Adult

Julio has recently moved into his own apartment and uses public transportation to get around the community. He has been using a manual wheelchair for mobility. He has a part-time job at a local department store and plays wheelchair basketball with the local men's team. Julio's employer contacts his rehabilitation counselor with concerns over recent complaints from coworkers regarding Julio's personal hygiene. The rehabilitation counselor meets with Julio to discuss the problem. Julio is adamant that he has not been experiencing incontinence on the job, and that he washes his clothes and showers before going to work. Although she believes that Julio is telling the truth, the counselor also notices a strong odor. She accesses the Life Course Model Web site and learns that skin breakdown can be a significant issue for those with spina bifida and can cause strong odor as well. She also recognizes that Julio should be making regular appointments with health care providers specializing in maintaining his health status. She refers him to the nearest adult spina bifida clinic. The nurse coordinator speaks with Julio, and gives him additional information on skin care and pressure relief maneuvers that she found through links in the Life Course Model Web site. She sets him up to see a physiatrist in the clinic to treat the pressure ulcer and obtain a new cushion. The physiatrist previously found a PT who specializes in seating assessments

by consulting professional organizations listed in the Life Course Model Web site. The physiatrist and PT work as a team to prescribe a new cushion and refer him back to his rehabilitation counselor to discuss funding options for the new equipment through the vocational rehabilitation program. Julio's rehabilitation counselor sets up a meeting with Julio's employer to explain the situation regarding his health. She helps him to fill out any necessary paperwork and they request a medical leave of absence until Julio is able to return to work again. In addition, she helps Julio to set up reminders to perform daily skin checks. Together they consult the Web site for ideas. She and Julio decide that a laminated reminder in his shower and a daily alarm on his Smart Phone to confirm that he has completed his skin check should help prevent this from occurring in the future.

SUMMARY

The care of a person with spina bifida requires multidisciplinary care from a variety of health care professionals. As a child grows and develops, the circle of providers enlarges to include community as well as new support systems and health care providers. Collaboration of all of these services and providers is important to the development and transition to adulthood for the child and family. The Life Course Model can be used by the patients, their families, and those clinicians involved in the growing child's care to assist in development of the individual with spina bifida to live as independently and successfully as possible.

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