

Transitions Into Adolescence

Overview

Transitioning from childhood into young adulthood is a delicate time for most teens but for teens with Spina Bifida, the turmoil can be even greater as they progress from pediatric care to adult health care; school environment to work place; and home to community living

However, while it is now estimated that 85 percent of all children with Spina Bifida live into adulthood, concerns regarding personal and physical barriers play greater roles for these special teens. Just as parents assist children without Spina Bifida with this transition, parents of children with Spina Bifida and the professionals who work with them can also foster independence and provide encouragement for mastering self-help skills.

Pediatric care to adult health care

A successful health care transition requires sensitivity, cooperation and commitment of a transition team comprised of the teens, parents, pediatricians and new providers of adult health care. The team should identify adult health care providers who are willing to accept the primary health care role while integrating both adult and pediatric providers in the first few months during the transition. Teens should adopt and maintain the role of care coordinators, maintaining their own health care records. However, understanding one's own limitations and knowing when to ask for help are part of the transition process. Additional education and training should be provided as needed.

School environment to workplace

The Americans With Disabilities Act of 1990 guaranteed equal opportunity in employment, the Individuals With Disabilities Education Act of 1990 provided transition services for students with disabilities, and the Rehabilitation Act Amendments of 1992 increased the role of state vocational rehabilitation counselors. Yet, even with this special protection, teens as young as age 14, and their families need to actively pursue these services through Individualized

Education Plans (IEP), created by school counselors, special education teachers and the teens themselves.

The successful transition strategy should identify available agencies along with their services and ascertain how all services will be coordinated. Additionally, the IEP should evaluate the students' interests and skills, create a plan to match their vocational and/or educational goals, and create a process to measure progress toward the goals.

Making the transition from home to community living

Teens should be encouraged to develop decision-making skills that relate to community living-from daily activities like grooming, cooking and housekeeping to more complex skills like managing finances and acquiring agency services.

Independent living skills courses, offered by many agencies, may be helpful to teens as they acquire household skills. However, when independent living is the goal, the value of a social support network cannot be overestimated. Unlike physical and medical barriers, loneliness and depression are invisible barriers to a successful transition. Teen contact with successful young adult role models should be encouraged.

Conclusion

Sensitivity and support work hand in hand with developing life skills. Throughout the transition from childhood to adolescence, much depends on the early efforts and coordination of the teens, families, physicians, school counselors and other professionals. While ultimately, the responsibility falls on the teens with Spina Bifida, motivation, education, and encouragement are their keys to success.

This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.