



Transitions Into Adolescence

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Advances in medical care over the past 25 years have markedly increased the survival and longevity of persons with spina bifida (spina bifida). At least 85% of children with spina bifida are now expected to live into adulthood. Thus, teens with spina bifida and their parents are faced with issues relating to "transition." Transition into adolescence is the movement from child-centered to adult-oriented activities. It is a three-pronged process that depends on early education and coordination of efforts by all involved persons. The major areas of transition include moving:

- 1) from child and family-centered pediatric care to adult oriented health care
- 2) from school environment to work place
- 3) from home to community living

The passage from childhood to young adulthood can be a time of internal turmoil for any teen. It may be even more stressful for the teen with spina bifida. During this period, the teen is experiencing rapid changes in physical, cognitive, emotional, and social growth, yet must master decision-making, autonomy and independence. For adolescents with spina bifida, the journey is more difficult as they face additional barriers such as lower extremity weakness, scoliosis, learning disabilities, neurogenic bowel/bladder, limited life experiences, etc.

The process of transition not only means the teen must master a new set of skills, but he/she must also experience a change of attitude from dependence to independence. This change in attitude is not something that occurs overnight. It is more easily accomplished if independence has been fostered throughout the child's life. Parents should teach the child with spina bifida self help skills at similar ages as they would children without spina bifida. However, the child's physical limitations and intelligence must be taken into consideration. Often creative solutions can be found to by-pass a specific deficit and aid the child towards independence.

At the same time that parents encourage independence, they must also be willing to "let go" of control. They must also be willing to let the child make mistakes and learn from the decision-making process. The child will need to use problem-solving skills to cope with the effects of a "bad" decision. Additionally, in the journey towards independence, the teen must realize that it is "okay" to ask for help. Understanding one's own limitations and making the decision to ask for help are both part of the transition process.

"Readiness" is extremely important when considering the transition from pediatric to adult health care delivery systems. The teen's age alone is not always the best measure of whether or not he/she is ready for this transition. Adolescents acquire readiness skills at different rates *depending on* their intelligence, their knowledge about their own disability(ies) and *whether or* not they have made decisions about their own health care in the past. It would be helpful if the parents and professionals encouraged the child to learn as much as possible about spina bifida. The child should also be encouraged to perform his or her own care (e.g. intermittent catheterization, bowel program or medication administration). This will foster autonomy and independence. Finally, the child would gradually assume a larger role in decision-making regarding his/her own medical and surgical care.

The parents and pediatric health care providers must also be "ready" for the transition. Often there is the tendency to see the adolescent with spina bifida as a perpetual child. They may not let the child make decisions about his/her own care in order to "protect" him/her. Even worse, parents may continue to dress the child or do his/her caths and bowel program. They may also sincerely feel that it would be best to obtain medical care from pediatricians and pediatric specialists. Strong emotional attachments often develop between patient, their parents and the doctors. The pediatric specialists may view themselves as the experts in spina bifida regardless of the patient's age. Physicians that care for adults are often reluctant to accept persons with spina bifida. Many of them are unfamiliar with spina bifida. Information about spina bifida is not normally provided in adult health training programs. Thus, the teen may suddenly find him/herself as the "teacher". This may be a frightening experience.

Adult spina bifida clinic teams are extremely rare. Thus, adults with spina bifida will need to learn how to navigate among many different physicians and clinics. They must sift through many pieces of information from various sources. Then they must develop their own health care plan. There is a high likelihood that this new uncoordinated web of care will result in many holes.

Successful transition in health care requires the cooperation and commitment of the teen, the parents, the pediatrician and the new providers of adult health care. It should begin years before the child "ages out" of pediatric services. The process should be planned rather than take place when there is a medical crisis. It should take place gradually. As the child enters adolescence, someone must evaluate the teen's readiness. The teen's intelligence (mental age) and his/her level of understanding of spina bifida are important. But even more important is the teen's level of self-care and decision-making. Check lists have been developed to evaluate these skills. (See resource list.) When skills are found to be lacking, they must be taught.

A survey of adolescents between the ages of 11 and 14 with physical disabilities (Hosler, 1989) revealed that 57% were unable to discuss or explain their disability. 50% of the teens who were

taking medications could not name the medications or give the reason for which they were being taken. 90% were unable to describe their long-term therapeutic goals.

Another study (Capelli, 1989) showed that self-care behavior (for example, doing own caths and bowel care, taking own medication, making doctors appointments, performing daily health care procedures, etc.) was more important than "book knowledge" in predicting a successful transition.

Patient education is extremely important in preparing for successful transition. The process may take place quickly or over a long period of time depending on the teen's prior knowledge and experience. Ideally, the preparation should include:

1. A comprehensive "transition interview" (Hassler, 1986) in an appropriate setting (e.g in the doctor's office rather than an examining room). The physician should establish an alliance by explaining the purpose of the interview. He/she should use language that is neither too trendy nor too technical. He/she should be non-judgmental and ask open-ended non-threatening questions. Normal issues about puberty as well as those issues specific to teens with spina bifida should be discussed (i.e. folate supplementation, genetic counseling symptoms relating to Chiari malformation, hydrosyringomyelia, tethered cord, sexual function, skin checks, and prevention of obesity and secondary disabilities). If misconceptions exist, they should be discussed and explained correctly. Afterwards it is helpful to have the teen summarize the new information that he/she has learned. It helps the pediatrician assess how much the teen really understood. It also gives the teen a chance to explain his/her condition to an adult. This is a skill he/she will need in the future when the teen/young adult obtains medical care from a physician with little or no training in spina bifida. The teen and pediatrician should then discuss future health care goals. They should determine who will provide the teen's future health care. If the teen is not already maintaining his/her own personal record, then he/she should be strongly urged to do so at this point. Various abbreviated health care records have been developed by clinics and agencies for personal use.
2. Next, the two should proceed toward a "teaching physical exam" (Willson, 1986). It should be done in privacy - without the parents. Patients should be encouraged to ask questions throughout the examination. The exam should start with the least threatening areas. The doctor should address the "normal concerns" of all adolescents (e.g. puberty and sexuality). He/she should also discuss the effect that spina bifida will have on sexual function, marriage and child bearing.

Transition will be smoother when the teen has a good understanding of spina bifida and his/her unique medical needs and he/she has taken on responsibility for his own care throughout childhood. Ideally, the transition process should include the development of an individualized care plan. One person, preferably the teen with spina bifida, should be identified as the care coordinator. This role may vary depending on whether or not the teen has access to an adult interdisciplinary spina bifida clinic team. More than likely, he/she will not. Thus, the young adult will need to recruit a "custom built team", of specialists to provide health care.

As the time approaches for the actual "passing of the baton" from pediatric to adult care, education of the "new" physician may be necessary. Ideally, the pediatrician and new doctor may want to enter a partnership of care during a three to six month period. The pediatrician (and spina bifida team members when available) can educate the new doctor regarding spina bifida. He/she/they can provide expertise and support as the new doctor becomes familiar with his/her new patient and spina bifida. Open communication between the two primary care providers will facilitate a smoother and better-planned transition for the young adult. If the teen has been followed by a family or general practitioner who agrees to continue primary care, education regarding spina bifida should not be necessary. However, the physician may need information regarding secondary conditions as a result of spina bifida. And, there is still a need for the teen, parents and physician to accept the new role of the teen, not the parents, as the "final say" in medical decision-making. Adult surgeons (urologists, orthopedists, and neurosurgeons) who will be assuming the care of the teen or young adult may also need to "be educated" about spina bifida. Regardless of the time an effort expended by all involved in the transition process, a change in the style of care may still seem like abandonment.

Recommendations to assist with a smooth transition from pediatric to adult health care:

- 1) Parents and professionals should encourage children to accept responsibility for self-help skills (e.g. bowel and bladder management) early in life.
- 2) The physician, nurse or spina bifida team should assess readiness for transition in both teen and parents early. Additional education and training (e.g. in self-care) should be provided as needed. The teen should also be given opportunities to make decisions in his/her own health care role.
- 3) As a team, the teen, parents and professionals should identify adult health care providers who are willing to accept the primary health care role.
- 4) The spina bifida team or pediatrician should encourage cooperative care of both pediatric and adult-care providers for the first few months during the transition process.
- 5) All should encourage the teen to maintain his/her own portable health care records and to begin functioning in his/her new job as "care coordinator."
- 6) Parents and professionals should support the teen in his/her new role, then let go. However, do not abandon him/her if asked for help later down the road.

Transition From School to Work or Post Secondary Education

For most teens, high school diploma and graduation mean a job well done and the beginning of a more independent life style. However, graduation for a student with spina bifida may mean the sudden loss of multiple supports and services to which he or she was accustomed. The Individuals With Disabilities Education Act of 1990 reflected a major policy shift. Transition services were mandated as part of the "Individualized Educational Plan (IEP)". The Rehabilitation Act Amendments of 1992 increased the role of state vocational rehabilitation counselors working with teens with disabilities enrolled in school. It was expected that by

working together, the counselors and special education teachers would reduce the possibility of missed services after graduation. The Americans With Disabilities Act of 1990 stated that there be equal opportunity after graduation of people with disabilities in employment, public accommodations, transportation, telecommunications and state and local government services including state universities. One should expect then, that, the teen with spina bifida in the 1990's should have a much better opportunity for securing a job or a college education.

However, these costly services do not just happen. In reality, the teen and family must become aware of the services and request them. This is done through the IEP. Transitional planning should be included in meetings that discuss the teen's IEP when he/she reaches 16 years of age. In ideal situations, it should even begin earlier. At this point the teen should be an active member of the IEP team and help plan his/her own transition. In planning, a transition strategy, the team should:

- 1) Identify the agencies that will be involved.
- 2) Determine the services that each agency will provide.
- 3) Describe how all services will be coordinated.
- 4) Evaluate the student's interests and skills and develop a plan to match these to his/her vocational goals and the services being recommended.
- 5) Outline the process that will be used to measure the student's progress towards his/her goals. See Resource List for guides, checklists and workbooks.

Again, just as with transition in health care, the earlier the child begins to make decisions and take on responsibility for educational/vocational issues, the smoother the transition will be.

Guidance through mentor and volunteer activities in various work situations may help the teen become more aware of his/her interests, strengths and weaknesses and assist in making wiser career choices.

Recommendations to help with a smooth transition from school to the job force:

- 1) Encourage the school to begin transition planning when the teen turns 14 years old...remind them of their responsibility when he/she turns 16.
- 2) Become familiar with your state's rehabilitation counseling services and enroll the teen as early as possible.
- 3) Encourage the teen to explore a variety of careers through part-time jobs, volunteer work, or guidance with mentors.
- 4) Be a good listener so the teen can openly discuss his/her career goals and concerns.

Transition From Home to Community Living

The ability to live independently in the community depends on many factors. The transition can occur quite smoothly if there is enough preparation and everyone is motivated. Social and organization skills are very important. These skills are best learned in settings where children with spina bifida can participate in activities with non-disabled peers. When independent living is identified as a goal, the IEP can be used to assist the teen in reaching this goal. The teen should be encouraged to develop decision-making skill that relate to community living such as:

- 1) Social skills and assertiveness training
- 2) Grooming, hygiene and clothing care
- 3) Finding and acquiring services from various agencies (i.e. SSI, attendant care)
- 4) Managing finances and household budget
- 5) Hiring, training, supervising and firing personal care attendants
- 6) Homemaking, cooking and nutritional issues
- 7) Accessing public transportation
- 8) Identifying and taking part in leisure opportunities

Peer support and development of a social support system is necessary in preventing social isolation when the young adult moves out of the family home. In fact, the lack of peer support and a social support system may be the main reason for moving back home. Unlike physical and medical barriers, loneliness and depression are invisible barriers to a successful transition. Independent living skills courses may be helpful in this area of concern as well as in helping the young adult acquire practical household skills. Your local Spina bifida Association may be able to offer guidance regarding agencies with successful programs.

Recommendations to facilitate a smooth transition from home to community:

- 1) Encourage child to take responsibility for his/her own self-care, budgeting of weekly allowances and household chores consistent with physical and mental abilities.
- 2) Promote teen contact with successful young adult role models. Encourage visitation to various types of independent living settings.
- 3) If attendant care services will be needed, begin services while the teen is still living at home. Allow him/her to interview prospective attendants, and then select, hire and supervise the employee.
- 4) Identify local independent living resources and enroll the teen in an independent living skills course as soon as he/she meets age requirements.
- 5) Develop a "game plan" with realistic deadlines to achieve each step towards independent living.
- 6) Create a notebook that will include emergency information as well as important phone numbers and resources for managing one's own household.

- 7) If a problem emerges, or to move the process along, seek the services of an experienced family counselor who can assist the parents and teen in defining boundaries and responsibilities.

Conclusion

Transition is a long and variable process. It will typically have its "up's" and "down's". In all areas of teen transition, success depends on the early efforts and coordination on the part of the teen, the family, the physician, the school, and each of the professional with whom the teen comes in contact. Ultimately, the responsibility falls on the person with spina bifida. Adequate motivation, education, skill acquisition and encouragement are the issues. If gaps in knowledge or skills are noticed along the way, the young adult must be willing and able to ask for help. He/she must realize that this is "okay," It is critical that these teens have an adequate support system composed of family, peers, professionals, personal care attendants and members of the teen's vocational, religious and community environment.

References

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9. Willson DD, Hostler SL. *The Teaching Physical Exam: AM* Charlottesville, VA: Children's Rehabilitation Center, 1986.

Transition Resources

1. Children's Association For Maximum Potential POB 27086, San Antonio, TX, 78227 (210) 671-2598 -- Portable Medical Record.
2. Good Shepherd Home Raker Center Planning Checklist Available From Social Work Services Department Of Good Shepherd Raker Center, 601 St. John Street, Allentown, PA 18 103, (610) 776-3199.

3. Kluge Children's Rehabilitation Center, 22270 Ivy Road, Charlottesville, Virginia 22903. (804) 924-8184 --- Adolescent Autonomy Project Materials Cited Above
4. National Center For Youth With Disabilities (NC-Y-D), University Of Minnesota- Box 721, 420 Delaware Street SE, Minneapolis, INLN 55455. (612) 626-2825 --- Transition Research, Directory Of Transition Projects And Numerous Helpful And Practical Materials.
5. National Council Of Independent Living Will Provide Information On Centers For Independent Living Around The Nation. Write NCIL, 21 Wilson Blvd., Suite 405, Arlington, VA 22201, Or Phone (703) -525-3406.
6. PACER Center, 4826 Chicago Avenue South. Minneapolis, MN 55417-1055 (612) 827-2966 --Numerous Materials Including Very Practical Workbooks Entitled. Students In Transition Using Planning And Information For Parents Of High School Students With Disabilities In Transition To Adult Life
7. West MA. Assessment For Adolescents With Special Needs: A Guide For Transition Planning. Seattle, WA: University Of Washington Press, 1988 --- Workbook With Helpful Checklists.

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