

## Changing Expectations

Ten years ago, an individual with spina bifida did not expect to go snow skiing with his/her peers; today this person can expect to join in the fun of recreation and friendships with the aid of adaptive sports equipment and more accessible facilities. This is just one example of the many changing expectations for people with disabilities. There are many choices available today that were not available even a few years ago. More than choices, attitudes are changing as well. People are beginning to understand that a disability is just one part of a person. Persons with disabilities, like anybody else, need to work, socialize, recreate, and receive adequate health care. With the enactment of the Americans with Disabilities Act in 1990, individuals with disabilities have a legal right to participate in all aspects of life. They can expect to achieve lives of quality into adulthood and take part in all aspects of adult living and community participation.

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*“I believe she will be a very productive citizen—holding a job, driving a car, living on her own, and being involved in various activities in her community.”*

*A Parent Participant in the Study*



## The Journey to Adulthood

What is the work of childhood from a developmental standpoint that enables an individual with spina bifida to achieve a high quality of life into adulthood? Growing up is a process that covers the first two decades of life. It is a period of important achievements, each contributing to the child's ability to become successively more independent. While these achievements can be measured one by one, a useful way to think of them is in terms of building blocks that all children need to achieve to move from one stage to the next. In the early years, moving about and exploring things with the eyes, mouth and hands are the ingredients of independence for the toddler. The preschool child's task is to acquire language to communicate effectively with others and to assume the basic responsibilities of self-care in eating, dressing, and toileting. Having mastered these skills, the child enters the world of the school, with each grade building on the initial achievement of fundamental skills of writing, reading and using numbers. In the structured setting of the classroom and the informal setting of the playground and neighborhood, the middle years of childhood focus on the skills of being a member of a group through shared activities and responsibilities. In adolescence, becoming independent takes the form of exploring identities, activities, and friendships.

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*“To study how children grow up, we can use one of two strategies. One is to look at groups of children of different ages and compare and contrast their activities and achievements. Another is to follow a group of children of the same age over time. In our study, we were able to use both of these approaches. This allowed us to learn from both of these approaches as we compared different age groups and followed individual children, teens, and young adults from one year to the next. Recognizing the importance of the world in which individuals with spina bifida live and learn, we value the information these individuals, their family members, and teachers have shared with us.”*

Dr. Rune Simeonsson, Principal Investigator







# What Have We Learned?

## Quality of Life

In general, individuals with spina bifida in the study reported that their quality of life is high. When families of individuals with spina bifida were asked to rate their child's quality of life, they also tended to rate it highly.

Quality of life for individuals with spina bifida is a highly personalized concept and appears to be unrelated to the extent of the disability. Contrary to popular belief, the level of spinal lesion, the need for assistive devices such as a wheelchair, or a limitation in learning were not significant predictors of quality of life. Quality of life ratings were instead based on many different factors and influences of daily living and were associated with a variety of challenges, experiences, and expectations.

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*"We have plenty of food, a good home, two vehicles, good clothing, and are active in our community."*

*"I have friends and am doing fine in school."*

*"We are a caring supportive family and we encourage each other. We have family, friends, and relatives and professionals who support us."*

*"At school I feel good about myself because I can do things others can do."*

*"Our religious beliefs and how we interact with each other as a family improve our quality of life."*

*"My husband and I have a good sense of humor which helps a lot."*

*Study Participants with Spina Bifida and their Families with a High Quality of Life*



## Challenges

Though individuals with spina bifida reported having a high quality of life, they also described facing challenges and barriers that affect their ability to fully engage in life experiences. Some of these challenges are not directly caused by spina bifida, but are instead “secondary” to it. These are known as **secondary conditions**. Based on the information shared, we have learned that as individuals with spina bifida grow older, they may experience more difficulty in some of these “secondary” areas. We also learned which secondary conditions are most prevalent or common in each of the age groups studied. In essence, the study helped us to understand what an individual with spina bifida is most likely to experience.

Four areas – ① Physical ② Personal/Social ③ Self Care ④ Academic – in which **secondary conditions** were experienced are described on the following pages. We have also included **recommendations**, which emerged from the research, that individuals with spina bifida, families, schools, and communities can utilize to help reduce the occurrence of these secondary conditions.

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## ① Physical

When looking at the groups of individuals with spina bifida of different ages and comparing their reports of physical difficulties, individuals of all ages from birth through young adulthood reported experiencing common physical challenges such as pain, skin breakdown, pressure sores, mobility limitations, latex allergy, and difficulties with endurance and balance. Due to the nature of spina bifida and the complications that may accompany this condition, the groups also reported physical challenges that differ across the ages. Some individuals between the ages of 6 and 18 years reported having scoliosis and breathing difficulties, during a time of rapid growth. As youth reach the teen years through young adulthood, many also reported difficulties with weight gain and concern about sexuality.

### RECOMMENDATIONS:

- **Disability education** Begin teaching the child with spina bifida about his/her disability, as early as the preschool years. As the child matures, continue to update and review the information with him/her to make sure he/she has a good basic understanding. The individual with spina bifida should be aware of any danger signs regarding complications, medications, or allergies associated with their disability, such as latex allergy or shunt malfunction. Adolescents and young adults with spina bifida can take on a more independent role to monitor their body functions and stay updated on current information about their disability.
- **Preventive care** Schedule regular appointments for the child with spina bifida with a general pediatrician or primary care doctor, and with specialty doctors as needed to monitor the regular changes of his/her growing body and any specific needs regarding the disability. Be aware of potential secondary conditions that may occur at the various ages so that the individual with spina bifida, parents, and health care providers can take steps to prevent or minimize these

consequences. As the child enters the elementary and teen years, give them increased opportunities to become more independent in managing their preventive health care.

- **Nutrition and physical activity** Keep updated on information about eating a healthy diet and getting adequate physical activity. Both nutrition and activity can play an important role in helping individuals with spina bifida maintain a healthy weight, minimize pressure sores, and increase balance and endurance. Families can support their child with spina bifida by providing regular opportunities for physical activity, healthy food choices, and good role models of healthy living. Investigate your local YMCA, Adapted Sports Program, Rehabilitation Center, Parks and Recreation Department, or gym to learn about what physical activity opportunities are accessible in your area. Remember that these life long habits are established in childhood.
- **Skin care** Practice routine skin care - check the skin regularly for sores and irritated skin areas. Make sure braces, crutches, and wheelchairs fit well as a way to monitor and prevent skin problems. Pay close attention to areas of the body that have decreased sensation. Individuals with spina bifida should move their body every 15 minutes, stay clean and dry, and drink plenty of water. Begin teaching children with spina bifida about their skin care in the pre-school years and encourage more independent self-care as they age.
- **Sexuality education** The ability to love and to be loved does not change when a person has spina bifida. Provide information for the elementary school-aged child through the teen years regarding sexuality. Find accurate general information, books, and resource centers that can answer your child's questions in an age-appropriate way regarding topics such as maturing bodies, intimacy, dating, pregnancy, and sexually transmitted diseases. There will be some issues that are common to all youth, while teens with spina bifida may have some specialized concerns regarding their disability and sexuality.



## ② Personal/Social

Individuals with spina bifida often experience difficulties with personal and social issues. Some families in the study reported their children who are age five years and younger encounter challenges with isolation, exclusion, and poor social skills. As a child with spina bifida progresses from early childhood through adolescence, increasing difficulties with self-esteem, confidence, body image, depression, social skills, isolation, exclusion, and dating/relationships are not uncommon. These issues are typical challenges of growing up for all youth and are most evident during the adolescent years; however, youth with spina bifida reported increased difficulties with these issues, possibly related to the additional challenges of having a disability. As individuals with spina bifida reach adulthood, many also reported facing increased difficulties with low self-esteem, lack of confidence, poor body image, isolation, exclusion, social skills, relationships, and dating.

### RECOMMENDATIONS:

- **Making choices** Beginning in the early years, provide regular opportunities for the child with spina bifida to make choices,



problem solve, and even make mistakes. This may be simple occurrences such as the preschooler choosing their clothes for the day, the 10-year old choosing their room decorations, or the teen choosing their hairstyle. When children have opportunities to practice making choices, recognizing successes, and identifying problems with their choices and options for solving them - they become more equipped to function independently and interact with others.

- **Access to social opportunities** Individuals with spina bifida should be given access to the same social opportunities that are available to their peers. This can be accomplished by providing age-appropriate experiences to include interactions with others in social situations, both in and out of school, and offering opportunities to participate in community activities such as play groups, scouting, volunteering, clubs, camps, church activities, and classes. These are venues through which individuals with spina bifida can identify and build on their personal strengths and thereby increase self-esteem and confidence as well as opportunities to practice social skills. These activities can also provide alternate learning opportunities for children and youth who may have a hard time with the “ABC’s” of school.
- **Develop interests** Provide opportunities for the child with spina bifida to develop interests and make choices regarding their hobbies and other recreation activities, such as fishing, visiting museums, music, dance, art, and sports. The child’s interests and preferences will change over time, which is a normal part of growing up. Whatever their interest, each experience will provide ways for the individual to develop friendships with peers who have similar interests and to build self-esteem. These experiences will give children, teens, and young adults with spina bifida the opportunity to demonstrate and develop social skills and to develop a sense of identity and belonging.
- **Transportation** For the person with spina bifida, transportation can be critical to promote socialization yet can be complicated due to mobility limitations and/or use of a wheelchair. Become familiar with the accessible transportation services in your area (contact Family Support Network of NC Central Directory of Resources). As early as possible, begin teaching your child about his/her

adaptive equipment. Have adolescents and young adults become proficient with their equipment such as how to breakdown, transport, and set up their wheelchair as well as learn about adaptive driving lessons and equipment. If persons with spina bifida are familiar with their equipment and have the resources for transportation, they will be more able to travel alone or with others and have additional opportunities to be independent and socialize with their peers.

- **Advocacy** Become knowledgeable about the Americans with Disability Act (ADA): a law that was enacted in 1990 to extend the rights of people with disabilities into the private sector. The ADA prohibits discrimination on the basis of disability in the areas of employment, public services provided by state and local governments, public services operated by private entities, transportation, and telecommunications. Knowledge of this act can enable individuals and families to advocate for themselves and/or their child regarding access to the environment and participation in all aspects of community living. Families are often their child's best advocate and can be great role models for teaching these skills. However, it is essential to also provide opportunities throughout the elementary, middle, and high school years for the child with spina bifida to learn about his/her rights and to practice advocating for him/herself so that the child can grow towards independence.

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*"We want her to do as much as the other children her age.  
We try not to have any limits to what she can't do."*

*"I've made friends in every class."*

*"We encourage him to try things."*

*"We've taken a strong advocate role..."*

## ③ Self Care

As all youth mature, they become more independent in varying aspects of daily living. As individuals with spina bifida reach adulthood, they too reported gaining independence and experiencing fewer difficulties with self care issues such as grooming, toileting, and transferring.

### RECOMMENDATIONS:

- **Self care skills** Families can begin teaching their preschool child with spina bifida the same general self care skills that all children learn, such as brushing their hair and teeth, dressing, and bathing. Fostering self care abilities can help children with spina bifida feel more confident and self-assured. As the child matures through the school years, teach him/her about proper rest, body awareness, stress and pain management, and hydration. There may be some self care skills that are specific to spina bifida, such as bowel/bladder programs, taking medications, skin care, and transfers. All of these self care skills will enable individuals with spina bifida to take charge of their health and increase their independence.
- **Exercise** During the early years through the teen years, families can encourage and participate in regular exercise and physical activity for themselves and the child with spina bifida. Physical activity can help to increase strength, dexterity, and balance - all of which can improve the skills needed for dressing and transferring.
- **Adaptive equipment** Various adaptive equipment is also available to assist with specific self care challenges that individuals with spina bifida may encounter. Families and individuals with spina bifida should be familiar with equipment available and local agencies and organizations that provide equipment sales or loans.
- **Self-management of health care** As children with spina bifida enter the school years, families can provide opportunities for them to begin learning steps to manage their health care needs, such as asking questions at doctor visits, keeping medical records, making appointments, and obtaining prescriptions. In the elementary years, the child might prepare questions with the assistance of a parent before a doctor's visit, and progressively increase their level of health care independence in the teen years. The health care needs of individuals with spina bifida can be fairly complicated, so it is important for youth to begin practicing self-management of their health care early.





WHEELS OF STEEL

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- **Health insurance** Health insurance is a critical area for persons with spina bifida. Often their needs are complex and financially exhaustive. Families and individuals with spina bifida will want to become as knowledgeable as possible about their health insurance options and ways to advocate for themselves or their child. Having as much information as possible will help individuals obtain access to needed specialists, therapists, tests and procedures, equipment, medical supplies, and/or medications. Health insurance is an important area as children are growing up, as well as when youth transition into adulthood and face employment decisions.
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*“She’s doing her own activities of daily living.”*

*“I am trying to get him to do more for himself”*

*“We work hard in helping our child to do things he wants to do such as getting into the tub for a bath and brushing his teeth.”*

*“Some things I do well-like making the bed, folding clothes, washing dishes, keeping the house together.”*

## ④ Academic

Many families and individuals with spina bifida from the study reported difficulties with academic issues over the years. For children birth to five years old, some difficulties with pre-academic issues such as problem solving and learning/attention were common. Challenges with academic activities such as problem solving, learning/attention, reading, writing, math, and spelling occurred often as individuals with spina bifida aged and moved through the school years into adulthood.

### RECOMMENDATIONS:

- **Partner with teachers** Develop relationships with the child’s teacher/s, beginning early in the preschool years and throughout the school years. Positive communication regarding the child’s strengths and special needs can only optimize the child’s experience

and help each teacher be an informed partner to best meet the child's needs in the classroom.

- **Be proactive** Proactive families can help teachers and schools to identify and request any necessary outside resources, such as therapists, tutors, or other services, that will help the child with spina bifida be academically successful. Ensuring a positive school experience for children with spina bifida will promote positive post-school outcomes such as opportunities for higher education and successful employment. (Contact the Exceptional Children's Assistance Center for more information regarding how to advocate in the schools.)
- **Get involved in the IEP** Many students with spina bifida receive special education services. Both the child and parent should be involved in the development of the child's Individualized Education Plan (IEP) to ensure that the plan's goals and objectives address academic issues that match the needs of the child.
- **Partner with school personnel** Get to know and assist school personnel, such as the school nurse, PE, art, and music teachers, to develop the necessary support for adapted programming. These partners may also assist with identifying areas an individual with spina bifida excels in, especially if some aspects of academics are difficult.
- **Develop a transition plan** When the teen with spina bifida reaches 14 years old, both the family and the teen should be involved in the development of a transition plan to ensure that priorities are successfully addressed regarding the youth's transition into post secondary school, work, and/or independent living. This is a specific requirement for the Individualized Education Plan (IEP) that was strengthened during the latest reenactment of the Individuals with Disabilities Education Act (IDEA) in 1997. This law guarantees that all eligible children and youth with disabilities receive a free appropriate public education designed to meet their unique educational needs. Contact your local Vocational Rehabilitation agency and invite them to be a part of the transition planning team, so that the teen with spina bifida can begin exploring ideas regarding future career options.

## Summary and Conclusions

Although individuals with spina bifida may experience secondary conditions, the role of support has shown to be a large factor that minimizes these challenges. Family support has been reported as a critical component as well as support given to families from outside sources such as friends, relatives, churches and other community groups. These supports have shown to help reduce secondary complications for individuals with spina bifida as well as ensure that they can participate fully in life activities and experiences.

While individuals with spina bifida face many challenges growing up - whether they are social, physical, or academic - remember that the person with spina bifida is first and foremost a person with similar desires, likes, talents, frustrations, and concerns as all people. They will experience the same developmental milestones as all individuals - from saying "NO!" in the toddler years, to becoming more independent and social in the teen years, to thinking about relationships and employment in the adult years.

We are fortunate to live in a time of positive change and opportunities for people with disabilities. Expectations are changing for the positive to include individuals with disabilities in all aspects of community living. Unfortunately, change is usually a slow process and many of the physical and attitudinal barriers of society have not kept pace with the new positive expectations. As individuals with spina bifida and family members who support them, what can you do during this time of change?

- Be patient with yourself and others - big changes most often come in little steps.
- Value the uniqueness and strengths of yourself or your child with spina bifida.
- Celebrate your small incremental achievements.
- Let others who provide support know they are appreciated.
- Speak up.
- Set your expectations high.

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As you are improving the environment for individuals with spina bifida, you are enriching the community and quality of life for all.





## Resources

### **North Carolina**

#### **Spina Bifida Association of North Carolina**

5632 Ebley Lane  
Charlotte, NC 28227  
Phone (800) 847-2262  
Email: [sbanc@mindspring.com](mailto:sbanc@mindspring.com)  
<http://www.sbanc.org>

#### **Family Support Network of North Carolina (FSN)**

UNC-CH, Campus Box #7340  
Chapel Hill, N.C. 27599-7340  
Phone (800) 852-0042  
<http://www.med.unc.edu/commedu/familysu>

#### **Exceptional Children's Assistance Center (ECAC)**

PO Box 16  
Davidson, N.C. 28036  
Phone (704) 892-1321 or (800) 962-6817  
<http://www.ecac-parentcenter.org>

#### **Division of Vocational Rehabilitation Services**

Department of Human Resources, PO Box 26053  
Raleigh, NC 27611  
Phone (919) 733-3364 or (919) 733-5924 (TTY)

#### **North Carolina Assistive Technology Project**

Department of Human Resources  
1110 Navaho Drive, Suite 101  
Raleigh, NC 27609-7322  
(919) 850-2787 (V/TTY); (800) 852-0042  
<http://www.mindspring.com/~ncatp>

## **National**

### **National Spina Bifida Association of America**

4590 MacArthur Blvd. NW STE 250

Washington, D.C. 20007-4226

(202) 944-3285

<http://www.sbaa.org>

### **The Hydrocephalus Foundation (HyFI)**

910 Rear Broadway

Saugus, Massachusetts 01906

Phone (781) 942-1161

<http://www.hydrocephalus.org>

### **World Arnold Chiari Malformation Association Web Site**

<http://www.presenter.com/~wacma>

### **Family Village**

Waisman Center

University of Wisconsin-Madison

1500 Highland Avenue

Madison, WI 53705-2280

Phone: (608) 263-5973, TDD (608) 263-0802

<http://www.familyvillage.wisc.edu>

### **National Transition Network**

430 Wulling Hall, 86 Pleasant Street, SE

Minneapolis, MN 55455

Phone: (612) 624-1062

<http://ici2.coled.umn.edu/ntn>

### **PACER Center (Parent Advocacy Coalition for Educational Rights)**

4826 Chicago Avenue South

Minneapolis, MN 55417-1098

Phone: (612) 827-2966, (800) 53- PACER (in MN), TDD (612) 827-7770

<http://www.pacer.org>

### **The Beach Center on Families and Disability**

3111 Haworth, University of Kansas

Lawrence, KS 66045

PHONE/TDD (913) 864-7600

<http://www.lsi.ukans.edu/beach/BEACHHP.HTM>

### **The National Information Center for Youth with Disabilities**

P.O. Box 1492

Washington, D.C. 20013

Phone (800) 695-0285

<http://www.nichcy.org>

### **Adolescent Health Transition Project**

Division of Adolescent Medicine, CHDD, Box 357920

University of Washington, Seattle, WA 98195.

<http://depts.washington.edu/healthtr>

## Publications

**Access North Carolina.** NC Division of Travel and Tourism, Department of Commerce, Raleigh, NC 27611, (919) 733-4171, 1-800-VISIT-NC.

**Children with Spina Bifida A Parent's Guide.** Marlene Lutkenhoff, editor. (1999). Bethesda, MD: Woodbine House.

**Insights Into Spina Bifida.** Newsletter available from Spina Bifida Association of America, (202) 944-3285.

**Living Your Own Life: A Handbook for Teenagers by Young People and Adults with Chronic Illness or Disabilities.** Minneapolis, MN. PACER Center, Inc.

**Living with Spina Bifida: A Guide for Families and Professionals.** Sandler, Adrian. Available from Spina Bifida Association of America, (202) 944-3285.

**Newsletter of the Spina Bifida Association of North Carolina**  
Available from Spina Bifida Association of N.C., (800) 84-SBANC.

**North Carolina Recreation Resource Guide.** (1999.) Available from the North Carolina Office on Disability & Health, (919) 966-2932.  
<http://www.fpg.unc.edu/~ncodh>

**People with Disabilities & Chronic Illness: Questions You Should Ask Your Health Plan.** Laura Sutton Elsberg & Pam Silberman. North Carolina Institute of Medicine. PO Box 3360. Chapel Hill, NC 27515. (919)966-8918. <http://www.nciom.org>

**Recreation: A Great Way to Be Active.** (2000). Available from the North Carolina Office on Disability & Health, (919) 966-2932.  
<http://www.fpg.uc.edu/~ncodh>

**Sexuality and the Person with Spina Bifida.** Sloan, Steven. Available from Spina Bifida Association of America, (202) 944-3285.

**Social Development and the Person with Spina Bifida.** Lollar, Donald. Available from Spina Bifida Association of America, (202) 944-3285.

**Spinabilities: A Young Person's Guide to Spina Bifida.** (1997). Cincinnati Center for Developmental Disorders. Bethesda, MD: Woodbine House.

**Taking Charge: Teenagers Talk about Life & Physical Disabilities.** (1992). Kriegsman, Kay. Bethesda, MD: Woodbine House.