

Toolkit for Educators

Resources That Promote a
Healthy School Environment for
Students Living with
Spina Bifida



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

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

Welcome to the *Toolkit for Educators: Resources That Provide a Healthy School Environment for Students Living with Spina Bifida!*

This resource is the result of discussions that took place at a September 2014 conference sponsored by Spina Bifida Association of Northeastern New York (SBANENY). A group of adults with Spina Bifida, parents of children and adults with Spina Bifida, and educators had a dialogue about shared concerns regarding challenges that are commonly experienced by all parties in the education of children with Spina Bifida. The group agreed that a comprehensive guide would provide educators with critical information to not only support greater educational success but also promote a safe and healthy environment for all. With that goal in mind, this *Toolkit* began to take form.

Representatives of Spina Bifida Association of Northeastern New York have worked over the past year to gather a variety of information and resources about Spina Bifida and the impact that this may have on learning for a student with this disability. This *Toolkit* is the result of a collaborative effort of educators, school administrators, adults with Spina Bifida, and parents, and their desire to share information to educate those who will be working with students with Spina Bifida. The goal of the *Toolkit* is to provide a better understanding of Spina Bifida and how the disability may impact students and their success in school. The purpose of the *Toolkit* is to provide valuable information for all those who are involved in the educational program of students with Spina Bifida.

We would like to credit the national Spina Bifida Association and their work on this topic entitled *Beyond Crayons* which provided the foundation for our *Toolkit for Educators*. *Beyond Crayons* may be viewed online at www.spinabifidaassociation.org.

Thank you to the following representatives of Spina Bifida Association of Northeastern New York who provided their expertise and experience to complete this project:

- Vanessa Chamberlain, BS (Nursing), MS (Special Education), Parent
- James Dunham, BS (History and Education), MS (Special Education), MS (Educational Administration), Retired Elementary Principal and Special Education Teacher
- Helen Eggenberger-Lucas, HS Special Education Teacher, MS, Parent
- Hali Holmes, BS Human Development & Family Studies, Early Childhood Educator, Parent
- Lyndsi Holmes-Wickert, MS Ed, Adult with Spina Bifida
- Margaret Smith, MS Ed, Special Education Teacher
- Karen Wentworth, CRC, Executive Director SBANENY

For additional information or questions, please contact Spina Bifida Association of Northeastern New York.

123 Saratoga Road, Scotia, NY 12302 • t 518-399-9151 • f 518-399-5639
f /SBANENY • website: sbaneny.org

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

TABLE OF CONTENTS

What is Spina Bifida?	1 - 2
Continence Management in Schools	3 - 4
The Goals of Bowel Management	5
Hydrocephalus & Shunts	6 - 7
Orthopedics	8
Natural Rubber Latex Allergy	9 - 10
List of Latex in the Home & Community	11
Social Development	12 - 13
Adapted Physical Education	14
Educational Issues for Children with Spina Bifida	15 - 18
Additional Resources	19 - 20
Tell Us About Your Child (Parents)	21
Tell Us About Yourself (Student)	22
Notepad	23

What is Spina Bifida?

What is Spina Bifida?

Spina Bifida literally means “split spine.” Spina Bifida happens when a baby is in the womb and the spinal column does not close all the way. Every day, about eight babies born in the United States have Spina Bifida or a similar condition of the brain and spine.

What causes Spina Bifida?

No one knows for sure. Scientists believe that genetic and environmental factors act together to cause the condition.

What are the different types of Spina Bifida?

Occult Spinal Dysraphism (OSD)

Infants with this have a dimple in their lower back. Because most babies with dimples do not have OSD, a doctor has to check using special tools and tests to be sure. Other signs are red marks, hyperpigmented patches on the back, tufts of hair or small lumps. In OSD, the spinal cord may not grow the right way and can cause problems as a child grows up. Infants who might have OSD should be seen by a doctor, who will recommend tests.

Spina Bifida Occulta (SBO)

It is often called “hidden Spina Bifida” because about 15 percent of people have it and do not know it. Spina Bifida Occulta usually does not cause harm, and there are no visible signs. The spinal cord and nerves are usually fine. People find out they have it after having an X-ray of their back. It is considered an incidental finding because the X-ray is normally done for other reasons. However, in a small group of people with SBO, pain and neurological symptoms may occur. Tethered cord can be an insidious complication that requires investigation by a neurosurgeon.

Meningocele

A meningocele causes part of the spinal cord to come through the spine like a sac that is pushed out. Nerve fluid is in the sac, and there is usually no nerve damage. Individuals with this condition may have minor disabilities.

Myelomeningocele (Meningomyelocele), also called Spina Bifida Cystica

This is the most severe form of Spina Bifida. It happens when part of the spinal cord and nerves come through the open part of the spine. It causes nerve damage and other disabilities. Seventy to ninety percent of children with this condition also have too much fluid on their brains. This happens because fluid that protects the brain and spinal cord is unable to drain as it should. The fluid builds up causing pressure and swelling. Without treatment, a person’s head grows too big, and he/she may have brain damage. Children who do not have Spina Bifida can also have this problem, so parents need to check with a doctor.

How is Spina Bifida treated?

A child with Meningomyelocele usually is operated on within two or three days of birth. This prevents infections and helps save the spinal cord from more damage.

A child with Meningocele usually has it treated with surgery and, more often than not, the child is not paralyzed. Most children with this condition grow up fine, but they should be checked out by a doctor because they could have other serious problems, too.

What can you do to prevent Spina Bifida?

Women who are old enough to have babies should take folic acid before and during the first three months of pregnancy. Because half of pregnancies in the United States are unplanned, the Spina Bifida

Association asks women to take a vitamin with 400 mcg (0.4 mg) of folic acid each day during the years of their lives when they are possibly able to have children.

Women who have a child or sibling with Spina Bifida, have had an affected pregnancy, or have Spina Bifida themselves should take 4000 mcg (4.0 mg) of folic acid for one to three months before and during the first three months of pregnancy.

What is folic acid?

Folic acid is a vitamin that the body needs to grow and be healthy. It is found in many foods, but the man-made or synthetic form in pills is actually better absorbed by our bodies.

What conditions are associated with Spina Bifida?

Children and young adults with Spina Bifida may have problems with walking and getting around or going to the bathroom, latex allergy, obesity, skin breakdown, gastrointestinal disorders, learning disorders, depression, tendonitis and sexual issues. They also can have emotional and social problems.

What physical limitations exist?

People with Spina Bifida must learn how to get around independently by using things like crutches, braces or wheelchairs. With help, it is also possible for children to learn how to go to the bathroom on their own. Doctors, nurses, teachers and parents should know what a child can and cannot do so they can help him/her (within the limits of safety and health) be independent, play with kids that are not disabled and to take care of themselves.

Can Spina Bifida be detected before birth?

Yes. There are three tests.*

- 1) A blood test during the 16th and 18th weeks of pregnancy. This is called the alpha-fetoprotein (AFP) screening test. Abnormal results occur in about 75-80% of women who have a fetus with Spina Bifida. AFP

testing is not the most reliable form of detection, and is not frequently done anymore.

- 2) An ultrasound of the fetus. This is also called a sonogram and can show signs of Spina Bifida such as the open spine. This is the way that most Spina Bifida pregnancies are detected.
- 3) A test where a small amount of fluid from the womb is taken through a thin needle. This is called maternal amniocentesis and can be used to look at protein levels.

*Parents should know that no medical test is perfect, and these tests are not always right.

Can children with Spina Bifida grow up and live full lives?

Yes. With help, children with Spina Bifida can lead full lives. Most do well in school, and many play in sports. Because of today's medicine, about 90 percent of babies born with Spina Bifida now live to be adults, about 80 percent have normal intelligence and about 75 percent play sports and do other fun activities.

How is Spina Bifida managed?

As type and level of severity differ among people with Spina Bifida, each person with this condition faces different challenges and may require different treatments. Of educational consideration, all of these treatments may affect the student both during and after the school day.

The best way to manage Spina Bifida is with a team approach. Members of the team may include neurosurgeons, urologists, orthopedists, gastroenterologists, physical and occupational therapists, speech/language therapists, orthotists, psychologists and social workers.

Contributing Editor
Gregory S. Liptak, MD, MPH

Continence Management in Schools

What is a neurogenic bowel and bladder?

The nerves at or below the level of the lesion (usually near the base of the spine) may not function normally in people with Spina Bifida. The damaged nerves cause varying degrees of paralysis (neuromuscular weakness) and decreased sensation. This means most children with Spina Bifida have problems with lower body function which includes mobility.

The connections between the brain, spinal cord, bladder and bowel do not correctly send messages. Therefore, sensation and voluntary emptying of bowel and bladder are not always possible. This is called a “neurogenic” or “neuropathic” bladder or bowel. Urinary and bowel control in children and adolescents are important for short and long term health and also in the development of independence. Therefore, bowel and bladder continence is a central focus for children with Spina Bifida.

A neurogenic bladder either does not empty completely, causing urine to “back up” into the kidneys (which can cause permanent damage over time), or it leaks continuously (incontinence).

Furthermore, children with neurogenic bladder may have frequent urinary tract infections.

Clean Intermittent Catheterization (CIC)

This is the primary method to prevent problems and give the child social continence. In CIC, a small flexible tube is inserted into the bladder to drain the urine. It is a simple, quick procedure that takes no longer than it takes to urinate normally. Some children are not able to perform self-catheterization through the urethra. In such cases, the child may have catheterizable “stoma” (surgical opening) in the belly button or side of the

abdomen. This option makes it possible for many young children and teens to handle catheterization independently. If this is not already achieved before entering school, then learning self-catheterization should be included in the child’s IEP. The need for assistance should decrease with age.

CIC is done every day, and as often as the child’s doctor recommends, which is typically every three to four hours.

Also CIC:

- Helps to avoid urinary tract infection (UTI)
- Helps to avoid serious bladder and kidney damage
- Is necessary to become (socially) continent
- Has to be combined with bowel training if there is constipation

Care and Storage of Catheters:

Unless otherwise stated by parents or physician, CIC is done with clean washed hands. Gloves are not necessary. Some catheters can be easily disposed of, but some need to be washed out and laid out on a paper towel to dry. In such cases, public bathrooms would not be an acceptable place to leave them. The nurse’s office may be most appropriate.

Bowel Management

(Managing Incontinence & Constipation)

Because most children with Spina Bifida also experience difficulty controlling bowel movements, a bowel management program may be necessary for both health and social acceptance. As children grow older, bowel continence offers an enormous increase in successful social development and self-esteem, which impacts overall success in school.

Bowel management in school may include:

- Recognizing and reporting bowel accidents or soiled clothing
- Removing or replacing clothing
- Inserting suppositories
- Assembling supplies
- Cleaning up supplies and restroom
- Participating in bowel washouts or increasing personal responsibility for bowel program
- Communicating with school nurse or trusted employee or friend

Constipation for those with Spina Bifida is a life-long medical issue that cannot be cured. Children do not outgrow it. This means that children with

Spina Bifida have problems with lower body function, which includes mobility, bowels, and bladder.

ADDITIONAL RESOURCE

“Bowel Management and Spina Bifida.”

Complimentary copies are available through Spina Bifida Association of NENY for families & school personnel.

The Goals of Bowel Management

A key goal of bowel management is to give the child good social continence, especially during school hours. Collaboration between home and school is essential for good social adjustment.

Although bowel management may seem overwhelming at first, it will soon become part of the daily routine. Children accomplish this skill at varying times due to differences in level of paralysis, balance, fine motor control, body shape, and cognitive development.

The bowel management goals are:

- To prevent constipation and achieve continence
- To empty bowels at an appropriate time and place, and to prevent having accidents
- To remain clean between toileting times
- To avoid serious problems caused by poor management

Soiling will occur, and is often a sign of fecal impaction called overflow incontinence. This is not a behavioral issue. It is a medical problem that

should be addressed with the child's care team. Bowel and bladder management are inseparable and each affects the success of the other.

How is bowel incontinence managed?

- Even in the absence of sensation, sitting on a toilet and pushing is often helpful
- A balanced diet (high in fiber and fluid)
- Exercise if possible to keep the stool at the right consistency
- Medication (softeners & laxatives) or suppositories
- Regular lengthy bowel washouts that are usually able to be completed at home
- Routine is vital for successful bowel management

ADDITIONAL RESOURCE

"Bowel Management and Spina Bifida."
Complimentary copies are available through Spina Bifida Association of NENY for families & school personnel.

Hydrocephalus & Shunts

Most people with Spina Bifida also have hydrocephalus. Hydrocephalus means there is a build-up of cerebral spinal fluid (CSF) around the brain. Like a bathtub with the water on and a partially clogged drain, this CSF on the brain cannot drain fast enough. This CSF is made by brain cells to protect the brain and spinal cord. When there is too much CSF it can be dangerous.

Most of the time, it is easy for doctors to see that there is too much CSF on the brain by using imaging techniques to measure the CSF-filled pockets, or cavities, called ventricles. The ventricles of the brain get too big when there is too much CSF. The CSF must be drained regularly in order to prevent too much pressure on the brain. The most common treatment for hydrocephalus is to insert a tube, called a shunt, to drain excess CSF from the head to another space so the body can remove it naturally.

Shunt Problems

The most common problem with shunts is that they can get blocked up, break, or come apart. The signs of shunt problems in people with Spina Bifida are different for each person. This can make it hard for families and health care providers to know what's going on. The most common sign of a shunt problem is headache. Vomiting and nausea can happen too, but not always.

Less common signs of a shunt problem include:

- Seizures (either the onset of new seizures or an increase in the frequency of existing seizures)
- A significant change in intellect, personality, or school performance
- Back pain at the Spina Bifida closure site
- Worsening arm or leg function (increasing loss of sensation, weakness, worsening coordination or balance, worsening orthopedic deformities)
- Increasing scoliosis
- Worsening speech or swallowing difficulties
- Changes in bowel or bladder function

Infections

Infection is a major problem that can happen with shunt operation. Infections are commonly treated with antibiotics and with surgical removal and replacement of the shunt system.

Signs and symptoms of an infection include:

- Fever
- Neck stiffness
- Pain
- Redness
- Drainage tenderness from the shunt incisions or tract

Making Decisions

The opinion of a health care provider is very important when working with someone with Spina Bifida and shunted hydrocephalus.

When making decisions, things to consider are:

- Complaints of abdominal pains
- Pay attention to a parent's gut feeling about shunt problems. These feelings are usually right.
- Be aware that shunt problems can cause many symptoms that may not be obviously shunt related.
- Be on the lookout for shunt problems, and when the child shows behavioral or physical changes, contact the parents, guardian or physician.

Physical Activity & Hydrocephalus

Children with hydrocephalus are encouraged to live and play normally with other children their developmental age. Therefore, sports, swimming and most other activities are allowed unless a physician states otherwise.

Tips for safe play with a shunt:

- Avoid putting the child in an upside down position because shunts drain best with gravity and head up positioning
- Protect the child's neck with safety equipment
- Shunt tubing goes down the side of the head and neck, just under the skin. Try to prevent damage to the tubing through rough play, and discourage activities that are likely to injure the head or neck

ADDITIONAL RESOURCES

A Teacher's Guide to Hydrocephalus. Booklet available through Hydrocephalus Association at this link:

http://www.hydroassoc.org/docs/A_Teachers_Guide_to_Hydrocephalus.pdf.

Children's picture book about hospitalizations:

Lutkenhoff, Marlene, and Teresa Rodgerson. *Detour Ahead*. Washington, D.C.: Spina Bifida Association of America, 2008. Print.

Orthopedics

Most children with Spina Bifida have orthopedic problems such as clubfoot, dislocated hip(s), spinal curvatures, and contractures (tightness) of the knee, hip, and/or ankle which will further impact their ability to walk. Growth during the school years accounts for many orthopedic complications that may develop such as curvature of the spine and spinal cord problems which can cause neurological complications. Contractures of the hip, knee and ankle may occur. As children with Spina Bifida grow and body proportion changes, it becomes more physically demanding to walk.

Although many children may begin school walking with a walker or crutches, many older children elect to use a wheelchair as their primary way of getting around the school. This frees their hands, reduces energy expenditure, and allows them to keep pace with their friends. For those children, choosing a lightweight, maneuverable chair makes it easier to keep up a normal school routine including wheelchair sports and aerobic cycling.

Exceptions:

- Students with a ventricular shunt should not participate in activities where they are upside down because the shunt may not work in that position.
- These students are at high risk of head or neck injury.

The orthopedist on a child's health care team will monitor the child with periodic examinations and x-rays. Along with the physical therapist, the orthopedist will decide what kinds of surgeries, equipment or braces the child may require as he/she grows.

Because children with Spina Bifida may not feel parts of their lower body, injuries including fractures may occur. Furthermore, it should be expected that children and teens with Spina Bifida will require orthopedic surgeries on the spine and lower limbs. In such cases, they might miss weeks or even months of school due to hospitalization and recovery time. However, normal participation in physical activities should not be discouraged out of a sense of protection or fear of injury. As noted earlier, students with a ventricular shunt should not participate in activities where they are upside down or at high risk of head or neck injury.

ADDITIONAL RESOURCES

Hip Function & Ambulation Health Information Sheet, *Spina Bifida and the Spine*, available at spinabifidaassociation.org

Natural Rubber Latex Allergy

People with Spina Bifida are at high risk for latex allergy.

What is natural rubber latex?

Natural rubber latex (NRL) is a milky substance tapped from the *Hevea Brasiliensis* (a tropical rubber tree). It can be heated and molded into hard rubber products like tires, or it can be dipped to make softer products like balloons or medical examination gloves.

Latex allergy means that a person is allergic to proteins in the natural rubber latex. Although anyone can develop a latex allergy, it is thought to be caused by significant long term exposure to latex proteins that are released during processing of the rubber.

The amount of latex exposure needed to produce sensitization or an allergic reaction is unknown, but softer rubber dipped products that have been processed longer (like gloves and balloons) are seen as more allergenic and frequent exposure to latex products increases the risk of developing the sensitivity.

People who have Spina Bifida and catheterize, or have had several surgeries from very early life, such as bladder surgery or shunt revisions, are at very high risk for latex allergy because of a “cumulative” effect over time. Symptoms of latex sensitivity can be minor but, without warning, may become life threatening. Many people are unaware that they are sensitized to latex because the

symptoms can be vague and non-specific. Those people are at risk for a serious reaction.

What are the symptoms of latex allergy?

- Itching
- Skin redness, hives or rash
- Sneezing
- Runny nose
- Itchy, watery eyes
- Scratchy throat (hoarse throat)
- Cough
- Wheezing/shortness of breath

The most serious reaction to latex is anaphylaxis, a type of shock. An anaphylactic response to latex is a medical emergency. Signs and symptoms include:

- Difficulty breathing caused by swelling of lips, tongue or windpipe
- Severe wheezing
- Severe drop in blood pressure (hypotension)
- Dizziness
- Loss of consciousness
- Confusion
- Slurred speech
- Rapid or weak pulse
- Blue hue of the skin, including lips and nail beds
- Diarrhea
- Nausea and vomiting

Latex Items

Because of its low cost, durability and versatility, natural latex has been widely used in the United States for over a century and is used in the production of many common items. Although most medical items are labeled, household or recreational items which contain latex may not be labeled. For that reason, the American Latex Allergy Association and the Spina Bifida Association work diligently to keep a current list of products that contain latex, and their “safe” (non-latex) alternatives. (See page 11.)

What are cross reactions to latex allergy?

People allergic to latex may also be allergic to the proteins in some fruits and vegetables. Some of them include: banana, avocado, chestnut, kiwi, apple, carrot, celery, papaya, potato, tomato and melon. Due to nutritional risks, people should not avoid eating these foods unless they have had a reaction to them and are advised by a dietary or medical professional to avoid them.

What steps should I take to prevent latex allergy?

The best way to prevent developing latex allergy is to avoid contact with latex or latex contaminated powder. Contact occurs through contact with skin, inhaling latex proteins, or internally through

medical procedures or surgery, when latex touches the skin, mouth, eyes, genital areas or bladder. Severe reactions can occur if latex enters in the bloodstream. Powder from latex balloons or gloves gets into the air. People with Spina Bifida are at high risk for latex allergy and should avoid exposure to natural latex products from birth. Products made of silicone, plastic, nitrile or vinyl can be used instead.

Those Who Have Had a Serious Reaction to Latex Should:

- Wear a medic-alert bracelet or necklace
- Carry two auto-injectable epinephrine devices
- Carry sterile non-latex gloves and other non-latex medical items for emergencies
- Discuss latex allergy avoidance and develop an Action Plan with health care providers, schools, day care, camps, visitors and anyone else who are involved with the person who has Spina Bifida.

ADDITIONAL RESOURCES

www.aaaai.org

www.latexallergyresources.org

www.osha.gov/SLTC/latexallergy

NOTE: The following chart provides a guide to some of the most common objects containing latex and offers some alternatives. It is not meant to be a comprehensive listing. ALWAYS CHECK THE PRODUCT’S PACKAGING. If in doubt regarding the safety of an item, call the manufacturer.

LATEX IN THE HOME & COMMUNITY

Frequently contains LATEX	LATEX-Safe Alternatives
School/Office/Art supplies: paints, glue, erasers, fabric paints, grips for writing utensils, duct tape. Laboratory supplies (e.g. gloves, Bunsen burner tubing)	Elmers (School Glue, Glue-All, GluColors, Carpenters Wood Glue, Sno-Drift paste) FaberCastel erasers, Crayola (except stamps, erasers), Liquitex paints, DickBlick tempera, acrylic paints and soap erasers, Play-Doh, Pro-Craft, Clic Eraser, Pentel erasers, pens, and pencils, 3M Post-it Notes, Staedtler Mars Plastic Eraser
Balloons	Mylar balloons, self-sealing Myloons, Mister Balloon
Balls: Koosh balls, tennis balls, bowling balls, ball pits	PVC (Hedstrom Sports Ball), Nerd Foam Balls, Gertie Balls, Googlie Imperial Toys
Carpet backing, gym floor, gym mats	Broadloom carpets contain no NRL. For other products, provide barrier cloth or mat
Chewing gum	Bubblicious, Trident (Warner-Lambert), Wrigley gums (check new products), Bazooka gum, Bubble Yum, Ice Breakers gum
Clothes: liquid appliques on tee-shirts, elastic on socks, underwear, sneakers, sandals	Cloth-covered elastic, neoprene (Decent Exposures, NOLATEX Industries), Buster Brown elastic-free socks (Vermont Country Store)
Condoms, contraceptive sponges, diaphragm	Polyurethane (Avanti), female condom (Reality) Wideseal Silicone Diaphragms (Milex), Trojan Supra Condom, FemCaps
Costumes: masks, face paint, nail polish, etc.	Check all products
CPR mannequins and medical training aids	Most Laerdal products
Crutches: tips, axillary pads, hand grips	Cover with cloth or tape
Dental dams, cups bands, root canal material, orthodontic rubber bands	PURO/M27 intraoral elastics (Midwest Orthodontic), wire springs, sealant (Delton) dams (Meer Dental, Hygenic Corp), John O Bulter, Earloop masks (Richmond)
Diapers, incontinence pads, rubber pants	Huggies, First Quality, Gold Seal, Tranquility, Always, some Attends, Drypers Diapers (not training pants), Confidence (Paper-Pak), Pampers, Luvs, Seventh Generation Diapers
Feeding nipples	Silicone, vinyl (selected Gerber, Evenflo, MAM, Ross, Mead Johnson)
Food handled with latex gloves, chopsticks	Synthetic gloves for food handling
Handles on racquets, tools, bicycles	Vinyl, leather handles or cover with cloth or tape
Kitchen cleaning gloves	PVC MYPLEX (Magla), cotton liners (Allerderm)
Mattress/pressure relief	Check each one for latex content
Miscellaneous items	Some medical stickers by MediBadge, UAL, CushieTushiePotty Seat, Bumbo Seat
Newsprint, ads, coupons, lottery scratch tickets	None
Pacifiers	Soothies (Children's Med Ventures) selected Binky, Gerber, Infa, Kip, MAM
Paints, sealants, stains, etc.	There is NO NATURAL RUBBER in latex paint, though it may be present in some waterproof paints and sealants
Play pits, playground surfaces, playground equipment (e.g. large rubber balls) Toys brought by other children into the classroom	Natural rubber latex maybe a component of surfaces, Boundless Playgrounds
Rubber bands, bungee cords	Plasti bands
Toothbrushes/infant massager	Soft bristle brush or cloth, Gerber/NUK, all Oral B products
Toys: Stretch Armstrong, old Barbies	Jurassic Park figures (Kenner), 1993 Barbie, Disney dolls (Mattel), many toys by Fisher Price, Little Tikes, Playschool, Discovery, Trolls (Norfin), Silly-putty
Water toys and equipment; beach thongs, masks, bathing suits, caps, scuba gear, goggles	PVC, plastic, nylon, Suits Me Swimwear
Wheelchair cushions	Jay, ROHO cushions, Sof Care bed/chair cushions (Gaymar)
People who have allergic reactions to latex may also have food allergies, including: bananas, tomatoes, potatoes, avocados, and kiwi fruit	

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

Social Development

Social development for all people begins at birth and continues throughout life. School years provide a tremendous and vital opportunity to develop qualities and skills that promote social progress. During these important years, children learn to interact in a broadening arena of school and community activities. Each child's temperament will affect his/her social development. The specific ways that Spina Bifida and hydrocephalus influence social development are not yet fully understood. However, research shows that children with Spina Bifida may have difficulty with executive functioning and may not pick up on social cues. School interactions are a vital and often challenging part of the growing process. Similar to children without disabilities, some children with Spina Bifida are passive and may require encouragement to get involved in activities. Others may need guidance and help to interact at an age appropriate level in group settings.

Encouraging social skill development:

- Talk appropriately to the child.
- Give the child feedback and positive messages.
- Seek opportunities for participation in structured activities including extracurricular programs.
- Involve the child in mainstreamed education as much as possible.
- Foster independence and self-advocacy.
- Be aware of what the child knows about himself/herself (self-identity) and what he/she may or may not want others to know.
- Expect the child to take responsibility and be accountable.

- Offer opportunities for success and failure as a normal part of life experiences and to learn how to deal with frustrations that may occur.
- Encourage "authentic" (meaningful) friendships.
- Be aware of potential bullying due to differences.
- Give the child the same courtesy that you give all of the children in the classroom, especially as it relates to self-care skills such as bathrooming.
- Offer opportunities for the child to "give back" by volunteering or participating in community activities.
- Have frequent, open, honest communications between the student, the school and parents.
- Always be mindful of confidentiality.

Factors that challenge social skill development

- Frequent illness and/or hospitalizations, surgeries
- Fatigue
- Learning problems
- Difficulty understanding social interactions
- Limited mobility
- Restrictive environments due to either inaccessible areas or over-protectiveness
- Continence/hygiene issues
- Transitioning into new schools or classrooms
- Being shunned, self-imposed feelings of being an outsider, too much time alone
- Difficulty with problem solving or using good judgement

- Putting the child or teen in situations that increase his/her risk for injury, exploitation or abuse

ADDITIONAL RESOURCES

Greenspan, Stanley I., Serena Wieder, and Robin Simons. *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*. Reading, MA: Addison-Wesley, 1998. Print.

Lavoie, Richard D. *It's so Much Work to Be Your Friend: Helping the Child with Learning Disabilities Find Social Success*. New York: Simon & Schuster, 2005. Print.

Teaching Your Child the Language of Social Success. N.p.: Paw Prints, 2011. Print.

Thomas, Pat, and Lesley Harker. *Don't Call Me Special: A First Look at Disability*. New York: Barron's, 2002. Print.

Tell Us About Your Child (Parents)/ Tell Us About Yourself. See Pages 21 & 22 of this Toolkit.

Adapted Physical Education (APE)

Physical activity is necessary for social and physical development, but the functional level (orthopedic, neuromuscular, social, and cognitive) of a child with Spina Bifida varies according to the level and severity of the nerve damage, presence of hydrocephalus and other associated secondary conditions.

There is no specific physical education plan for a student with Spina Bifida. Things that should be given consideration include:

- Conditions involving the hips, knees, feet, and scoliosis may limit safe participation and require bracing (AFO's, KFO's), crutches for ambulation, a wheelchair or a walker.
- Hydrocephalus requiring a ventricular shunt occurs in most students with the severe form of Spina Bifida (myelomeningocele). The shunt is used to remove excessive cerebrospinal fluid from the head and prevent brain damage. Children with hydrocephalus should be included in normal activities but avoid those which could cause head or neck injury, and impede proper shunt function, such as neck twisting or hanging upside down for extended periods.
- Bowel and bladder accidents may occur during physical activity. Children with Spina Bifida should be permitted to use the bathroom for catheterization, bowel management or to change soiled clothing as needed.
- Abdominal, orthopedic or neurological surgeries are common in children with Spina Bifida. Post-operative orders should be followed until the child is healthy enough for full participation.
- Avoid using latex products in the physical education environment. (Refer to latex list in

schools, courtesy of Latex Allergy Association of America). (See page 11.)

- When planning physical education activities, consider that children with Spina Bifida may have hand-eye limitations and slower response times.
- As with all children, cognitive function varies in children with Spina Bifida. This may affect the student's attention span, ability to compete or self-advocate, developmental stage in relation to chronological age, ability to follow instructions and understand rules, use of equipment and being safe in the physical environment. All of these should be given consideration.

With awareness and thoughtful planning, the APE environment can be safely and creatively modified to suit the needs of the student with special needs.

ADDITIONAL RESOURCES

Physical Activities for Young People with Severe Disabilities (Canales & Lytle, 2011)

www.pecentral.org/adaptedphysed

Educational Issues for Students with Spina Bifida

First and foremost, students with Spina Bifida must have a safe school environment. They will need to have safe access and egress from their school and within their school. Also, of immediate importance, the school personnel need to be aware of the students with Spina Bifida very high likelihood of being latex allergic. The school should avoid using latex products whenever possible. It is also important for the student to understand their allergy and learn to advocate for themselves when latex is present. (See pages 9 through 11 regarding latex allergies.)

Accessibility issues:

Building level:

****A fire/emergency evacuation plan which should be shared with the local fire department**

- Ramps inside and outside of the school
- An elevator in a multi-level building with access for the student
- Wide doorways
- An accessible bathroom with grab bars
- Accessible drinking fountain
- Classrooms with enough space to accommodate a student's wheelchair (including turning space) and other equipment, and a one to one aide when needed
- An accessible locker
- Accessible general areas (i.e., gym, cafeteria, auditorium)
- Desks and tables high enough to accommodate a wheelchair in each of the student's classrooms
- Private location for catheterization and other necessary personal care (nurse)
- Extracurricular activities held in accessible part of building
- Temperature controlled classrooms, as needed
- Temperature controlled transportation, as needed

Students with Spina Bifida are able to understand material presented in the classroom, however, their processing speed is often an issue for them. This is seen more frequently when the student has hydrocephalous.

Note: IT IS VERY IMPORTANT TO BE ON THE LOOKOUT FOR SIGNS OF SHUNT FAILURE AND TO SEEK IMMEDIATE MEDICAL CARE. See pages 6 and 7 regarding hydrocephalus and shunt problems.)

Some students with Spina Bifida exhibit memory difficulties, requiring re-teaching to reinforce the content of the material. Making associations will help the students to retain information presented.

Students with Spina Bifida often have a strength with language based academics, such as history, ELA, and even the sciences which are language driven, such as Biology, as opposed to Physics and Earth Science which necessitate spatial relationship concepts. Even with that said, however, attention must be given to the students' actual comprehension of material in these classes, and to their ability to apply the learned material.

As briefly mentioned above, academics which include spatial relationships can be more challenging for students with Spina Bifida. Math is also an area of struggle, possibly due to the students' difficulty with spatial relationships, though this is not a certain cause. Math procedures, retrieval, and sequencing difficulties can cause many students with Spina Bifida to struggle in this area.

Certain class accommodations or modifications are needed to help **many students with Spina Bifida to succeed**. Students will not need all of these accommodations, but here is a list of accommodations which can assist in student success.

(Accommodations are teaching supports that are used when the student is participating in the same

course work as their general education peers. Accommodations do not change expectations to the curriculum grade levels. Modifications refer to changes made to the curriculum to meet the needs of the student, such as lower grade level materials and different expectations in grading.)

Classroom Accommodations:

- Extended time to complete assignments
- Preferential seating
- Copy of class notes
- Check for understanding
- Outlines, graphic organizers to assist in predictions and summarizing
- Lessons taught using auditory, visual and kinesthetic modalities
- Calculator
- Use of a laptop
- Allowance to use e-mail to submit completed assignments to teacher
- Chunking of material into smaller sections
- Re-phrase, simplify directions
- Allow student to use assistive technology for written work such as speech-to-text and text-to-speech software as needed
- Flexibility with homework assignments (to allow time for outpatient therapy, home therapy, self-care activities)
- Modified work load
- Assistance with getting materials (i.e., Laptop) in and out of backpack or bag –Possibly a one to one aide; peer helper
- Preferential seating near door as well as electrical outlets
- Breaks when needed

Program Accommodations:

- Adaptive physical education (See page 14 on this topic.)
- Buddy-system for assistance with materials, cafeteria use, opening doors, etc.
- Homework assignment notebook to help with assignment retention
- Visual daily schedule

Testing Accommodations:

Some students may need:

- Extended time
- Tests read in a separate location to minimize distractions
- Calculator
- Alternate mode of response – dictation, oral response

These accommodations should be available on classroom assessments, standardized tests, college placement tests and in college, as needed and permitted.

There should be an opportunity for staff in-services about the student's disability prior to the student's school attendance.

Materials to Consider:

- Extra set of books to keep at home
- Recorded books
- Assistive technology equipment, such as computer, iPad, page turner, speech-to-text and text-to-speech software/devices
- Portable fan
- Water bottle

An assistive technology assessment should be considered for any student who has upper extremity weakness or limitations. Staff should be then trained in the assistive technology provided to the student.

Scheduling Accommodations:

- Allow students to leave classes early to travel to their next class, which will allow them sufficient time and the ability to move through the halls when they are less crowded
- Provide time in their schedule for catheterization and bowel management (See page 3 - 5 on this topic.)
- Prolonged time might be required for self-care during after school hours.
- Understand that numerous absences may occur due to doctor's appointments and surgeries.

Finally, it is important to note that, just like any other student, each child with Spina Bifida is unique. There is no specific accommodation or setting that fits every student. Children with Spina Bifida want to make friends like their peers and to feel that they fit in, even though they might have some needs that are different than their fellow students. Please be sensitive to this and encourage positive peer relationships. It is also very important to communicate often with parents and to learn from them, as they usually know their children's strengths, challenges, and needs better than anyone. As with any student, a positive relationship between home and school will help students with Spina Bifida have a successful, enjoyable school experience!

ADDITIONAL RESOURCES:

Guare, Richard, Peg Dawson, and Colin Guare. *Smart but Scattered Teens: The "Executive Skills" Program for Helping Teens Reach Their Potential*. New York: Guilford, 2013. Print.

Cooper-Kahn, Joyce, and Laurie C. Dietzel. *Late, Lost and Unprepared: A Parents' Guide to Helping Children with Executive Functioning*. Bethesda: Woodbine House, 2008. Print.

Contributing Editors:

Helen Eggenberger & Hali Holmes. For further information contact Spina Bifida Association of NENY at 518-399-9151, admin@sbaneny.org.



THE JEFFRAS' PROGRAM THAT PROMOTES
A HEALTHY SCHOOL ENVIRONMENT
FOR STUDENTS WITH SPINA BIFIDA

QUICK REFERENCE GUIDE FOR EDUCATORS OF THOSE WITH SPINA BIFIDA

Summary	Preschool / Early Elementary School	Later Elementary School	Middle School / High School	College / Young Adulthood
Reading				
<p>While sight word reading and decoding can be a problem, they are often much better developed than reading comprehension skills.</p> <p>Isolated reading disability (achievement <25th percentile) in children with Spina Bifida is rare (~3%), while patterns of combined reading/math disabilities are common (26%)</p>	<p>Letter knowledge, sight word reading, and pseudoword decoding are often areas of relative strength in children with Spina Bifida. These strengths in basic reading often mask the emergence of reading comprehension difficulties at later ages.</p>	<p>Sight word reading and decoding remain relative strengths for children with Spina Bifida during elementary school, but difficulties in reading comprehension often become increasingly apparent with grade.</p> <p>Reading comprehension skills are typically strongest at the sentence level, but can be quickly overwhelmed by the integrative demands of reading paragraphs and longer texts.</p>	<p>Word reading strengths typically persist in later grades. Reading comprehension difficulties, however, remain common when youth with Spina Bifida are required to construct meaning, integrate information, and draw inferences from paragraphs and longer texts.</p>	<p>Reading comprehension often remains less developed than word reading accuracy in many adults with Spina Bifida. Problems with inferential comprehension may persist.</p> <p>Functional reading skills are often adequate for daily adult life. Stronger reading and math skills are associated with a broader range of life experiences in adulthood for individuals with Spina Bifida.</p>
Math				
<p>Math disability is a common area of lifetime difficulty in Spina Bifida.</p> <p>Estimates suggest that 29% of children with SB have an isolated math learning disability (achievement <25th percentile), and an additional 26% have math and reading disabilities (2).</p> <p>Math disability in Spina Bifida can be identified at an early age.</p>	<p>One-to-one counting correspondence, rote counting, and matching-based-on-quantity are common areas of early math difficulty. Preschool screening of these skills is a useful way to identify children with Spina Bifida at risk for math disability who may require intervention.</p>	<p>Math fact retrieval is often intact in youth with Spina Bifida, but may be performed more slowly (6) or performed using less-mature counting strategies (e.g., finger counting, "counting up").</p> <p>Math procedures (e.g., "borrowing from zero" during subtraction) can be areas of difficulty, and may result from periodic attentional "slips" and/or from an overt lack of procedural math knowledge (6).</p>	<p>Math becomes increasingly complex in higher grades, and topics such as geometry and estimation place increased demands upon common areas of cognitive weakness in Spina Bifida, e.g., working memory, executive functions, mental manipulation of visual / spatial information.</p>	<p>Difficulties in computation accuracy, speed, math problem solving, and functional numeracy can persist, and can interfere with "real world" functional skills such as price comparisons, value of coins, banking and budgeting, and time concepts.</p> <p>To a greater extent than functional literacy, functional math skills are related to self-reported levels of social and personal autonomy in Spina Bifida.</p>
Executive Functions				
<p>ADHD in youth with Spina Bifida falls at around 30%, with inattentive type most frequently noted.</p> <p>Many youth with Spina Bifida struggle with task initiation, planning, and organization.</p>	<p>Children with Spina Bifida often respond well to the routine of early classroom structures, including "built-in" prompts and step-by-step directions.</p>	<p>The transition into third and fourth grades (e.g., "reading to learn" instead of "learning to read") places additional organizational demands upon children with SB, and this change in expectations often "unmasks" underlying difficulties in executive functions.</p>	<p>Transition into middle school puts added organizational demands upon youth with Spina Bifida, and often includes extra tasks (e.g., catheterization) they must "remember to remember" to complete.</p>	<p>Executive functioning difficulties appear to persist into young adulthood in many individuals with Spina Bifida, and should be actively accounted for in the process of transition into college or work settings.</p>
Processing				
<p>Strength is often seen in the ability to form associations (e.g., associative processing) such as forming associations between words and their definitions). Weaknesses often occur in the ability to integrate information (e.g., assembled processing).</p>	<p>Strengths in forming associations often support the development of good functional language skills, categorical knowledge, and age-appropriate word reading abilities in children with Spina Bifida.</p>	<p>In early adolescence, youth with Spina Bifida often find it increasingly difficult to comprehend complex oral and written language. This is most evident when oral or written communication requires the active construction of meaning and the integration of multiple sources of information, e.g., word definitions, past experiences, social context, etc.</p>	<p>Difficulty integrating information can disrupt social competence, particularly if the adolescent with Spina Bifida has trouble using past and current social experiences to assess how well he or she is being received by others.</p>	<p>While young adults with Spina Bifida often report high quality of life, many also report social participation restrictions, unemployment, and difficulty moving into more independent living arrangements. For these reasons, school-based efforts to address processing concerns and learning difficulties prior to young adulthood are essential.</p>

Additional Resources

Physical Activities for Young People with Severe Disabilities (Canales & Lytle, 2011)

www.pecentral.org/adaptedphysed

Executive Functioning & Non Verbal Learning Disabilities

Hannaford, Carla. *Smart Moves: Why Learning Is Not All in Your Head*. Arlington, VA: Great Ocean, 1995. Print.

Moss, Samantha, and Lesley Schwartz. Martin. *Where's My Stuff?* San Francisco, CA: Zest, 2007. Print.

Guare, Richard, Peg Dawson, and Colin Guare. *Smart but Scattered Teens: The "Executive Skills" Program for Helping Teens Reach Their Potential*. New York: Guilford, 2013. Print.

Guare, Richard and Peg Dawson. *Executive Skills in Children & Adolescents*. New York: Guilford, 2010.

Hannaford, Carla. *Smart Moves: Why Learning Is Not All in Your Head*. Arlington, VA: Great Ocean, 1995. Print.

Thompson, Sue. *The Source for Nonverbal Learning Disorders*. IL: LinguSystems, 1997.

Health Topics

"Bowel Management and Spina Bifida." Complimentary copies are available through Spina Bifida Association of NENY for families & school personnel.

A Teacher's Guide to Hydrocephalus. Booklet available through Hydrocephalus Association at this link:

[http://www.hydroassoc.org/docs/A Teachers Guide to Hydrocephalus.pdf](http://www.hydroassoc.org/docs/A_Teachers_Guide_to_Hydrocephalus.pdf).

Hip Function & Ambulation Health Information Sheet, "Spina Bifida and the Spina."

Latex Allergies: www.aaaai.org, www.latexallergyresources.org, www.osha.gov/SLTC/latexallergy

Social Emotional

Lavoie, Richard D. *It's so Much Work to Be Your Friend: Helping the Child with Learning Disabilities Find Social Success*. New York: Simon & Schuster, 2005. Print.

Lutkenhoff, Marlene, and Teresa Rodgerson. *Detour Ahead*. Washington, D.C.: Spina Bifida Association of America, 2008. Print. (Children's picture book about hospitalizations.)

Greenspan, Stanley I., Serena Wieder, and Robin Simons. *The Child with Special Needs: Encouraging Intellectual and Emotional Growth*. Reading, MA: Addison-Wesley, 1998. Print.

Teaching Your Child the Language of Social Success. N.p.: Paw Prints, 2011. Print.

Thomas, Pat, and Lesley Harker. *Don't Call Me Special: A First Look at Disability*. New York: Barron's, 2002. Print.

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

Student Advocacy Handbook: For High School Juniors and Seniors Transitioning to College. New York: Team, 2007. Print.

Beyond School Into the Community: A Guide to Transition from School to College, Work & Community Living for Students with Disabilities in the Capital District. Capital Region BOCES. www.capregboces.org.

People First: Communicating with and about People with Disabilities. Published by NYS Department of Health.

Disability Etiquette: Tips on Interacting with People with Disabilities. United Spinal Association.

Tell Us About Your Child (Parents)/ Tell Us About Yourself. See Pages 20 & 21 of this Toolkit.

Parent Resources

Rubinstien, Marcia Brown. *Raising NLD Superstars: What Families with Nonverbal Learning Disabilities Need to Know about Nurturing Confident, Competent Kids.* London: Jessica Kingsley, 2005. Print.

Silver, Larry B. *The Misunderstood Child: Understanding and Coping with Your Child's Learning Disabilities.* New York: Three Rivers, 2006. Print.

Cooper-Kahn, Joyce, and Laurie C. Dietzel. *Late, Lost and Unprepared: A Parents' Guide to Helping Children with Executive Functioning.* Bethesda: Woodbine House, 2008. Print.

About Hydrocephalus: A Book for Parents. San Francisco: U of California, Departments of Neurological Surgery and Pediatrics, 1996. Print.

Teaching Your Child the Language of Social Success. N.p.: Paw Prints, 2011. Print.

Tanguay, Pamela B. *Nonverbal Learning Disabilities at Home: A Parent's Guide.* London: Jessica Kingsley Pub., 2001. Print.

Picture Books for Your Library Media Center

Bertrand, Diane Gonzales., Robert L. Sweetland, and Eida De La. Vega. *My Pal, Victor = Mi Amigo, Victor.* Green Bay, WI: Raven Tree, 2003. Print.

McMahon, Patricia, and John Godt. *Dancing Wheels.* Boston: Houghton Mifflin, 2000. Print.

Senisi, Ellen B. *All Kinds of Friends, Even Green!* Bethesda, MD: Woodbine House, 2002. Print.

Student Advocacy Handbook: For High School Juniors and Seniors Transitioning to College. New York: Team, 2007. Print.

Tanguay, Pamela B. *Nonverbal Learning Disabilities at Home: A Parent's Guide.* London: Jessica Kingsley Pub., 2001. Print.

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

Tell Us About Your Child- For the Parent

What are your child's strengths/challenges?

What can your child do independently?

What does your child need assistance with?

What social skills does your child have/need help with?

Are there any triggers for negative behaviors? Please describe.

What are your goals for your child?

What does the child know about his or her disability?

What are your child's specific medical concerns?

What else would you like us to know?

Tell Us About Yourself- for the Student

What do you like/dislike?

What do you know about your disability?

What do you like to do with friends?

What do you like about school?

What is challenging about school?

Tell us about your family.

What else do you want us to know?

Notepad



Promoting the prevention of Spina Bifida and enhancing the lives of all affected.

123 Saratoga Road, Scotia, NY 12302 • t 518-399-9151 • f 518-399-5639

f /SBANENY • website: sbaneny.org

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