

A Guide for School Personnel Working With Students With Spina Bifida

Developed by

The Specialized Health Needs Interagency Collaboration

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Kennedy Krieger Institute

and the

Maryland State Department of Education

Division of Special Education/Early Intervention Services



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INTRODUCTION

The large majority of students with Spina Bifida are in educational programs within regular schools, usually in regular classes. For this reason, it is critical that school personnel involved with them, especially teachers and school nurses, be familiar with the condition, its related medical difficulties, and associated learning difficulties. This guide is intended for school personnel who work with students with Spina Bifida. It presents both medical and educational information in everyday language that is useful in a school setting.

MEDICAL INFORMATION

Spina Bifida: What It Is and How It Happens

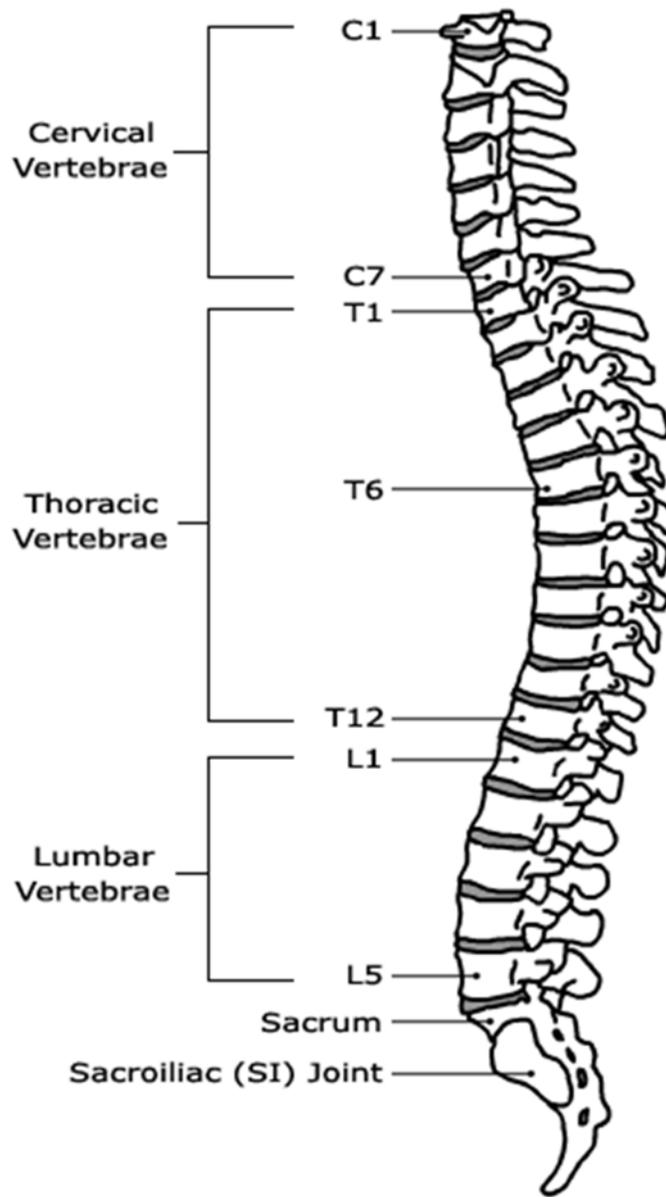
Spina Bifida refers to the incomplete closure of the spinal column and the bones that surround the spinal cord. Medically, the problems relate to the malformation of the underlying spinal cord and the nervous system. The spinal cord is the largest nerve in your body. This cord connects the brain to the other parts of your body. The brain plus the spinal cord is called the central nervous system (CNS). It starts at the base of the brain (brainstem) and extends to the lower back. The spinal cord is protected by a kind of bone tunnel made up of vertebra (the spinal column). The nerves in the spinal cord are called upper motor neurons. Their job is to carry messages back and forth from the brain to the spinal nerves. The spinal nerves branch out from the spinal cord to other parts of the body and are called lower motor neurons. These nerves exit and enter each vertebra and communicate with a specific area of the body. Motor and sensory nerves outside the CNS are called the peripheral nervous system (PNS).

The defect resulting in Spina Bifida develops in the spinal column during the first 28 days of pregnancy when the CNS is developing. A failure of the spinal column to close often allows the spinal cord and surrounding material to protrude out of a portion of the back. In such cases, this problem is surgically corrected shortly after birth.

It is common to describe the nature and severity of spinal cord involvement by determining the level of the Spina Bifida lesion. The first seven vertebrae are called the cervical vertebra (C1-C7), with the first vertebra at the base of the skull. The cervical nerves are responsible for the movement and feeling in the arms, neck and upper respiratory system. This is rarely the location of the spinal cord lesion. The next 12 vertebrae are the thoracic vertebrae (T1-T12). They are from the bottom of the neck through the chest to the curve of the back. The lumbar vertebrae (L1-L5) make up the lower back and the lumbar nerves supply the trunk and abdominal area. The sacral vertebrae (S1-S5) are in the tailbone area and the sacral nerves supply the legs, bladder, bowel and sexual functioning. The nerves of the spinal cord end at L2, but the remaining nerves hang down from the lumbar and sacral regions. (See Figure 1). Spina Bifida usually occurs in the thoracic, lumbar or sacral regions. In general, thoracic lesions result in the most motor and sensory system disruption and sacral lesions result in the least.

There are many types of Spina Bifida, including occulta, meningocele, lipomeningocele and myelomeningocele, which is the most common type. The primary focus of this guide will be problems mainly seen in individuals born with a myelomeningocele and who have the most nervous system involvement. Students with other types of Spina Bifida and even milder forms of myelomeningocele may enter the school system with concerns that are specific and not as extensive as those with the more severe and complex forms of myelomeningocele that are discussed here. It should be a goal of all school personnel to see the student first as an individual, one who happens to have Spina Bifida, and then to identify appropriate accommodations, if needed.

Figure 1



Prevention and Folic Acid

Recent studies have shown that the risk of having a child with Spina Bifida or other neural tube defects, may be reduced by at least 50 percent by increasing a woman's daily intake of folic acid. The Food and Drug Administration recommends that all women of childbearing age take 0.4 mg of folic acid every day. This is 100 percent of the recommended daily allowance. It is especially important that this dose be taken prior to becoming pregnant and during the first trimester of pregnancy. If a woman has already had one child with Spina Bifida, her risk of having another child with Spina Bifida, or other neural tube defects, can decrease by as much as 70 percent if she takes 0.4 mg of folic acid daily.

Folic acid is a B vitamin and is found in dark, leafy green vegetables such as broccoli and spinach, whole grains, egg yolks, citrus fruits and juices, most berries and legumes such as dried beans and soy beans. Many foods have been fortified with folic acid. These include some breakfast cereals, rice, breads, pastas and foods made with enriched flour or cornmeal. Since the average American diet does not supply the recommended level of folic acid, it is suggested that an over-the-counter multivitamin supplement containing folic acid be taken.

Secondary Medical Conditions Associated with Spina Bifida

- **Brain abnormalities:** Spina Bifida has historically been thought of as an orthopedic condition. However, a number of brain abnormalities typically occur with Spina Bifida, which also makes it a “cognitive” condition.
 - **Dysgenesis of the Corpus Callosum:** Many individuals with Spina Bifida have a reduction in the size (or a complete absence) of the corpus callosum. This is a white matter structure that connects the two halves of the brain, making it important for integrated thought and coordinated motor action.
 - **Cortical thinning in the posterior brain regions:** Several studies have shown that the cortex in the back portion of the brain of individuals with Spina Bifida is reduced. This is particularly true in the areas that process visual spatial information.
 - **Potential cortical thickening in the anterior brain regions:** Emerging research suggests that the frontal lobes of the brain of students with Spina Bifida may actually be larger than normal. This suggests incomplete “pruning” of the neurons in this area during early development. The frontal lobes are important for executive functions (see below). Cortical “inefficiency” (due to a lack of pruning) in the frontal areas of the brain may explain some of the executive dysfunction seen in students with Spina Bifida.
- **Abnormalities in the cerebellum and brainstem:** Most students with Spina Bifida also have an *Arnold Chiari Type II malformation*. This occurs when the part of the skull that holds the cerebellum and brainstem is too small, resulting in parts of the cerebellum and brainstem shifting down into the spinal column. This shifting may disrupt the functions of the cerebellum and brainstem, which can cause problems in the areas of motor coordination, timing and attention. Symptoms associated with a Chiari malformation can be persistent and can increase over time. Since the brainstem is involved, there may be

critical areas of cranial nerve dysfunction. The student may have weak eye muscles resulting from oculomotor dysfunction, putting them at risk for amblyopia if not treated.

Gagging and swallowing problems may be associated with pharyngeal dysfunction. There may be changes in the quality of a child's voice, such as hoarseness, that suggests a laryngeal dysfunction. Respiratory centers are also located in the brainstem. In severe situations, an individual may experience apnea (mainly associated with sleep). There may also be subtle changes in upper extremity functioning over time. Some students may demonstrate changes in writing and increased tone in their upper extremities.

The main role of the school is to be aware of the student's baseline status and alert the family of any changes. The changes are usually gradual, such as a decrease in handwriting legibility before spasticity becomes very evident. Certainly the involvement of the school occupational therapist would be helpful in assessing for early changes in upper extremity functioning. This therapist should be in communication with the student's Spina Bifida team. Treatment ranges from monitoring to neurosurgical intervention in severe situations where there has been demonstrated neurological deterioration.

- **Hydrocephalus:** Chiari malformations can also contribute to the development of hydrocephalus. Hydrocephalus (hydro-water, cephalus-brain) occurs when there is an increase in the amount of cerebrospinal fluid (CSF) in the brain. The CSF normally drains from the brain, down the spinal cord and back up to the brain. In students with Spina Bifida, hydrocephalus is almost always caused by the Arnold Chiari Type II malformation. The abnormal positioning of the brainstem causes disruption of the flow of CSF and shunting is often required shortly after birth. In many children with Spina Bifida, shunts must be revised periodically due to blockages or malfunctions.
- **Shunt malfunction:** Students with hydrocephalus may have a shunt surgically placed to help drain excess fluid from the brain. It is placed in the ventricles of the brain and travels alongside the neck to the peritonium in the abdomen, thus the name VP shunt. For this reason, it is important that students with a shunt not participate in contact sports. At times, the shunt may malfunction and need to be replaced or revised. This could occur in either the ventricle or the abdomen. It is important as an educator to know the signs of shunt failure. Children experiencing shunt malfunctions can present in many different ways, but some of the more common symptoms shown during shunt malfunction include:
 - Personality changes
 - Headache
 - Changes in vision
 - Deterioration in school performance
 - Decrease in sensory or motor function
 - Swelling along shunt tract
 - Irritability
 - Increased head size
 - Vomiting
 - Seizures

➤ Lethargy

- **Effects on nerves and function:** When the spinal cord is not completely formed, as in Spina Bifida, the nerves are affected. Messages cannot be sent or received by the nerves below the location of the lesion.
- **Bowel and bladder:** Depending on the location of the lesion, a student's bladder and bowel function may be affected. The nerves which control the bladder are the ones most often damaged. Students with Spina Bifida often cannot feel when their bladders are full and cannot empty their bladders of urine. These students can learn to empty their bladders with a procedure called *clean intermittent catheterization or CIC*. The students use a catheter, a small straw-like device, to empty their bladders. The catheter is inserted into the bladder to drain it of urine and then it is removed. This is usually done every 2-6 hours throughout the day. If your student requires CIC, he may need to miss a portion of your class in order to perform CIC in a private setting (i.e., nurse's office, restroom). Younger children may require some adult assistance or supervision until they are independent with the steps involved in CIC. A student might also have a continent stoma called a *mitranoff* that is emptied every 4 hours via a catheter into the stoma. (A stoma is a surgically constructed opening, especially one made in the abdominal wall to permit the passage of waste or urine, American Heritage Dictionary, Copyright 2007, by Houghton Mifflin Co.) This procedure allows the student to catheterize at waist level and be independent. Do not be surprised if your student is catheterizing through their belly button.

Many students with Spina Bifida also cannot feel the need to move their bowels, nor control when they have a bowel movement because the nerves controlling these are usually affected. Although they cannot achieve bowel control, they can achieve bowel regulation and continence using a regime so their bowels can be emptied on a schedule. This may involve eating a lot of fiber, laxatives, and a regular toileting time for bowel movements, usually at home during non-school hours. Some students will have a procedure done that is called an *antegrade continence enema or ACE*. This is a procedure that allows the student to do enemas through the continent stoma and then transfer to the toilet to empty their bowels. The enema is usually done as part of their nighttime routine. However, it is possible that a student might have an accident at school, which needs to be handled sensitively and discreetly by allowing the student to go to the nurse to clean up and change clothes. It is recommended that students keep a change of clothing at school to use in case of an accident.

- **Ambulation:** As previously mentioned, students with Spina Bifida do not have normal nerve development and function below the level of the lesion in the spinal cord. The higher up the spinal cord that the lesion occurs, the greater the paralysis. Although a student with Spina Bifida may have partial or complete paralysis, he may still be able to walk with a variety of assistive devices as indicated below.

<u>Level</u>	<u>Functional Mobility Goals</u>
S1-S5	Increased ability to walk with fewer or no supportive devices
L1-L5	Walking can be a viable function, with the help of specialized leg and ankle braces. Students with lower level lesions walk with greater ease with the help of assistive devices. Wheelchair for any distances.
T2-T12	A few individuals are capable of limited walking with extensive bracing. This requires extremely high energy and puts stress on the upper body, offering no functional advantage. Can lead to damage of upper joints. Wheelchair for most activities.

Some orthopedic conditions associated with Spina Bifida are scoliosis, kyphosis and tethered spinal cord. Scoliosis is an abnormal curvature of the spine. Kyphosis is a forward rounding of the upper back. A tethered spinal cord is when the spinal cord remains attached to the surrounding skin and prevents it from growing normally. The cord then becomes stretched and damaged, resulting in progressive neurological, urological and/or orthopedic problems. Complications of these conditions could interfere with regular school attendance. Students that have the diagnosis of scoliosis or kyphosis might wear a brace during the school day, often called a clam shell because of how it opens. If your student wears a brace, it is important for the school nurse to regularly check the student's skin for signs of breakdown. Children who are nonambulatory are more prone to developing a condition known as osteoporosis, which means "porous bones". This causes the bones to become brittle and weak.

- **Skin problems:** As mentioned, students with Spina Bifida usually have a loss of sensation below the level of the lesion. They do not have normal skin sensitivity to pain, touch or temperature. This puts them at risk for injury to their skin from sources such as hot bath water, heaters/radiators and hot metal surfaces in the summer, such as bus seat belts and prolonged exposure to cold in the winter. Some students have even received burns from sitting hot laptops on their laps.

Warn students of any of these circumstances if they are encountered during the school day and remind them to protect their skin. When sitting in a classroom chair or their wheelchair, pressure is placed on their skin by the chair surfaces and their bones. Children with Spina Bifida often do not feel uncomfortable and subsequently do not naturally shift positions in order to relieve the pressure. When this happens, the blood supply to that part of the skin is cut off and pressure ulcers or *decubiti* can develop. If these are left untreated, they can become infected and possibly affect the bone. It is necessary for students with Spina Bifida to complete pressure relief, meaning shift their weight or change their position frequently (about every 20-30 minutes) in order to protect their skin. This is usually accomplished by having the student perform a "wheelchair push-up", which means pushing up on the arms of their wheelchair until their bottom clears the chair surface. Ideally, students should be independent with this and it should not disrupt their school day. However, younger students and students just beginning a skin care program may need some adult supervision or cueing

initially. Students who do not have the upper body strength to correctly complete a “push-up” might need assistance from an adult to help tip the manual wheelchair back while the student is in class. Students may also develop redness or sores from braces or shoes that don’t fit well. It is important to report any redness or swelling that you notice to the school nurse.

LATEX ALLERGY IN STUDENTS WITH SPINA BIFIDA

Latex Allergy: What It Is and How It Happens

Latex is the sap from the *Hevea brasiliensis* tree and is a form of natural rubber. It is used to make many items found in the medical, home and school environments. Students with Spina Bifida are at high risk for developing an allergy to latex. A higher risk for developing a latex allergy has also been reported in other groups of students, such as those with cerebral palsy, ventriculoperitoneal shunts or those having multiple surgeries. Although the cause is not known, the current theory is that students may be sensitized through early, repeated exposure to latex due to multiple surgeries, diagnostic tests and/or procedures. Exposure can occur when products containing latex come into contact with the student’s skin or mucous membranes or when powder from latex products (i.e., gloves) becomes airborne and is breathed in. Serious reactions can occur when latex enters the bloodstream through injections or contact with internal organs during surgery. Most children with Spina Bifida use some form of latex precautions even if they are not known to be allergic to latex, in order to prevent development of the allergy.

*Students who are allergic or sensitive to latex may also be allergic to foods such as bananas, kiwi, papaya, avocados and chestnuts.

Symptoms of Allergic Reaction to Latex

Allergic reactions to latex can include redness where contact was made, watery and itchy eyes, sneezing, coughing, skin rash, hives and swelling of the hands or face. It is possible that a student may have a severe reaction and go into life-threatening anaphylactic shock. Symptoms of this include a drop in blood pressure, wheezing, rapid heart rate, flushing of the face and swelling of the throat.

Preventing Allergic Reactions to Latex in the School Environment

It is important that all school staff be educated regarding latex allergy using information such as this guide. The existing recommendation by experts for preventing latex allergic reactions at school is to avoid exposure to latex. In order to do this, staff should survey their instructional environments, (i.e., classrooms, gym, playground), and treatment environments, (i.e., health suite, cafeteria) to identify items that contain latex and thereby pose a potential risk for exposure. These items should be removed from the environment and replaced with alternative non-latex materials.

A list of items typically found in schools that contain latex and suggested substitutions is included below. The list is not totally inclusive, as new items are constantly being produced. If

you are not certain whether an item contains latex, check with the supplier prior to using it with a student who is sensitive or allergic to latex. It is also critical for each school to have emergency protocol in place for recognizing and treating any allergic reactions in students with latex allergies.

This list 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.

Frequently contains LATEX	LATEX-Safe Alternatives
School/Office/Art supplies: paints, glue, erasers, fabric paints, grips for writing utensils, duct tape	Elmers (School Glue, Glue-All, GluColors, Carpenters Wood Glue, Sno-Drift paste) Faber-Castell 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, Scotch Magic Tape
Balloons	Mylar balloons, self-sealing Myloons, Mister Balloon
Balls: Koosh balls, tennis balls, bowling balls, ball pits	PVC (Hedstrom Sports Ball), Nerf Foam Balls, Gerlie Balls, Google 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 (Wm. W. 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, NO LATEX Industries), Buster Brown elastic-free socks (Vermont Country Store)
Condoms, contraceptive sponges, diaphragm	Polyurethane (Avanti), female condom (Reality), Widespread Silicone Diaphragms (Miles), Trojan Supra Condom, FemCaps
Costumes: masks, face paint, nail polish, etc.	Check all products
CPR manikins 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	PURDOM27 intraoral elastics (Midwest Orthodontic), wire springs, sealant (Deltan) dams (Meer Dental, Hygenic Corp), John O Butler, 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
Feeding nipples	Silicone, vinyl (selected Gerber, Evenflo, MAM, Ross, Mead Johnson)
Food handled with latex gloves	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 (Allendum)
Mattress / pressure relief	Check each one for latex content
Miscellaneous items	Some medical stickers by MediBadge, UAL, Cushie Tushie Potty 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.
Playpits, playground surfaces	Natural rubber latex may be 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

Frequently contains LATEX	LATEX-Safe Alternatives
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)
Wheelchair tires	Recommend using leather gloves
Zippered plastic storage bags	Waxed paper, plain plastic bags, Ziploc bags, Glad Press N' Seal

Associated Allergies

Foods include: banana, avocado, chestnut, kiwi, pear. Plants include: Poinsettia and milk weed pods.

About These Lists

These lists are offered by the Latex Committee of the Nursing and Healthcare Professionals Council of the Spina Bifida Association as a guideline to individuals, families, and professionals. It is updated annually.

The information contained in these lists is constantly changing as manufacturers improve their products and as we learn more about latex allergy.

PLEASE NOTE: The latex content of products may vary between companies and product series. Companies that offer "alternatives" may ALSO make many LATEX products. We recommend that you check with suppliers before exposing individuals with latex allergies to the product.

REMEMBER: Always check the label—even if the product is on this list. If a product has recently replaced latex, many institutions will continue to use the old stock before they replace it with the new.

For More Information

For the most current version of this list, visit the SBA Web site at www.spinabifidaassociation.org.

Online Resources

Spina Bifida Association
www.spinabifidaassociation.org

American Latex Allergy Association/ALERT

www.latexallergyresources.org

Type I Versus Type IV Allergic Reactions: How do they Differ?

www.latexallergyresources.org/Newsletter/newsletterArticle.cfm?NewsletterID=16

Centers for Disease Control and Prevention—latex in vaccine packaging

www.cdc.gov/vaccines/pubs/pinkbook/downloads/appendices/B/latex-table.pdf

Decent Exposures

(latex free undergarments)

1-800-524-4949

www.decentexposures.com

OSHA

www.osha.gov/SLTC/latexallergy

American College of Allergy, Asthma & Immunology

www.acaai.org

ROLE OF THE SCHOOL NURSE

The school nurse has a very important role in ensuring that the medical needs of the student with Spina Bifida in the school setting are being met. The school nurse must be involved even before the student begins school in order to help with a smooth and safe transition. The school nurse is the health expert in the educational setting, and as such is part of the Individualized Education Plan (IEP) and 504 Plan teams. The school nurse uses the nursing process to assess, plan, implement and evaluate care for students with Spina Bifida and works with teachers, parents and school administrators so that the student can be safe in the school setting and able to focus on learning. If the child has an IEP, the school nurse should have goals related to the student's health needs that reflect an understanding of the student's medical condition. Goals should also focus on the student developing self-care and advocacy skills related to their medical condition. These should be included in an Individualized Health Plan (IHP) to be attached to the IEP.

Some key items that need to be addressed prior to the student attending school are listed below to help guide the nurse. The school nurse's appraisal/assessment should include parent input, review of medical information and physician's orders to assist with developing a plan of care, as well as an emergency plan. When speaking with the parents and reviewing the medical information, it is important for the school nurse to gather the following information:

- Level of the lesion
- Type of Spina Bifida
- Does the student have Arnold Chiari Type II malformation? If yes, were there any interventions?
- Does the student have a shunt? If yes, what type of shunt is it and have there been any revisions? If yes, when was the last revision and what part of the shunt was revised?
- Does the student have a latex allergy? If yes, what are the student's symptoms and is there an order for an epipen?
- A complete list of medications that the student is taking for seizures or bowel and bladder management, even if they are not taken while at school. What medications will be taken at school?
- If the student has seizures, what type are they, when was the last one and are there any interventions to be taken at school?
- Does the student need to be lifted? If yes, is any equipment needed?
- What is student's bladder management program?
 - Is clean intermittent catheterization completed through the urethra or a stoma?
 - What is the catheterization schedule?
 - Can the student self catheterize?
 - What position does the student need to be in for catheterization?
 - Is student dry between catheterizations?
 - What is the bladder management program if it is not catheterization?
 - Has student ever had a urinary tract infection? If yes, what were the symptoms?
- What is student's bowel management program? Are there any problems with leakage or accidents?

- What does student use for mobility?
 - Braces? Ankle-foot orthoses? Crutches? Walker?
 - Wheelchair? Is it manual, motorized or have power-assist wheels? Is the student able to self-propel the wheelchair?
 - Understand how to work the student's wheelchair. If the wheelchair is electric and can be shifted into manual mode, know how to do that. If it is a manual chair, know how to recline the chair, release the supports, etc. The physical therapist should be able to help with this.
- Does the student have any signs of skin breakdown? If yes, where is it and what is the treatment? If the student uses a wheelchair, how is pressure relief performed (wheelchair push ups, tilt wheelchair back, transfer to regular chair)?

Once information has been gathered, the school nurse should also consider the following:

- Transportation (does the student require a lift bus or an air conditioned bus?)
- Cathing needs/bathroom facilities on field trips
- Training needs of staff and students
 - Be prepared to train the school staff on Spina Bifida in general (i.e.-signs and symptoms of shunt failure, latex allergies) as well as specifics related to the student (i.e.-level of lesion, toileting needs, time needed for toileting).
 - If the student has a private duty nurse, are you aware of the routine and equipment that the nurse is using? Make sure that you understand the **Nurse Practice Act** of your state and your role as outlined in it. Does your school require a contract?
 - Arrange for the student to visit the school when it is empty so he can navigate the hallways, check lockers and feel comfortable with the arrangements for personal care before beginning school. Coordinate with physical and occupational therapy, if needed.
 - A presentation to the student's classmates should be considered if they have not had any experience with students with disabilities. Ask the student if he wants to be involved and what type of information he is comfortable having shared with his classmates. Other potential topics might include how to act around the student (only if he is not present), personal space and wheelchair safety. If the student is comfortable with it, a question time at the end of the presentation is also helpful. It keeps the student from having to answer the same questions over and over on an individual basis.
- Emergency plan (a sample emergency plan form is included at the back of this guide)
 - Exit strategies from the building in all areas
 - What medical equipment will be needed
 - Evacuation method from upper floors of multi-level building if student cannot be carried (identify area where student should be taken to be supervised by an adult)

The school nurse should obtain orders from the student's physician. These may include, but not be limited to:

- Catheterization
 - Size of catheter
 - Schedule for catheterization
 - How often to change catheter

- When to notify the physician (i.e.-temperature >100, foul smelling urine, sediment)
- Seizures
 - Type of seizures
 - Medication to be given
- Latex allergies
 - Signs of latex allergy
 - Treatment of exposure
- Any physical limitations (i.e.-regarding physical education)

EDUCATIONAL CONSIDERATIONS FOR THE STUDENT WITH SPINA BIFIDA

Introduction

Over time, it has become increasingly clear that students with Spina Bifida not only have physical and medical issues, but may also have learning difficulties that may impact their success in school.

IDEA and Section 504

There are federal laws that outline and protect a child's right to services that enable him to attend a school program without being discriminated against because of his disability. More specifically, the two laws that apply to students with Spina Bifida are the Individuals with Disabilities Education Improvement Act of 2004, commonly referred to as IDEA, and Title V of the Rehabilitation Act of 1973, commonly referred to as Section 504.

IDEA is the most comprehensive law that deals with a child's right to a "free and appropriate public education" or FAPE. This law covers the provision of special education and related services such as physical therapy, occupational therapy, speech/language therapy, special transportation, etc. The majority of children with an IEP receive special education instruction because their disability has an effect on their learning and education. This is often the case with students with Spina Bifida and is discussed in greater detail below. Although Spina Bifida is not one of the disability categories listed in IDEA, a child with Spina Bifida generally qualifies for services under the category of "learning disability".

Section 504 prohibits discrimination on the basis of disability from any program that receives federal funds, including public schools. It ensures that children with disabilities have equal access to education. To qualify for services under Section 504, the child's disability must substantially limit one or more of his "major life activities". These are defined as "caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working". Children who receive services and/or accommodations under Section 504 will have a 504 Plan written. The 504 Plan is a legal document outlining the specifics of services and accommodations to assist the student in the regular education setting. Students with Spina Bifida who do not have a learning disability will most likely have a 504 Plan if they require accommodations in order to participate in their educational program.

Modifications and Accommodations

Many students with Spina Bifida will require some physical modifications and/or accommodations. Others may require scheduling accommodations, testing accommodations, classroom accommodations and/or program accommodations. Schools should review the following lists in planning for a student's attendance at their school.

- **Physical accommodations**
 - Building accessibility may require:

- ramps inside and outside of the school
 - an elevator in a multilevel building with free access for the student
 - doorways wide enough to accommodate a student's wheelchair
 - accessible general areas (i.e.-gym, cafeteria, auditorium)
 - an accessible bathroom with grab bars
 - classrooms with enough space to accommodate a student's wheelchair (including turning space)
 - an accessible locker
 - Desks and tables high enough to accommodate a wheelchair in each of the student's classrooms
 - A fire/emergency evacuation plan which should be shared with the local fire department
 - Provide a private location for catheterization and other necessary personal care
 - Temperature controlled environment
 - Temperature controlled transportation
- **Scheduling accommodations**
 - Allow students to leave classes early to travel to their next class, allowing them sufficient time and the ability to move through the halls when they are less crowded
 - Provide time in their schedule for catheterization
- **Testing accommodations**

Testing accommodations can include various combinations of the following, based upon the individual student's needs:

 - Extra time on tests/assignments
 - One-on-one evaluation
 - Alternate response mode (i.e.-oral response, dictation of written answers)
 - Alternate presentation (i.e.-orally)
 - Give take-home tests
 - Reduce number of choices on multiple choice tests
 - Allow test to be taken over several sessions or several days
 - Use of a laptop
 - Use of calculator
 - Use of external prompts (i.e.-list of keyboard shortcuts)

Various combinations of the above testing accommodations should be provided as needed on classroom tests as well as standardized tests such as district-wide tests, advanced placement tests and college entrance exams. Guidance counselors should familiarize themselves with the documentation needed by the College Board to obtain these accommodations on college entrance exams and the timeline for filing the appropriate forms. They should also connect students with Spina Bifida with the Disability Support Services Office at the colleges that they are interested in to discuss programs and services available on their campus.

Guidance counselors should provide students and/or their colleges of choice with the documentation necessary (i.e.-a copy of their 504 Plan, copy of doctors' notes) to obtain these services only at the request of the student and his family. It is also critical that a referral be made

to Vocational Rehabilitation because they may be instrumental in providing the student with many of the services and/or equipment needed to attend college. The most important thing to remember when helping the student as he plans for the college search and application process is to **start early!!!** If the student has an IEP, this should be part of the formal transition plan that begins during the calendar year that a student turns 14. This is when a course of study is determined to help a student transition from secondary education to postsecondary life. At the age of 16, the transition plan expands to include a coordinated set of activities and community experiences. The transition plan is revised yearly.

Additional school-based accommodations can including various combinations of the following as needed:

- **Classroom accommodations**
 - Extended time to complete written assignments
 - Use of a laptop
 - Assistance with getting laptop and/or materials in and out of backpack or bag
 - Allowed to have list of keyboard shortcuts on student's desk
 - Preferential seating near door as well as electrical outlets
 - Allowed to carry fluids

- **Program accommodations**
 - Adaptive physical education
 - Assistance with set-up for meals and/or snacks
 - Decreased written demands
 - Significantly decreased homework assignments (to allow time for outpatient therapy, home therapy and increased time to complete self-care activities)
 - Modified work load
 - Peer buddy for assistance with materials, cafeteria use, opening doors, etc.
 - Peer note taker
 - Volunteer homework buddy
 - Provide homework assignment notebook
 - Provide sample of finished project
 - Provide procedure for finished project
 - Provide a visual daily schedule
 - In-servicing staff and/or students about the child's disability
 - Moving the location of a class to make it accessible
 - Extracurricular activities held in accessible part of building
 - Allow student to e-mail completed assignments to teacher
 - Allow student to use speech-to-text and text-to-speech software

- **Presentation accommodations**
 - Write key points on the board
 - Provide visual aids, organizational outlines
 - Include a variety of activities during each lesson
 - Provide study guides
 - Have student review key points orally

- Have student repeat and explain directions
- **Assignments/Worksheets**
 - Simplify complex directions
 - Highlight key concepts on handouts
 - Give frequent short quizzes and avoid long tests
 - Provide alternative/extra options for assignments
 - Break lengthy outside reading assignments into smaller assignments

Be certain to consider all of the necessary accommodations needed for the student to participate in field trips.

- **Materials to be provided**
 - Extra set of books to keep at home
 - Copies of teachers' notes
 - Taped lectures
 - Taped books
 - Assistive technology equipment
 - Speech-to-text and text-to-speech software/devices

If a student with Spina Bifida has any decreased function of his fingers, hands or arms, he may need to use an assistive device to help him with written work in school. The school system should complete an assistive technology evaluation to determine the student's exact needs. Any assistive device or software needed should be provided by the school system. The **assistive technology specialist** should train the student and staff in the use of the device. Once training is complete and the student is able to use the device functionally, services should continue to be provided on a consultative basis to address any future concerns or additional needs.

With regards to transportation to and from school, a student with Spina Bifida may need to be transported on a lift bus, unless his physician clears him to transfer from his wheelchair to a regular bus seat. The transportation office needs to make sure that there is an appropriate system on the bus for securing the wheelchair for safe transportation. As previously mentioned, the bus should be climate controlled.

It is also important to be aware of psychosocial issues related to having a student with Spina Bifida in your class. Although many people, students and staff alike, may want to help the student as much as possible, it is important to promote his independence as much as possible. Allow him to do what he can without immediately jumping in to help. Always ask the student if he wants help and how he wants you to help. Students should also be taught to do this as a matter of courtesy and respect. Include the student in as normal a fashion as possible, taking into account what is developmentally appropriate for the student's age. For example, a student in kindergarten does not need to stay in his wheelchair all day. Take him out of the wheelchair during circle time or story time and let him sit on the floor or a mat with the other children. The student's physician and/or physical therapist can provide information on how to do this safely. If a student does not have functional use of his arms or hands, devise a system for him to let you know that he wants to answer a question (i.e.-his aide will raise his hand). Do not be bound by

only the suggestions provided in this booklet. Providing an inclusive school program for a student with Spina Bifida will require creativity on the part of his teachers and peers.

Academic Strengths and Weaknesses That Affect Learning

Research in the area of learning and Spina Bifida has led to developing the following learning profile of students with Spina Bifida.

- Most students have an IQ in the average range.
- Verbal skills are usually stronger than nonverbal skills, particularly if the nonverbal tasks have a speed or motor requirement.
- A Verbal IQ score is a better predictor of a student's educational achievement scores than the Performance or Full Scale IQ score.
- Word reading and spelling skills are usually better, while reading comprehension and math skills are usually weaker.
- Multiple shunt revisions are associated with lower intelligence scores.
- The higher the level at which the spinal cord is affected, the greater the possibility that intelligence and academic skills may be negatively impacted.
- Central nervous system (CNS) infections diminish intelligence.
- Students with SpinaBifida often demonstrate perceptual-motor problems.

In many instances, students with Spina Bifida have often unfairly been viewed as “lazy” or “unmotivated,” when they were actually having learning problems. For this reason, it is critical that school staff who work with students with Spina Bifida are educated about their potential learning problems and strategies for addressing them. Some of the most common patterns of learning strengths and weaknesses in children with Spina Bifida are described below.

- **Reading Comprehension:** In many cases, reading skills are an area of strength for students with SpinaBifida. It is possible, however, for them to be very good “word readers” or “decoders” but still have difficulty *understanding* what they are reading. Reading comprehension difficulties are actually very common in students with SpinaBifida and can be very frustrating for the student, teacher and parents. Reading comprehension difficulties often become more of a problem around third or fourth grade, when the school curriculum shifts from an emphasis on “learning to read” to “reading to learn.” To determine a student's specific reading comprehension difficulties, it is important to use tests that require him or her to make conclusions and draw inferences from paragraph-length reading passages (rather than just single sentences).
- **Math skills:** Mathematics is a common area of difficulty for students with Spina Bifida. Although they often have visual-spatial difficulties, current research shows there is little evidence suggesting that visual-spatial problems are the cause of the math problems. Instead, they appear to involve the following:
 - *Math procedural knowledge:* Successful math calculation requires students to know and use specific procedures, such as “regrouping” when completing multi-digit subtraction problems. Recent studies suggest that many students with SpinaBifida

have difficulty learning these types of math procedures and continue to use inaccurate approaches (e.g., subtracting smaller numbers from larger ones rather than “regrouping” during multi-digit subtraction). Some students eventually learn the correct procedures, but many still do not use them consistently when completing math problems. It is important to determine if the student uses math procedures inconsistently (due to a lack of attention/concentration) or not at all (due to a lack of procedural math knowledge) in order to determine the appropriate instructional intervention.

- *Math fact retrieval:* There is evidence that some students with SpinaBifida are less “automatic” in their basic math fact retrieval. Instead of recalling memorized math facts when completing calculation problems, students with SpinaBifida often continue to use less efficient strategies that they have learned (e.g., “counting up” from the highest number, such as 5, 6, 7, 8, when calculating $5+3$). These strategies are generally slower and less efficient. It is not unusual to see students with SpinaBifida using their fingers or hash marks to calculate even simple calculations. These less efficient strategies slow down the completion of math calculations and increase the chances of making careless mistakes during longer, multi-step calculations.
- *Math estimation:* Children with SpinaBifida frequently have difficulties with math tasks that require estimation, which makes it difficult for them to make a reasonable guess as to the measurements (e.g., size, mass, or length) of an object. This can also result in a failure to detect obvious errors during math calculations (e.g., $99-23=16$).

Neuropsychological Strengths and Weaknesses that Affect Learning

As previously discussed, a number of differences in brain development typically occur with Spina Bifida. These result in a pattern of learning strengths and weaknesses that impacts students’ classroom performance. This pattern of strengths and weaknesses has been well described by researchers such as Jack Fletcher, Maureen Dennis and Marcia Barnes, and knowing this pattern often helps teachers put the learning difficulties of students with Spina Bifida into perspective.

Students with Spina Bifida often have strengths in *associative processing*, which is the process of forming associations between different things when they are presented together over and over. For instance, students with Spina Bifida usually learn the names of things very easily, especially when the object and the name of the object are presented together at the same time. Associative processes help the child “associate” or “group” several things together and learn that “this goes with that”. This can help facilitate learning across academic subjects. This cognitive strength also helps with word reading, since practice reading words builds a strong association between the words and the combination of letters that make up the words. Unfortunately, students with Spina Bifida frequently have problems with *assembled processing*, which is needed to help them put together knowledge and understand information presented to them. In reading, assembled processing involves identifying larger themes and building understanding from the individual words that have been read.

Students with Spina Bifida frequently use their strength in associative processing to develop good word reading skills, but then struggle to use assembled processing to integrate the individual words into meaningful ideas. This can be very frustrating for the students and their teachers, as the student with Spina Bifida frequently “sees a lot of trees” but don’t always “see the forest” when reading.

When students with Spina Bifida have difficulties in assembled processing, teachers may need to help them recognize larger themes or patterns, even if it may seem somewhat obvious. This type of help often allows the students to think about the information and engage in classroom discussions. Problems with assembled processing and other cognitive skills can result in broad learning problems that contribute directly to poor academic performance. Some specific areas of weaknesses that can occur in students with Spina Bifida include:

- Memory
- Comprehension
- Attention
- Impulse control
- Organization
- Sequencing
- Decision making/Problem solving
- Visual-motor integration

Any combination or all of these weaknesses may be a problem even when a student’s overall intelligence is in the average range or higher. The effects of these weaknesses become more obvious as school curriculums and demands become more complicated (about fourth grade). Although there seem to be more problems when a student has a shunt, learning problems may occur in students with or without shunts.

A student’s individual learning profile, including areas of strength and weakness, should be identified through a neuropsychological evaluation by a qualified examiner. This evaluation will assess a student’s intelligence, academic levels and basic learning abilities, as well as neuropsychological functions such as attention, perceptual-motor processes, reasoning and problem solving, organization, sequencing skills and memory.

The learning needs of youth with Spina Bifida are often missed by assessors considering formal criteria for a “specific learning disability,” particularly if testing focuses on individual skills, such as word identification, rather than integrated academic functions like reading comprehension. Depending on their profile and identified needs, children with Spina Bifida may qualify for special education and related services under Specific Learning Disability, Other Health Impaired, or another category. Information from the neuropsychological evaluation will also be helpful in developing an IEP for the student.

SUGGESTED STRATEGIES TO ADDRESS LEARNING WEAKNESSES OF STUDENTS WITH SPINA BIFIDA

Memory

There are different types of memory, such as visual (seeing) memory, auditory (hearing) memory, short-term memory and long-term memory. It is important to know what type of memory difficulty each student has.

- Deficits in prospective memory are very common in students with SpinaBifida. Prospective memory is “remembering to remember” to do things in the future. Students with SpinaBifida have many extra responsibilities they must “remember to remember” to complete at certain times during the day. For example, they may “forget” to go to the nurse’s office to perform self-catherization, even if they can easily remember the times that they are supposed to catheterize when asked. Linking prospective memory tasks to events (e.g., after breakfast) instead of times (e.g., 7 a.m.) helps facilitate memory for these tasks. The event acts as a naturally occurring cue for the student to perform the task (instead of having to watch the clock and wait for the right time to perform the task).

The following suggestions may also be helpful when addressing prospective memory problems:

- Use devices that provide external prompts or cues to complete tasks, such as a memory journal, calendar, homework sheet or student planner. Electronic organizational aids are becoming more available in the classroom and may be helpful.
- Watches and Smartphone with multiple alarm capabilities can be helpful in reminding students of routine care, such as pressure relief, catheterization and medications. These devices also allow students to be more independent in their self-care skills, instead of relying upon outside persons to prompt them.

Sometimes children with Spina Bifida have trouble remembering things because they were not actually paying attention when the information was first presented. These types of attention-related memory problems are common when the student is required to “divide his attention” and do two things at once. For instance, it is especially difficult for the student to listen to what the teacher is saying while he is also copying an assignment from the board. Reducing “dual task” situations like this can help the student with Spina Bifida focus his attention on the information being presented. The following suggestions may also be helpful when addressing attention-related memory problems:

- Be certain to get the student’s attention and establish eye contact before giving instructions or a demonstration.
- Preferential seating near the teacher or the front of the room.
- Reduce distractions in the environment as much as possible.
- Provide outline or copy of notes so student can focus on presentation.

Sometimes students with Spina Bifida have difficulty learning information efficiently with just one presentation. They often require repeated exposure to the material and/or additional learning

trials. Since students with Spina Bifida have strengths in associative processing (see above), they will usually benefit from opportunities for additional learning trials, practice or rehearsal. The following ideas can be used to address *learning efficiency* problems:

- Pair things (associate) that need to be remembered together. Pairing new information with previously learned information may aid retention.
- Allow the student with Spina Bifida to use a tape recorder so he can review the material later in the day. This will provide additional opportunities to form associations between pieces of information.
- Allow verbal rehearsal (repeating things over and over, such as spelling words or multiplication tables).
- Present information using a variety of modalities (i.e.-visual, auditory, tactile, kinesthetic).
- Help students identify broader themes in information to be learned. This will give them a context in which to organize individual facts or pieces of information.
- Instruct the student in the use of mnemonic devices, associative devices or “chunking.”
- Provide written lists of materials needed or tasks that need to be completed.
- Teach notetaking, outlining and summarization skills.

Even if the student with Spina Bifida has paid attention to and learned the information, she might have difficulty demonstrating this learning when asked to remember it later or when tested on the material. *Recall memory problems* are common in students with Spina Bifida when they are asked to “spontaneously recall” facts or pieces of information (i.e., “What is the name of the first president?”). Recall memory problems can often be addressed by requiring the student to “recognize” information instead of “recalling” it” (i.e., “Was the first president George Washington or Thomas Jefferson?”). For this reason, students with Spina Bifida usually do better when they are assessed using multiple choice tests, rather than short answer or free recall tests.

Comprehension

Students with Spina Bifida can usually repeat information and/or recite facts or individual pieces of information, but often struggle to understand broader themes of what they hear. Many students with Spina Bifida have good expressive vocabularies and frequently appear to understand more than they actually do. For example, they can often talk about aspects of their medical condition using technical words such as “myelomeningocele” and “hydrocephalus”, but frequently don’t know what they actually mean. Problems become more evident when they are asked to explain specific topics. At such times, their verbal explanations can become tangential, disorganized and “off track.” For this reason, it is very important for teachers to routinely assess comprehension of the material, rather than assuming that the student understands based on his expressive vocabulary. The following strategies may be useful accommodations for comprehension problems:

- Use visuals (i.e.-maps, models, demonstrations) to help the student get a “picture” in his mind of what is happening in a story or what is being said.
- Give simple verbal explanations.

- Have the student verbally paraphrase material just read or discussed to assess comprehension.
- Ask questions throughout a reading assignment to assess comprehension.
- Highlight important points while reading.
- Prerecorded reading material to be used simultaneously while the student is reading.
- Act out the story or have the student role play a certain character.
- Read the comprehension questions at the end of the story before beginning to read.
- Work with the student on identifying the “main idea” of a reading selection, story or conversation.
- Permit students to use “text-to-speech” software or devices (e.g., Kindle, WordQ) so that they can easily review texts several times without having to re-read it multiple times.

Attention

Students with Spina Bifida frequently have difficulty sustaining their attention over the course of a class period and/or may focus their attention on individual details rather than “the most important part” of a classroom presentation. This may lead to missing directions or assignments, failing to copy assignments from the board, completing work incorrectly or missing parts of conversations with their peers. Some suggestions are listed below that may be helpful when working with a student who is having difficulty paying attention. If consistent use of these strategies does not improve the student’s attention, discuss with your school’s team whether the student may need to be referred to a doctor for evaluation for ADHD.

- Establish an unobtrusive signal between yourself and the student to alert him to his inattention.
- Be certain to get the student’s attention and eye contact before giving instructions or a demonstration.
- Try preferential seating near the teacher or the front of the room.
- Reduce distractions in the environment as much as possible.
- Give short assignments.
- Break longer assignments down into shorter tasks or work on them in several short periods.
- Provide reinforcement for work completed on time.
- If necessary, reduce directions to individual steps (i.e.-give each one after completion of the previous one).
- Maintain physical contact while talking to the student (e.g., put your hand on his shoulder).

Executive Functions

This term refers to a number of different cognitive abilities that are thought to help individuals control impulsivity and generate goal directed action. Problems in these areas, or executive dysfunction, can occur even if the individual has age-appropriate intelligence. Considerable research evidence supports the idea that many individuals with Spina Bifida have aspects of

executive dysfunction, which has a negative impact upon school functioning. Several important components of executive functioning are described below.

- **Initiation**: Students with Spina Bifida can present as “passive” in class and dependent on others for cues to start on tasks that they know how to do. Establishing a predictable routine will help them learn when to start tasks, allowing them to become more independent. However, patient cues and reminders may still be necessary.
- **Organization**: A common problem for students with Spina Bifida is keeping things organized. This is a difficulty that will obviously impact a student’s school performance, particularly if he continually loses or misplaces materials, books, assignments and homework. A lot of time is wasted searching through notebooks and backpacks that are not well organized and are stuffed with papers and materials. Improved organizational skills can be facilitated with the following strategies.
 - Model organization for your student by keeping your own area and materials neat and well organized.
 - Provide direct instruction and physical assistance with organizing a notebook. Be vigilant in helping the student to maintain the order of his notebook and materials once it has been established.
 - Reduce verbal explanations and provide simple, concrete instructions.
 - Reduce the amount of materials used at one time.
 - Teach the student to think about the materials needed prior to starting an activity.
 - Provide the student with a written list of materials that will be needed for each activity throughout the day.
 - Provide times throughout the school day that students can use to organize their materials (i.e., before lunch, after recess).
 - Provide adequate transition time between activities.
 - Establish a routine.
 - Minimize materials kept in the student’s desk.
 - Provide the student with an organizational checklist and instruction in how to use it.
 - Provide structure for all academic activities.
 - Assign only one task at a time.
 - Reinforce the student for being organized, prepared with appropriate materials and locating completed assignments and homework quickly.
 - E-mail the student his assignments (rather than requiring him to copy it off of the chalkboard).
 - Provide a second set of textbooks so the student doesn’t have to plan/remember which books to bring home each evening.
 - Allow students to turn in assignments by e-mail (rather than making them transport written assignments back to school in their book bag).
- **Sequencing**: Students with Spina Bifida who have difficulty with attention, memory or organization, may also have difficulty with sequencing, or keeping things in the correct order. They may have all of the parts of a procedure or activity, but not in the correct order. This can definitely impact their skills in the areas of math (i.e., completing a multi-

step problem, making change, telling time, etc.) and written language (i.e., sequencing story events, writing a report, etc.). The following strategies are recommended for students with sequencing difficulties.

- Provide specific activities that involve sequencing (i.e., cooking, dot-to-dot, ordering story events, ordering a comic strip) and work closely with the student to emphasize the importance of having the steps in the correct order.
 - Consistently emphasize the daily schedule and that each activity is done at a specific time and in a specific order.
 - Provide the student with a daily/weekly schedule and refer to it often. Have students check off each subject or activity as it is completed.
 - Start with simple multi-step instructions (2-3 steps) and gradually build up to lengthier instructions as the student's sequencing skills improve.
 - Instruct the student in the use of associative or mnemonic cues to help them recall the correct sequence.
 - Change the sequence of an everyday activity (i.e., sitting at the lunch table before getting their lunch) and have the student put the steps in the correct order. This can be done verbally and/or visually (using picture cards of the steps).
- **Decision making and problem solving:** Students with Spina Bifida who have memory, attention, organizational and sequencing difficulties will most likely have decision making and problem solving difficulties. Making a decision involves choosing from multiple options. Solving a problem involves applying previously learned information or experiences to a new situation to come up with a solution to a new problem. Some suggestions for improving skills in this area are listed below.
 - Give the student plenty of opportunities to practice decision-making by offering them multiple options (i.e., Do you want to read a story, do seatwork or work at a station? Do you want juice, milk or water for snack?)
 - Always pair actions with consequences or outcomes so that the student begins to realize that certain consequences are related to each decision that she makes.
 - Model appropriate decision making and problem solving skills within the classroom.
 - Help the student make a written list of steps involved in problem solving and encourage him to refer to it throughout the process.
 - Provide practice in problem solving using role playing activities.
 - Provide direct instruction in cause and effect relationships.
 - Have the student verbalize the reason for real life outcomes.
 - **Visual-motor:** Visual-motor (eye-hand) difficulties are often seen in students with Spina Bifida who have shunts due to hydrocephalus. Visual perception problems mean that they have trouble “seeing” or “picturing” things in their heads, finding their way around and they are less coordinated. Poor fine motor skills, combined with visual perception problems, impact the student's ability to use educational materials and tools, move around their school environment and succeed in reading, math and writing activities. These suggestions have been found to be helpful when working with students with visual-motor difficulties.

- Use a multisensory approach to instruction. Instruct through all modalities (visual, auditory, tactile, gustatory, kinesthetic and smell), not just one.
- Students with Spina Bifida need to develop an awareness of themselves in space. They should be involved in physical exercises and adaptive physical education activities.
- Provide the student with many activities that give them practice in using their eyes and hands together. They should participate in a variety of fine motor tasks that involve a variety of materials (i.e., clay, paint, paper mache, crayons, markers, paste/glue, Magnatiles, etc.).
- Students with visual-motor problems will most likely have difficulty copying from the chalkboard. Allow the use of peer notetakers, provide the students with a printed copy of what is on the board or e-mail the information to them.
- In practicing copying from the chalkboard, reduce the amount of material to be copied and enlarge or highlight material to be copied.
- Many students with Spina Bifida will benefit from the introduction of keyboarding during elementary school, particularly if handwriting is slow and laborious.
- To further facilitate written language production, permit students with Spina Bifida to use “speech to text” programs such as Dragon Dictation software or WordSpeak.

RESOURCES

Books

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Children with Spina Bifida: A Parent's Guide, Edited by Marlene Lutkenhoff, R.N., M.S.N., Woodbine House, Bethesda, MD, 1999.

Teaching the Student with Spina Bifida, Edited by Fern L. Rowley-Kelly, M.S.W., L.S.W. and Donald Reigel, M.D., Paul H. Brookes Publishing Company, Baltimore, MD., 1993. (1-800-638-3775).

Porter, S., Haynie, M., Bierle, T., Caldwell, T and Palfrey, J. (1997). Children and Youth Assisted by Medical Technology in Educational Settings-Guidelines for Care, Second Edition. Baltimore, MD, Paul Brookes Publishing Company.

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“Answering Your Questions about Spina Bifida—A Guide from The Spina Bifida Program Department of General Pediatrics”, Children's National Medical Center, Washington, D.C., 1995.

“Directory of Services for Individuals with Spina Bifida and Related Disorders,” Chesapeake-Potomac Spina Bifida Association, Inc., and Kennedy Krieger Institute, Baltimore, MD.

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Barnes et al., (2006). Arithmetic processing in children with Spina Bifida: calculation accuracy, strategy use, and fact retrieval fluency. *Journal of Learning Disabilities*, 39, 174-187.

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Hetherington et al., (2006). Functional outcome in young adults with Spina Bifida and hydrocephalus. *Child's Nervous System*, 22, 117-124.

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Dennis, M., Landry, S.H., Barnes, M., & Fletcher, J.M. (2006). A model of neurocognitive function in Spina Bifida over the life span. *Journal of the International Neuropsychological Society* (2006), 12, 285–296.

Organizations and Websites

Spina Bifida Association of America
Toll free: 1-800-621-3141
E-mail: sbaa@sbaa.org
www.sbaa.org

Chesapeake-Potomac Spina Bifida Association, Inc.
P.O. Box 1750
Annapolis, MD 21404
Toll free: 1-888-733-0988
Fax: 1-410-295-9744
www.chesapeakepinabifida.org

March of Dimes
1275 Mamaroneck Avenue
White Plains, NY 10605
914-997-4488
www.modimes.org

National Information Center for Children and Youth with Disabilities (NICHCY)
1825 Connecticut Avenue, NW, Suite 700
Washington, DC 20009
Toll free: 1-800-695-0285
Fax: (202) 884-8441
E-mail: nichcy@aed.org
www.nichcy.org

Kennedy Krieger Institute
www.kennedykrieger.org

- Specialized Health Needs Interagency Collaboration (SHNIC) can be found under professional training, then click on Children with Specialized Health Needs in the Schools
- Put Spina Bifida in the Search box and click Search

www.familyvillage.wisc.edu/school.htm

REFERENCES

The following forms were reprinted with permission from Children and Youth Assisted by Medical Technology in Educational Settings Guidelines for Care by Stephanie Porter, Marilyn Haynie, Timaree Bierle, Terry Heintz Caldwell and Judith S. Palfrey. Published by Paul H. Brookes Publishing Company, Baltimore, Maryland, 1997.

- *Individualized Health Care Plan Checklist*
- *Background Information*
- *Procedure Information Sheet*
- *Emergency Plan*
- *Individualized Health Care Plan*

The chart of abilities and functional goals by level of injury was reprinted with permission from <http://www.spinalcord.uab.edu/show.asp?durki=30166>.

Name: _____ Date: _____

BACKGROUND INFORMATION

Brief health history:

Special health care needs of student: _____

Other considerations: _____

Student participation in care: _____

Baseline status (i.e. skin color, activity/energy level, blood pressure, pulse, temperature, respirations): _____

Medication (dose, route, time): _____

Diet: _____

Allergies: _____

Transportation needs: _____

What is the transportation emergency communication system? _____

Name: _____ Date: _____

PROCEDURE INFORMATION SHEET

Procedure: _____

Frequency: _____ Times: _____

Position of student during procedure: _____

Ability of the student to assist/perform procedure: _____

Suggested setting for procedure: _____

Equipment (include make and model when applicable):

Daily: _____

Emergency: _____

Checked by: _____

Checked by: _____

Storage: _____

Storage: _____

Maintenance: _____

Maintenance: _____

Home care company: _____

Home care company: _____

Child-specific techniques and helpful hints: _____

Procedural considerations and precautions: _____

INDIVIDUALIZED HEALTH CARE PLAN

Student Information:

_____	_____
(Name)	(Birthdate)

_____	_____
(Parent/Guardian)	(Address)

Mother/Guardian: _____

(Home telephone)	(Work telephone)
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Father/Guardian: _____

(Home telephone)	(Work telephone)
------------------	------------------

_____	_____
(School)	(Grade/Class)

Language(s) spoken: student: _____ Caregiver(s): _____

Immunizations: _____

(date and type) _____

Primary Physician: _____ Telephone: _____

Specialty Physicians: _____ Telephone: _____

In Emergency, Notify:

Name: _____ Telephone: _____ Relationship: _____

Name: _____ Telephone: _____ Relationship: _____

Name: _____

Date: _____

School Nurse: _____

INDIVIDUALIZED HEALTH CARE PLAN

Date	Health Need/Nursing Diagnosis	Goals	Action/Intervention	Evaluation