



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



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THE JEFFRAS' PROGRAM THAT PROMOTES
A HEALTHY SCHOOL ENVIRONMENT
FOR STUDENTS WITH 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 of the way. Every day, about eight babies born in the United States have Spina Bifida or a similar birth defect 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.

The Different Types of SB

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 serious problems as a child grows up. Infants who might have OSD should be seen by a doctor, who will recommend tests.

Spina Bifida Occulta

It is often called "hidden Spina Bi da" because about 15 percent of healthy people have it and do not know it. Spina Bifida Occulta usually does not cause harm, and has 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 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 very complicated and 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 parts 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 like it should. The fluid builds up, causing pressure and swelling. Without treatment, a person's head grows too big, which may cause brain damage. Children who do not have Spina Bifida can also have this problem, so parents need to check with a doctor.

How Spina Bifida is Treated

- A child with Meningomyelocele usually is operated on within two to 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 should be checked by a doctor because they could have other serious problems, too.
- A child with OSD should see a surgeon. Most experts think that surgery is needed early to keep nerves and the brain from becoming more damaged as the child grows.
- Spina Bifida Occulta usually does not need to be treated.

Preventing 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 the 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.

Associated Conditions

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

Physical Limitations

People with Spina Bifida must learn how to get around independently, by using things like crutches, braces or wheelchairs. With help, it also is 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 the child (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) blood test during the 16th to 18th weeks of pregnancy. This is called the alpha-fetoprotein (AFP screening test). This test is higher 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 usual way that most SB pregnancies are detected.

3) A test where a small amount of the fluid from the womb is taken through a thin needle. This is called maternal amniocentesis and can be used to look at protein levels.

Can Children with SB Grow Up & Live Full Lives?

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

Managing Spina Bifida

As type and severity differ among people with Spina Bifida, each person with the condition faces different challenges and may require different treatments. The best way to manage Spina Bifida is with a team approach. Members of the team may include neurosurgeons, urologists, orthopedists, physical or occupational therapists, orthotists, psychologists and medical social workers.

Contributing Editor

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SPINA BIFIDA
ASSOCIATION

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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 can't 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, here is some helpful advice:

- Abdominal pain
- 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 but doctors will always check the shunt to be sure
- Be on the lookout for shunt problems, and when the child shows suspicious behavioral or physical changes, contact 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 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 (helmets)
- 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

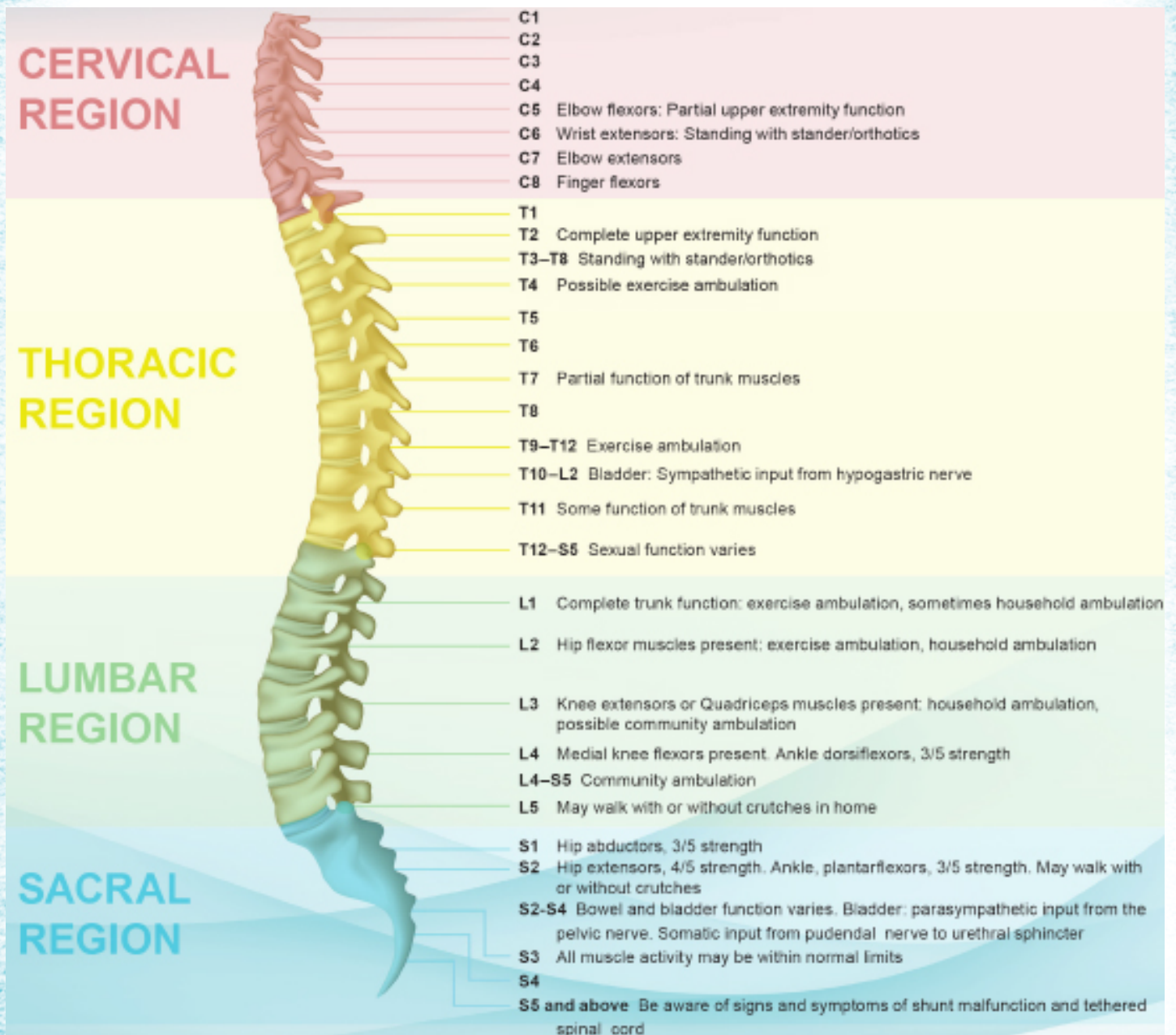


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SPINA BIFIDA & THE SPINE WITH FUNCTIONAL IMPACT



| Spine Level | Possible Muscle Function | Possible Orthopaedic Concerns | Possible Orthotics Needed | Possible Equipment for Functional Mobility | Possible Cognition, Executive Function |
|--|---|---|---|---|---|
| T6-9 T9-12 L1 | Upper trunk (abdominals) No LE function Abdominals + paraspinals = some pelvic control Complete trunk function Lower trunk (abdominals) Hip flexors (weak) 2/5 | Kyphoscoliosis, Lumbar hyperlordosis Coxa valga—hip dislocation Decreased bone density Fractures Contractures: Hip: abduction, flexion, external rotation Knee: flexion, extension Foot: heelcord, clubfoot | TLSO Night splints: body, hip abduction, KAF, AF Early: Parapodium, (10 months of age and up to 2 years) Later: stander, RGO, HKAFO, KAFO Caution: Preserve UE function with level transfers, stable seated posture. Maintain strength + flexibility of shoulders/ arms. | Community: Wheelchair/ wheelchair cushion, transfer board Home: Walker/Crutches (for household or exercise walking), Raised, padded commode seat. Bath bench Mirror for skin checks Stander: 1 hour/day minimum starting at 10-12 months of age. Driving with hand controls Learn public transportation | Executive function impairments can impact educational, social and self help skills. Cognitive function can vary with the degree of hydrocephalus number of shunt infections, and the involvement of the nervous system. Function may not be related to level of lesion or ability to walk. Support early assessment of attention difficulties, sensorimotor integration, visual perception, visual motor ability, psychosocial development in addition to fine/gross motor + communication ability. |
| L2 L3 | Hip flexors 3/5 Hip adductors 3/5 Knee extensors 3/5 | Scoliosis, Overuse of UE's Lumbar hyperlordosis Hip subluxation Coxa valga—hip dislocation Decreased bone density Fractures Contractures: Hip: flexion Knee: flexion, extension Foot: Heelcord, clubfoot | Night hip abduction splint Early: Parapodium (10 months of age up to 2 years) Later: Stander, RGO, HKAFO, KAFO (if quads are less than 3/5 strength) L3-5 May be temporarily addressed by twister cables or derotations straps | Community: wheelchair + cushion Home: Stander: 1 hour/ day minimum Early: may use walker or crutches Later: wheelchair in home | Independent living: Occupational Therapy Goals: Basic activities of daily living (BADLs) or bathing, dressing, grooming, bowel/ bladder program, skin care, moving/transportation in your home/community. Instrumental activities of daily living (IADLs). Shopping, meal preparation, use of home appliances. Early learning/practice of all ADLs is vital. |
| L4 L5 | Medial knee flexors 3/5 Ankle dorsiflexor 3/5 Hip abductors (weak) 2/5 Lateral knee flexors 3/5 Ankle invertors 3/5 Long toe extensors (palpate at ankle) | Lumbar hyperlordosis Coxa valga Contractures: Hip: flexion Knee: flexion (avoid crouch gait) Foot: Progressive calcaneus (tight heelcord) Calcaneovalgus Equinovarus—Clubfoot Paralytic Vertical Talus | Night hip abduction splint Early: Parapodium Later: RGO, HKAFO, KAFO, AFO (L3-L4 CCAFO) L4-5 Toeing in gait and weak gluteals may be temporarily addressed by twister cables and/or rotation straps Consider shunt malfunction and/or tethered cord | Community: wheelchair, walker, crutches, cane Strong medial hamstring needed for community gait Home: early on may need no support Later: may require UE support | Physical/ Occupational Therapy/ Gross Motor Goals: 1. Achieve/maintain full ROM. 2. Achieve/maintain full strength in intact muscles for ADLs and mobility. 3. Locomotion activities including ambulation skills (falling down, getting up), walk on various terrains, transfer to various surfaces (chair, car, bed). 4. Achieve maximal sitting tolerance with skin intact. 5. Attain cardiovascular endurance for function. 6. Ability to perform or direct care including care + maintenance of orthotics + equipment. 7. Obtain recommendations re: home modifications. 8. Document medical appts, follow up, surgical history. |
| S1 S2 | Hip abductors 3/5 Hip extensors (weak) 2/5 Plantar flexors (weak) 2/5 Hip extensors 4/5 Plantar flexors 3/5 Toe flexors 3/5 | Monitor hips closely Contractures: Foot: Calcaneus (tight heelcord) Calcaneovalgus Pes Cavus, Clubfoot Toe clawing (flexion) Heel/foot ulcers | AFO, SMO (supra malleolar orthotics), shoe inserts or no orthotics S1-2 Toeing out gait Use of crutches may decrease the valgus forces at the knee and also improve endurance | Community: walking with walker, crutches, cane. Gluteus lurch/ Trendelenburg gait aided by cane or crutches. Long distance alternative: lite weight wheelchair, bike, scooter Home: May need no support. | Transition to adult self care begins at birth. |
| S3-5 | All muscle activity + bowel/ bladder function may be normal | None | None or shoe inserts | None | |
| Shunt malfunction and/or tethered cord: May cause deterioration of daily living skills, progressive weakness, muscle contractures or orthopaedic deformities of the legs, scoliosis, back pain at the site of closure, deterioration of gait, changes in bowel and/or bladder function. | | | | | |

Muscle grades: 5 = normal
4 = good
3 = fair
2 = poor
1 = trace

Flexion = bend
Extension = straighten
Adduction = bring toward
Abduction = take away

Invert = move in
Evert = move out
Medial = inner
Lateral = outer

T = thoracic **L** = lumbar **S** = sacral **O** = orthosis
RGO = reciprocating gait orthosis
H = hip **K** = knee **A** = ankle **F** = foot
CC = crouch control **Gait** = walking style
Coxa = hip **Calcaneus** = heel bone **Talus** = ankle bone

UE = upper extremities/arms
LE = lower extremities/legs



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ORTHOPEDICS

Most children with Spina Bifida (SB) 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 deformities 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 SB 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 the 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 with a normal school routine including wheelchair sports & aerobic cycling. 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.

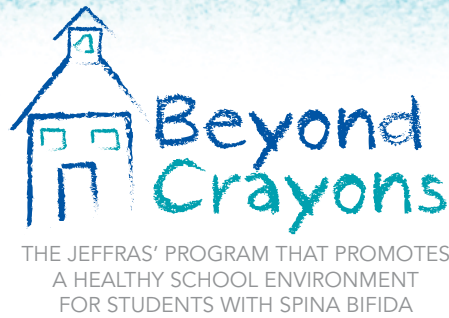
Because children with SB cannot feel parts of their lower body, injuries including fractures may occur. Furthermore, it should be expected that children and teens with SB will require orthopedic surgeries on the spine and lower limbs. In such cases, they might miss weeks or even months of school due 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. An exception to this is that students with a ventricular shunt to manage their hydrocephalus should not participate in activities where they are upside down (because the shunt may not work in that position), or at high risk of head or neck injury.

ADDITIONAL RESOURCES

[Hip Function & Ambulation Health Information Sheet SB and the Spine](#)



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CONTINENCE MANAGEMENT IN SCHOOLS

What is a neurogenic bowel and bladder?

In Spina Bifida (SB) the nerves do not function normally at the level of and below the deformity, which is usually in the lowest part of the back. The damaged nerves cause varying degrees of paralysis (neuro muscular weakness) and decreased sensation. This means all children with SB 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 SB.

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 a 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 isn't 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 frequently as "anyone" would need to empty their bladder.

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 & 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 SB 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 the 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 in SB is a life-long medical issue. Constipation in SB cannot be cured and children do not outgrow it. This means that children with SB have problems with lower body function, which includes mobility and bowels and bladder.

ADDITIONAL RESOURCES

Bowel Management & Spina Bifida



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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 it 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 (poop) 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 behavioural issue-it is a medical problem that should be addressed with the SB care team. Bowel and bladder management are inseparable and affect success of the other.

How do you manage bowel incontinence?

- 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 bowel washouts combined with, or in place of digital peri-anal stimulation and digital fecal extraction
- Routine is vital for successful bowel management

ADDITIONAL RESOURCES

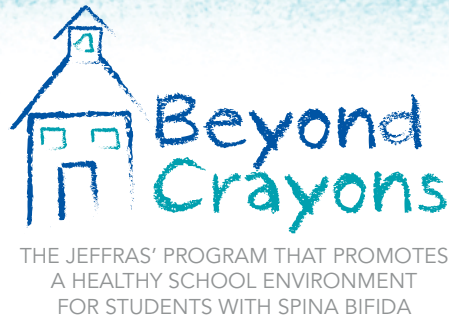
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NATURAL RUBBER LATEX ALLERGY

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 a sensitivity.

People who have Spina Bifida and catheterize, or have several surgeries from very early in life, such as bladder surgery or shunt revisions, are at very high risk for 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 (asthma)

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 products 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.

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, melon, and avocado. 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 the bloodstream. Powder from latex balloons or gloves gets into the air. Therefore, 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
- 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 is involved with the person who has Spina Bifida.

ADDITIONAL RESOURCES

www.aaaai.org
www.latexallergyresources.org
www.osha.gov/SLTC/latexallergy



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LATEX IN THE HOSPITAL ENVIRONMENT

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. **It is required by law that manufacturers must label any medical items that contain natural rubber latex.** ALWAYS CHECK THE PRODUCTS PACKAGING. If in doubt regarding the safety of an item, call the manufacturer.

| Frequently contains LATEX | LATEX-Safe Alternatives |
|---|--|
| Anesthesia: circuits, bags, oxygen masks | Neoprene (Anesthesia Associates, Ohmeda adult), some Vital Signs |
| Band-aids | Active Strip (3M), CURAD Neon, Readi-Bandages, NHP, Coverlet, some Airstrip, Advanced Healing |
| Blood pressure cuff and tubing (J&J) | Cleen Cuff (Vital Signs), nylon, some Trimline |
| Bulb syringe | Some Davol, Medline, RÜSCH, Premium, Baxter |
| Casts: Delta-Lite Podiatry, Orthoflex (J&J) | Scotchcast soft, Delta-Lites, recent Conformable Caraglas Ultra (J&J), liners (Gore) |
| Catheters: condom | Clear Advantage, ProSys NL, selected Coloplast, Rochester, PolyTech (Hollister) |
| Catheters: indwelling & systems, UDS | Some Am BioMed, Argyle, Bard, Cook, Dale, Kendall, Lifetech, Mentor/Coloplast, Rochester, RÜSCH, Vitaid, Adapters & plug (Addto) |
| Catheters: cardiac, vascular, pulmonary | Some World Medical, Am BioMed |
| Catheters: straight, coude, foley | Selected RobNel (Sherwood), Coloplast, Bard, RUSCH, Hollister, AstraTech, or Rochester catheters Be sure to check labeling on the box. Individual catheter packages are not always labeled. |
| Catheters: feeding | Accumark feeding catheter (Sims Portex) |
| Dressings: Dyna-flex, butterfly closures (J&J), Tensoplast (formerly Elastoplast), Action Wrap, Lyofoam (Acme), Spandage (Medi-tech), Telfa | Duoderm, Reston foam (3M), Opsite, Venigard, Comfeel, Sorbaview, Telfa (some) Xeroform, PinCare, Bioclusive, Montgomery strap (J&J), Webriil, Metalline, Selopor, OpraFlex, Centurion brief, some Airstrips, Rainbow Net (Surgilast), VAC, Warm-up |
| NOTE: latex in package only: Steri-strip wound closure system, Tegisorb, Active Strips (3M), Nu-Derm (J&J), CURAD | |
| Ear Plugs | Grainger (5F767) |
| Elastic wrap: ACE, Esmarch, Zimmer Dyna-flex, Dyna-flex, Elastikon (J&J), Coban (3M) | E-Cotton, CEB elastic (coNco), Champ (Carolon), Adban Adhesive, X-Mark (Avcor), Co-Flex (Tetra), PowerFlex (Andover), Comprilan (Jobst), Esmark (DeRoyal, NHP), 3M™ Coban™ LF Latex Free Self-Adherent Wrap, "CoFlex-AFD" and "Co-Flex NL" by Andover Healthcare |
| Electrode bulbs, pads, grounding | Some Baxter, Dantec EMG, Conmed, ValleyLab, Vermont Med, Staodyn, Neotrode |
| Endotracheal tubes, airways | Selected Berman, Mallinckrodt, Polamedco, Portex, RÜSCH, Sheridan, Shiley |
| Enemas | BabyLax, Enemeez, Bowel Management Tube (MIC), Pharmaseal set, all Fleet Ready-to-Use, cone irrigation set (Convatec), silicone retention cuff tip (Lafayette), Coloplast Cone Tip enema set |
| G-tubes, buttons | Silicone (Bard, Flexiflo, MIC, RÜSCH, Stomate) |
| Gloves: sterile, clean, surgical, orthodontic | Allergard (J&J), dermaprene (Ansell), N-DEX (Best), Safeskin Nitrile, Neolon, SensiCare, Tru-touch (Maxxim), Nitrex, Tactyl 1,2 (SmartPractice), Duraprene, (Allegiance Healthcare), Elastyren (Hermal, Center Labs), Boston Medical, Masel, Neotech, Biogel Skin Sense (Regent Medical) |
| Incentive deep breathing exerciser | Voldyne 5000 (Sherwood David & Geck), Triflo II |
| IV access: injection ports, Y-sites, bags, pumps, buretrol ports, PRN adapters, needleless systems | Polymer injection caps, burettes and Safsite (Braun), Abbot Systems, Walrus, Gemini (IMED), selected Baxter (InterLink), Statlock, Ready Med, ConMed, Clave, Alaris, Hudson, selected Sims, IV boards (Avcor), Terumo Pumps: Mach II, ADS 100, Clic-Open (vial top remover—Sepha Pharm) |

| Frequently contains LATEX | LATEX-Safe Alternatives |
|---|---|
| OR/Infection Control masks, hats, shoe covers | Some by Kimberly Clark, TECNOL, OR and sterile packs (CML, DeRoyal) twill ties |
| Ostomy supplies | Check with individual companies regarding latex content of products |
| Medication/Immunization vial stoppers | Some AmRegent, Astra, Bedford Labs, Fujisawa, Gensia, Glaxo, Lilly, Roche. Check the CDC website for up to date information at /www.cdc.gov/vaccines/pubs/pinkbook/downloads/appendices/B/latex-table.pdf |
| Miscellaneous items | Soft-Grip fabric clamp covers (Scanlan), Precision Dynamics ID bracelets |
| Penrose drains | Jackson-Pratt, Zimmer Hemovac |
| Pulse oximeters, thermometer probes | Nonin oximeters, selected Nellcor sensors, Diatec probe covers |
| Reflex hammers | Cover with plastic bag, Pedipals |
| Respirators | Advantage (MSA), HEPA-Tech (Uvex), PFR 95 (Tecnol), 3M 1860 |
| Resuscitators, manual | Certain Ambu, Armstrong, Laerdal, Puriton Bennett, Vital Blue, Respirationics, RÜSCH |
| Skin Adhesives | Mastisol (Ferndale) |
| Spacer (for metered dose inhalers) | ACE spacer (Center Labs), OptiHaler (HealthScan) |
| Stethoscope tubing | PVC (some Littman) cover with ScopeCoat or latex-free stockinette (Albahealth) |
| Suction tubing | PVC (Davol, Laerdal, Mallinckrodt, Superior, Yankauer) Medline, Ballard |
| Syringes, disposable | Terumo Medical, Abbott PCA Abboject, Norm-Ject (Air-Tite), EpiPen, selected BD syringes, AdvantaJet (Activa) |
| Tapes: pink, Waterproof (3M), Zonas, Moleskin cloth | Dermicel (J&J), Durapore, Microfoam, Micropore, Transpore (3M) Cath-Strip Molepad, Hytape Pink, STATtape |
| Waterproof (J&J), adhesive felt (Acme) | (Genetic Labs), Ice Tape (P.O.Pak), All-Felt (Universal Foot Care), Hypafix |
| Tonopen disposable covers (glaucoma tester) | None |
| Tourniquets | Children's Medical, GrafcO, VelcroPedic, X-Tourn straps (Avcor), Free-Band (Kent) |
| Theraband (also strip, tube), other OT supplies | REP Bands and Cords (OPTP), Exercise putty (Rolyan), new Thera-Band Exercisers |
| Tubing, sheeting | Plastic tubing—Tygon LR-40 (Norton), elastic thread, sheets (JPS Elastomerics) |
| Vascular/Compression stockings | Compriform Custom (Jobst), Latex Free TEDs, some varieties of Sigvaris |



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LATEX IN THE HOME & COMMUNITY

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. **Manufacturers are not required to label home and community products which contain natural rubber.** ALWAYS CHECK THE PRODUCTS PACKAGING. If in doubt regarding the safety of an item, call the manufacturer.

| Frequently contains LATEX | LATEX-Safe Alternatives |
|---|--|
| Balloons | Mylar balloons, Mister Balloon, plastic ballons |
| Balls: Koosh balls, tennis balls, bowling balls, ball pits | PVC (Hedstrom Sports Ball), Nerf Foam Balls, Gertie Balls, Googie Imperial Toys, AMF Bowling balls |
| 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 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 | PURO/M27 intraoral elastics (Midwest Orthodontic), wire springs, sealant (Delton) dams (Meer Dental, Hygenic Corp), John O Butler, Earloop masks (Richmond) |
| Diapers, incontinence pads, rubber pants | Huggies, First Quality, Gold Seal, Tranquility, Always, 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 | 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, Cushie Tushie Potty Seat, Bumbo Seat, Water Pik shower head and hose |
| Newsprint, ads, coupons, lottery scratch tickets | None |
| Pacifiers | Soothies (Children's Med Ventures), select 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 |

| 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) 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, masking tape, STATtape, Dixon/Ticonderoga Company (Erasers, Wooden Pencils and Art Supplies) |
| 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), Little Tikes, Playschool, Discovery, Trolls (Norfin), Silly-putty, some Fisher Price |
| 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 |



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THE JEFFRAS' PROGRAM THAT PROMOTES
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FOR STUDENTS WITH SPINA BIFIDA

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 their social development. The specific ways that SB and hydrocephalus influence social development are not yet fully understood, but school interactions are a vital and often challenging part of that growing process. Similar to children without disabilities, some children with SB are passive, and may require encouragement to get involved in activities; while others will need guidance and help to interact at an age appropriate level in group settings.

Successes in developing social skills in children with SB:

- Learning to strike up a conversation
- Knowing how to behave to make & maintain friends
- Learning to listen. Many children need extra help
- Developing a positive attitude
- Learning to interact in groups
- Learning to discuss SB with others

Encouraging social skill development:

- Give child feedback and positive messages
- Seek opportunities for participation in structured activities, including extra curricular programs
- Involve the child in mainstreamed education as much as possible
- Expect child to take responsibilities & be accountable
- Offer opportunities for the child to succeed and fail as a normal part of life experiences
- Offer opportunities for the child to "give back", by volunteering or other community activities

Factors that bolster social skill development:

- A variety of ways to interact, in & out the home
- Treating the child the same as non SB sibling.
- Participation in age appropriate (chronological and developmental) social groups
- Good hygiene
- Learning to deal with negative situations
- Frequent, open, honest communication between the school and parents

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 judgment; making decisions that put the child or teen at risk for injury, exploitation or abuse

ADDITIONAL RESOURCES

[Precocious Puberty Health Information Sheet](#)
[Men's Health Information Sheet](#)
[Women's Health Information Sheet](#)
[Preparations.org](#)



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EDUCATION ISSUES AMONG CHILDREN WITH SPINA BIFIDA

Children with SB may require extra support in school. This sheet explains some things about school that children with Spina Bifida and their families should know. They include:

- Evaluation and testing
- Getting into the right school and classes
- Getting the right services at school
- Meeting the child's social and emotional needs

Evaluation

In order to provide the right school environment for children with SB and Hydrocephalus, teachers and counselors need to identify children's strengths as well as areas where they need more support. For that reason, special testing is required. These tests help them to learn more about the child's intellect, achievements and general social and emotional functioning:

- Intelligence testing
- Academic testing
- Visual motor testing

Other tests might be given to help teachers and counselors learn more about a child's:

- Language ability
- Learning skills
- Social/emotional functioning

To get special services at school, the government requires these tests. Some people believe that the tests won't help, since their children are being compared with others who don't have disabilities. But for children with Spina Bifida, there are comparison data which provides substantial support for testing. This helps school systems find the right schools, classes and services.

When you start looking for help it is good to know about children with Spina Bifida and hydrocephalus in general, because most of this information relates the physical aspects of SB and hydrocephalus to intelligence and learning.

CHILDREN WITH SPINA BIFIDA & HYDROCEPHALUS OFTEN HAVE:

- Average IQs. But every child is different. So there can be a broad range of scores on IQ tests among children with Spina Bifida and hydrocephalus from exceptional performers to those with learning difficulties. Also, health problems may negatively impact performance
- Word skills and IQs higher than performance skills
- Poor hand-eye coordination, which could make things like hand-writing difficult
- Higher grades in reading and spelling than math (See SBA's reading / math competency info sheets)

Other Things to Know

- Verbal IQ scores are better at predicting how well a child will do at school than other parts of an IQ test
- The more the spinal cord is damaged, the greater the chance that a child will have learning problems.
- Children with severe hydrocephalus tend to have low IQs
- Even when children are very smart, other things will affect how well they do at school. These things are memory, comprehension, attention, impulsivity, sequencing, organization, and reasoning.

Memory, attention, sequencing, reasoning, etc. should be checked along with IQ. They are usually checked during a neuropsychological evaluation. These types of tests might check a child's ability to pay attention, impulsivity, or verbal learning. (See SBA's learning information sheet and the SB University presentation on non-verbal learning disorders.)

Once parents, teachers and counselors learn as much as they can from these tests, they must then use what they learned to help children get the most from school.

Testing for Everyone

Some parents ask if their children should have psychological or neuropsychological tests when they are already doing well at school. If a child is in early grades, it is important to have these tests done so future problem areas can be addressed early. It is especially important to learn about things like sequencing, organization and problem-solving. When children have problems in these areas, they tend to have less success as school gets harder. A difference usually is seen in 4th grade.

Interpreting Test Results & Placement

Many people think that once the test results are back, it will be easy to see what should be done for a child. This is not always true, because children with Spina Bifida and hydrocephalus show inconsistencies on these tests. Often, people assume that children with Spina Bifida and hydrocephalus who are not in a regular class will go in a class made for orthopedically handicapped (OH) children. This isn't always true. A child's learning disability usually is the biggest factor in this decision. Test scores may show that children could go in classes for children with mild to severe learning problems.

Knowing how to read the results and make decisions based on test scores is crucial. A child with Spina Bifida and hydrocephalus may have an average score on verbal IQ but below average in nonverbal IQ. This often makes the overall IQ score slightly below average. This does not necessarily substantiate placing a child in a class for those with severe learning problems.

Parents and educators must know that research shows that the verbal IQ is usually better at showing an SB child's overall functioning than the nonverbal IQ score. Nonverbal IQ is lowered by Spina Bifida, including hydrocephalus and Chiari malformation

Understanding this distinction is vital to ensure provision of the classes and services that are best for the child's needs. A psychologist can further explain the details of this.

Like all children, those with Spina Bifida can be placed in a range of classes. Parents, educators, health care professionals, and sometimes children must work together to choose the best option, which can become a part of the child's Individual Education Plan (IEP)

Learning problems

Beyond getting a child into the right classes, there are other decisions to make. Parents often ask how to work with the school if their children have perceptual motor, inattention, memory or other learning problems, but are in regular classes. Teachers often see these problems and will work with the parents and children. If a child is receiving special education services, the parent can ask that these problems be addressed in the IEP. More can be found in the SBA fact sheet "Learning Among Children with Spina Bifida" and the SB University presentation on non-verbal learning disorders.

Emotional Independence

Parents often hear from schools that their children aren't doing well because they are too dependent on the parents. Like all children, those with Spina Bifida may try to avoid school work, chores or personal care. This is normal. At the same time, some children with Spina Bifida and hydrocephalus can become too dependent on parents or others for things that they can do for themselves. Parents should be able to acknowledge this so they can help their children achieve emotional independence.

Homework

When a child has trouble with physical movement, board work and homework can be a problem. Most children with disabilities can identify alternative ways to learn. Therefore, it is often helpful for a child to have less homework as long as he or she is learning. Computers and calculators can be used to help with written work and math, which are often problems for children with Spina Bifida and hydrocephalus.

Drugs for ADHD

Some children require medication if they have problems paying attention or are easily distracted. These children might have Attention Deficit / Hyperactivity Disorder (ADHD). To know if a child has ADHD, he or she must see a health care provider who specializes in mental health issues. If the health care provider says the child has ADHD, then medications might be used. One indicator of successful treatment is a behavior change that is evident at both home and school.

Parents, teachers, older children and others must be aware of all these issues to provide the best education possible for children with Spina Bifida and hydrocephalus.

Children with Spina Bifida and hydrocephalus often have problems at school. So it is important to always focus on the child's best interests. When a student comes first, progress is possible.

Contributing Editor
Donald J. Lollar, EdD



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INDIVIDUAL EDUCATION PLAN (IEP)

What is an IEP?

An IEP is a written educational plan that is customized for one child. It is developed by a team of school personnel, the child and a parent or guardian. The IEP addresses a child's unique needs, and presents previous assessment information in relation to the current environment and classroom expectations in order to provide the most supportive and educational environment.

Why was it created and how does it work?

All special education services, policies and procedures are governed by the IDEA(A) – the Individuals with Disabilities Education Act, reauthorized in 2004. Those with disabilities are eligible for services and support from birth through age 22.

Most children with Spina Bifida (SB) should be eligible for special education within the public education system. Eligibility is determined by evidence that there is a disabling condition that adversely affects the education of the student in the regular education classroom.

There are 13 categories of disability covered by special education law. Most children with SB would qualify under the category of orthopedic impairment. However, parents and others should be cautioned that classifying students in this way does not mean that other emerging disabilities or areas of

academic weakness (learning disabilities, attention problems, etc.) do not need to be addressed by special education services provided.

Once the child is classified and found eligible for special education, all areas of development and academic progress in which the child is struggling should be discussed and addressed by their specialized educational program.

For every child receiving special education service, an Individual Education Plan (IEP) is mandated. This document should be reviewed and rewritten annually.

In addition, this IEP should be shared with and followed by all school personnel involved in the student's educational program. Each school district or state education system may have their own document and procedures for implementation, but federal regulations mandate a fairly uniform document which includes all of the following components:

1. Identification of the disability category under which the child qualifies for services.
2. Present level of performance - a review of the student's current functional levels, including identification and description of areas of both strengths and weaknesses.
3. Annual goals for each area in which the child is not on or above grade level or age appropriate competence and a list of measurable short term goals designed to guide the student's academic program toward those annual goals. Measures of performance should also be included in this section

(specific descriptions of how and when assessment will be done to monitor progress toward short term objectives and annual goals.

4. Educational placement - where the services will be delivered. One of the principle guarantees under the law is the least restrictive environment (LRE). This guarantees that special education services will be provided in a setting that mirrors general classroom education with non-disabled peers as closely as possible without sacrificing adequate educational services. The placement decision is one of the most critical ones for students and their parents or guardians. There are many pros and cons to both general classroom placement and alternative placements such as inclusion classrooms, resource room instruction, self-contained special education classroom, or even specialized schools.

5. Identification of any related services that will be provided to the student, such as speech therapy, physical therapy, counseling, etc. Federal law mandates that any of these services determined to be appropriate be provided at no cost to families.

6. Identification of any auxiliary aides necessary to facilitate learning, such as classroom computers or other technology tools, listening or speaking devices, or personal aides. These auxiliary aides must also be provided at no cost to families.

7. Accommodations are adjustments made in order to "level the playing field" during educational assessment or testing. These may include: additional time to complete assignments or tests, scribes for tests, or use of computers / calculators during assessments. Accommodations are particularly important in light of recent trends in many states toward high stakes standardized testing for accountability purposes. Students with disabilities and students receiving special education services are often inherently disadvantaged by these kinds of assessments. Parents (and students) should be aware of the following: whether or not their child will be required to participate in district wide standardized tests, what impact these tests may have on their child's academic program, and what specific accommodations will be implemented in order to

lessen the impact of the disability on test performance.

8. An Individual Transition Plan (ITP) is for all students 14 and older. This plan should establish annual goals related to post-secondary planning, such as: transportation, post-secondary education, independent living and employment.

Parents and students should actively participate in the IEP process on an annual basis. They should attend IEP meetings whenever they are scheduled, and come to the meetings prepared to ask important questions about placement, assessments and proposed annual goals.

Special Education Guarantee

1. Notification & Consent - schools must notify parents or guardians of any planned discussions about classification (the labeling of a student's disability to make them eligible for special education), IEP development or any changes in the student's placement or program. Lack of response to meeting invitations on the parent's part can be interpreted as implicit agreement with the committee's decisions.

2. Procedural Safeguards - All students eligible for special education services and their parents or guardians are entitled to due process with regard to the airing of grievances. Current law provides for mediation, impartial hearings and the right to seek representation by an advocate or lawyer. For more detailed information regarding procedural safeguards and legal rights under IDEA, please see go to: idea.ed.gov

3. Academic Progress/Educational Benefit -IDEA(A) guarantees that services provided will produce demonstrable benefit and academic achievement. One of the reasons that IEP's must be reviewed and updated annually is so all parties can ensure that services are effective and IEP goals are resulting in adequate progress. Practices that are not resulting in positive outcomes can and should be altered.

The IEP Committee

The team of individuals involved in the writing and review of the IEP should consist of:

- At least one special education teacher (preferably one directly involved in the student's services)
- At least one of the student's general education teachers
- A representative of the school, such as an assistant principal, guidance counselor or other school administrator
- A professional who can interpret any assessment data, such as a school psychologist
- A parent or guardian
- The student, if appropriate

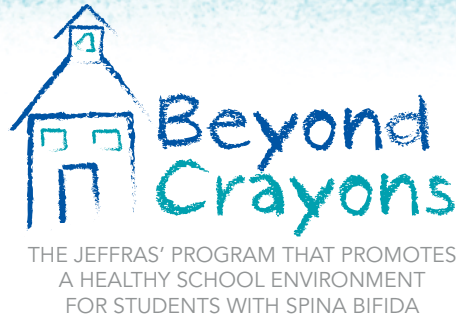
The IEP committee may also include related service personnel with knowledge of the student's needs such as: adaptive physical education teacher, speech therapist, guidance counselor, etc.

ADDITIONAL RESOURCES

ncl.org/students-disabilities/iep-504-plan/what-is-iep-parentcenterhub.org



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SECTION 504 PLAN

Background

Spina Bifida is the most common permanently disabling birth defect in the United States. Spina Bifida occurs when the spine of the baby fails to close. This creates an opening, or lesion, on the spinal column. This takes place during the first month of pregnancy when the spinal column and brain, or neural tube, is formed. This happens before most women even know they are pregnant. Because of the opening on the spinal column, the nerves in the spinal column may be damaged and not work properly. This results in some degree of paralysis. The higher the lesion is on the spinal column, the greater the paralysis. Surgery to close the spine is generally done within hours after birth. Surgery helps to reduce the risk of infection and to protect the spinal cord from greater damage.

The effects of Spina Bifida are different for every person. It is a life-long disability with ongoing medical challenges. Up to 90% of those born with the most severe form, myelomeningocele, also have hydrocephalus (fluid on the brain) and must have surgery to insert a "shunt" that helps drain the fluid. The shunt stays in place for the lifetime of the person and often needs to be adjusted with multiple surgeries as people grow and get older. Other conditions that are common for people with Spina Bifida include full or partial paralysis, nervous system complications, bladder and bowel control difficulties, learning disabilities, depression, latex allergy, and social and sexual issues. Quite often, however, they must have a series of operations throughout their childhood. Shunt Malfunction and latex allergy reactions are the most common health emergencies for students with Spina Bifida.

Plan Objectives & Goals

Successful integration of a child with Spina Bifida into school sometimes requires changes in school equipment or the curriculum. In adapting the school setting for the child with Spina Bifida, architectural factors should be considered. Section 504 of the Rehabilitation Act of 1973 requires programs that receive federal funding to make their facilities accessible. This can occur through structural changes (for example, adding elevators or ramps) or through schedule and location changes (for example, offering a course on the ground floor).

The student has a recognized disability, Spina Bifida, that requires the accommodations and modifications set out in this plan to ensure that the student has the same opportunities and conditions for learning and academic testing as classmates, with minimal disruption of the student's regular school schedule and with minimal time away from the classroom.

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Definitions used in this Plan

Myelomeningocele: This defect occurs when the meninges (protective covering of the spinal cord) and spinal nerves come through the open part of the spine. This is the most serious type of Spina Bifida; it causes nerve damage and severe disabilities.

Hydrocephalus, or water on the brain, occurs in 70-90% of myelomeningocele cases, and without treatment, mental retardation or death may result.

Meningocele: The protective coverings (meninges) come through the open part of the spine like a sac that is pushed out. Cerebrospinal fluid is in the sac and there is usually no nerve damage. Individuals usually suffer only minor disabilities. New problems can develop later in life.

Occulta: Spina Bifida Occulta is often called hidden Spina Bifida. In this usually harmless form of Spina Bifida, the spinal cord and the nerves are usually normal and there is no opening on the back. There is a small defect or gap in a few of the small bones (vertebrae) that make up the spine. The underlying defect is completely covered with skin. Frequently, there are telltale signs on close examination of the back. Although there may be no motor or sensory impairments evident at birth, subtle, progressive neurological deterioration may become evident in later childhood or adulthood.

Academic Accommodations

1. BOWEL AND BLADDER MANAGEMENT AND TRAINING

Many children with Spina Bifida need training to learn to manage their bowel and bladder functions. Some require catheterization, or the insertion of a tube to permit passage of urine. The courts have held that clean, intermittent catheterization is necessary to help the child benefit from and have access to special education and related services. The age at which a child begins to work toward urinary continence is individualized based on their physical capabilities and social situation. When a urinary continence program is initiated, it should be continued in a structured school environment. A successful bladder management program can be

incorporated into the regular school day.

2. EDUCATIONAL ISSUES

Children with Spina Bifida/Hydrocephalus often show unique learning strengths and weaknesses that affect their schoolwork. Parents and schools need to work together to help young people meet their physical, social, emotional, and academic goals. In order to fully evaluate the effects of Spina Bifida on development (such as intelligence, academic levels, visual perception and receptive and expressive language skills) it is often important to refer the child to have a special education assessment. Neuropsychological evaluations can provide more specific insight to changes in brain development and their effects on intelligence, language, learning, and development. These may include attention span, perceptual-motor processes, reasoning and problem solving, organization and sequencing skills, and memory. It is important for teachers to identify these problems early by watching for restlessness, distractibility, and forgetfulness. Difficulties may include:

ATTENTION

It is common for children with Spina Bifida to struggle with paying attention. They might miss assignments, mis-copy the assignments or work, be generally slow in completing work, or miss social cues from others. They generally are better able to pay attention when listening than when seeing.

Suggestions:

1. Seat child in the front row or near the teacher to reduce distractions.
2. Gain attention and eye contact prior to instructions.
3. Give clear, simple, step-by-step instructions and repeat if necessary. Check that the child understands what is expected of him/her.
4. Make short assignments that can be completed successfully.

COMPREHENSION

Children with Spina Bifida sometimes have a hard time understanding things even though they seem to understand. For example, some seem to speak well, but when they have to explain what they understood or respond to questions, they seem disorganized, and talk about irrelevant things.

Suggestions:

1. Use demonstrations and simplified expressions to help the child "get a picture" of what is being said

(or read).

2. As the child begins to read, talk with him/her about what he/she is reading to be sure he/she understands the content.
3. Help the child capture "the main idea" of a story, movie or conversation.

HANDWRITING DIFFICULTIES

Children with Spina Bifida often find handwriting to be a laborious task, with the end product being barely legible. Poor handwriting can stem from poorly developed hand and fine motor control, as well as problems with visual discrimination, and spatial judgment.

Suggestions:

1. Teach directionality of words and sentences.
2. Encourage the use of special grips on pencils or chubby pens.
3. Encourage correct posture for neater work.
4. Encourage the consistent use of one hand.
5. Systematic teaching of writing skills.
6. Focus on letter formation and the appearance of finished letters.

MEMORY

Children with Spina Bifida often have difficulty remembering things they see or hear. Even if they understand it, they may not remember it later. Children with this problem may find it difficult copying work from the blackboard and may only be able to remember one word at a time.

Suggestions:

1. Give brief, clear, simple instructions to compensate for poor short-term memory.
2. Repetition of information is often helpful for these children, like when they are learning multiplication tables or spelling words.
3. Teach and encourage the use of note-taking, outlining and summary skills.

ORGANIZATION AND PLANNING

Children with Spina Bifida may have trouble keeping things organized. This is clearly seen when school materials, papers, etc. need to be in order. Things tend to get lost or misplaced. This creates frustration, anxiety and anger among parents, teachers and at times even the child.

Suggestions:

1. Lead by example. Keep your own things organized. It may be helpful to place children with highly organized and structured teachers.

2. Reduce verbal explanations that are confusing; don't explain everything.
3. Limit the number of items that have to be used at one time.
4. Encourage organized work habits and explicitly explain basic strategies.

3. HYDROCEPHALUS

Many children with Spina Bifida also have hydrocephalus and require a shunt. The most common problems with shunts are that they can plug, obstruct, break or come apart, resulting in shunt malfunction. The signs of shunt malfunction are varied and can be confusing for everyone involved, but more importantly, they can sometimes be life threatening. Teachers must be aware of the symptoms of shunt malfunction.

COMMON SYMPTOMS

1. Headache
2. Nausea
3. Vomiting

LESS COMMON SYMPTOMS

1. Seizures
2. Change in intellect, performance, or personality
3. Increased swallowing problems
4. Worsening muscle function, balance, coordination
5. Worsening bowel or bladder function
6. Worsening scoliosis or orthopedic deformities
7. Pain at the Spina Bifida closure site

4. LATEX ALLERGY

People with Spina Bifida are at a significant risk of being allergic to natural rubber latex. Research studies have shown that up to 73% of people with Spina Bifida are sensitive to latex, meaning that exposure to it can cause serious health problems. This allergic sensitivity may even be so severe as to be life – threatening. Latex is often a hidden ingredient in consumer products. Gloves used in food preparation, balloons used in festive displays, and chopsticks among other items often contain latex.

The powder from balloons or gloves can absorb latex proteins and become airborne, causing reactions when breathed or touched by a latex sensitive person. Allergic reactions to latex proteins

can include watery and itchy eyes, sneezing and coughing, rash or hives, swelling of the windpipe, wheezing, difficulty breathing and/or the life-threatening collapse of circulation called anaphylactic shock. The only way to prevent allergic reactions to latex is by avoiding contact with items containing latex or latex contaminated powder. People who have allergic reactions to latex may also have food allergies, including: bananas, tomatoes, potatoes, avocados, and kiwi fruit.

Frequent concerns in the school setting often include use of rubber bands to store writing utensils and workbooks, laboratory supplies (e.g., gloves, Bunsen burner tubing), playground equipment (e.g., large rubber balls), and toys brought by other children into the classroom. In case of accidental exposure, it is important to contact the school nurse immediately.

5. EXERCISE AND PHYSICAL ACTIVITY

The student should participate fully in physical education classes and team sports. Physical education instructors and sports coaches must be able to assist with the participation in activities.

6. WATER AND BATHROOM ACCESS

The student shall be permitted to have immediate access to the bathroom or a private location to perform intermittent catheterization. The student shall be permitted to use the bathroom without restriction.

7. FIELD TRIPS & ACTIVITIES

The student will be permitted to participate in all field trips and extracurricular activities (such as sports, clubs, and enrichment programs) without restriction and with all of the accommodations, including necessary supervision by identified school personnel, set out in this plan.

The school nurse or other identified and trained personnel, if the school nurse is not available, will accompany the student on all field trips and extracurricular activities away from the school premises and will provide all usual aspects of care if needed (including catheterization). The school nurse or other personnel, when the school nurse is not

available, will be available at the site of all extracurricular activities that take place both on and away from the school premises. The school nurse or other personnel must be on the school premises or at the location where the activity is taking place whenever the student is participating in the activity. The student's catheterization and other medical supplies (e.g., epi-pen) will travel with the student to any field trip or extracurricular activity on or away from the school premises.

8. TESTS AND CLASSROOM WORK

If the student is feeling ill, they must have someone accompany them when leaving the room. Attempts should be made to allow for breaks in scheduling to address medical needs (e.g., access to water fountain, catheterization) in order to decrease the amount of instructional time missed. If this cannot be accomplished successfully, the student should be allowed time to make up examinations and coursework that they missed during the necessary break. The student should not be penalized for requiring the break through lower grades or reduced access to curriculum instruction.

The student should have no penalties for standardized testing when interrupted with Spina Bifida-related issues. For example: If he/she takes out 10 minutes for Spina Bifida management, 10 minutes of make-up time will be given.

The student shall not be penalized for absences required for medical appointments and/or for illness. The student will be allowed to make-up work missed due to time used to manage Spina Bifida-related problems or surgeries.

9. EMERGENCY EVACUATIONS

In the event of emergency evacuation or shelter-in-place situation, this 504 Plan will remain in full force and effect.

While the school nurse is responsible for caring for the student in an emergency evacuation, other school personnel will provide care if he/she is not available, as outlined in the 504 Plan. The school nurse or other identified personnel will be responsible for transporting the student's supplies, medication, and food to the evacuation or

shelter-in-place location. The school nurse or other personnel will remain in contact with the student's parents/guardians during an evacuation or shelter-in-place situation and provide updates about the student's health status and receive orders and information from parents and guardians regarding the student's care.

The student's parents and guardians will be permitted to pick up the student without any unnecessary delays as soon as the student can be safely discharged.

10. EQUAL TREATMENT & ENCOURAGEMENT

Encouragement is essential. While the school nurse is responsible for caring for the student in an emergency evacuation, other school personnel will provide care if he/she is not available, as outlined in the 504 Plan. The student shall be provided with privacy for intermittent catheterization. The school nurse and other staff will keep the student's Spina Bifida confidential, except to the extent that the student openly communicates about it with others.

11. IMMEDIATE PARENTAL NOTIFICATION

Notify parents/guardians immediately in the following situations:

- Symptoms of shunt malfunction or any other unusual symptoms such as continuous crying, headache, nausea, vomiting, extreme tiredness, or loss of consciousness.
- The student has a change in intellect, school performance or personality.
- The student has bowel/bladder-related accidents.
- The student refuses to eat or participate in the educational process.
- Any injury.
- Other: _____

EMERGENCY CONTACT INSTRUCTIONS

1. Call the home.
2. If unable to reach parent/guardian, call cell or work
3. If unable to reach parent/guardian, repeat steps for other parent/guardian.
4. If unable to reach parent/guardian, call the other emergency contacts.

EMERGENCY CONTACTS:

Parents/Guardians:

Name: _____

Home Phone: _____

Work Phone: _____

Cell Phone: _____

Name: _____

Home Phone: _____

Work Phone: _____

Cell Phone: _____

Other Emergency Contacts:

Name: _____

Home Phone: _____

Work Phone: _____

Cell Phone: _____

Name: _____

Home Phone: _____

Work Phone: _____

Cell Phone: _____

Student's Physicians:

Name: _____

Phone: _____

Name: _____

Phone: _____

SECTION 504 PLAN FOR:

Student: _____

School: _____

School Year: _____

Homeroom Teacher: _____

Bus Number: _____

Student's Birth Date: _____

Grade: _____

Disability: Spina Bifida

Diagnosis:

Myelomeningocele

Meningocele

Occulta

Hydrocephalus

Additional: _____

This Plan shall be reviewed and amended at the beginning of each school year or more often if necessary. Ongoing evaluation and monitoring is requested to assess the need for services.

APPROVED & RECEIVED:

Parent/Guardian: _____

Date: _____

Parent/Guardian: _____

Date: _____

APPROVED & RECEIVED:

School Representative: _____

Title: _____

Date: _____

School Representative: _____

Title: _____

Date: _____



This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.
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THE JEFFRAS' PROGRAM THAT PROMOTES
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MATH DIFFICULTIES & SPINA BIFIDA

Preschool

Many of the skills necessary for math begin to develop during the preschool years. There are many opportunities for preschoolers to learn these skills, both at home and school. For instance:

- Practice counting with your preschooler throughout the day, such as the number of toys, pencils, chairs, etc.
- Help your child learn to sort items by category by having him or her separate a group of items based upon shared characteristics (e.g., "Put the animal toys in this pile and put the baby dolls in this other pile. Let's count how many baby dolls you have. Do you have more animal toys or baby dolls?").
- Help your child learn concepts such as more and less by comparing different groups of items. For instance, create two unequal groups of items (e.g., blocks, pennies, etc.) and help your child learn to identify the group of items that has more or less. Help your child to focus on "number" by having them double-check their decisions about "more" and "less" by counting objects to be compared. For example, young children often think that the longer display of items has "more" even when it has the same number or even fewer items than a shorter display.
- Sharing of a pizza or other food by cutting it into equal pieces is an early form of division. Help your child to count the people, divide the food, and distribute it to each person one at a time.

- Play fun counting games that happen to have math concepts embedded in them, such as Candyland®, dominos, etc.
- Help your child to recognize and label simple shapes such as a square, a triangle, or a circle.

Kindergarten & Elementary School

Building Number Sense

Number sense is the building block for many areas of mathematics, including calculations. Number sense is the ability to understand the actual size of a number (e.g., 1 is smaller than 10, 10 is smaller than 100).

Children with Spina Bida often have difficulty understanding the actual size of different numbers, and may have difficulty identifying how far apart numbers are from each other on a "mental number line." For instance, it might be difficult for a youngster with Spina Bifida to identify which of the following two numbers (the number 9 or the number 19) is furthest away from the number 12. If this is a problem, children with Spina Bifida should practice making these kinds of comparisons using an actual number line in order to help them see the size of differences between numbers. Learning the size of differences between numbers on a number line helps build number sense in general.

Another way to build number sense is to find fun ways to learn different math combinations. A deck of playing cards (without the face cards) can be used to play "plus zero", "plus one", "minus one", etc., and build understanding of number combinations along the way. For instance, state the game (i.e., "add zero to every card I show you"), and then quickly go through the deck, allowing the child to add zero to each number shown. This helps the child begin to memorize the idea of "adding on," or "subtracting from," and begins to make it more automatic.

Problems with number sense can also result in children with Spina Bifida having difficulty comparing different amounts of items and judging which group has more simply by looking at them. For instance, a child with Spina Bifida may have difficulty "eyeballing" two groups of dots (when comparing a group of 11 dots to a group of 17 dots) and quickly deciding which group has the most items without counting them. Children with Spina Bifida can improve their number sense by practicing these types of comparisons, and quickly determining which group has the most items simply by "how big it looks." Children can then count the dots to check the accuracy of their answers (while also practicing adding skills).

As youth with Spina Bifida move further into elementary school, the need to develop number sense continues. Each grade presents larger number sets and concepts to be understood. One way of encouraging the ongoing development of number sense is to present the child with examples from real world situations. This helps students with Spina Bifida begin to understand "why" they are learning a particular skill. Teachers can support this by referencing the importance to math skills to different careers and by teaching meaningful student-centered problems (money, time, calendar, budgets, probability, data, etc) so students see the value in number and mathematics.

While classroom accommodations such as calculators can be helpful, many youth with Spina Bifida require special intervention to address their level of learning disability in number sense. Early screening of math skills is recommended for children

with Spina Bifida. Problems with number sense can be identified at an early age (e.g., age 5 or 6).

Understanding math procedures

Math calculation includes many different procedures, and children with Spina Bifida often have difficulty learning to use these procedures (e.g., borrowing carrying, long division). Even when youth with Spina Bifida learn these math procedures, many have trouble remembering to use them consistently. Several approaches can be helpful in improving a child's understanding of math procedures:

1. Set a goal of helping the youth with Spina Bifida develop an understanding of each math procedure, rather than simply learning the steps of doing them on paper.
2. Sometimes the use of "word pictures" can help develop an understanding of math procedures ["For this problem, I will be taking a smaller piece (i.e., 48) out of this larger piece (i.e., 92)"].
3. It is important that children with Spina Bifida spend time mastering math vocabulary, so that they recognize these terms when presented with "word problems." Math vocabulary is best taught with a corresponding visual or example problem. Word walls, picture glossaries, journals and problems of the day are helpful tools to reinforce math vocabulary. A new math vocabulary word should be introduced with classroom discussion, visuals, and then reviewed often to ensure understanding.
4. Many of the mistakes youth with Spina Bifida make when completing math procedures occur when they "go on cruise control" and do not keep the math concept "in mind" when doing the problem. For instance, when working on a problem $92-48$, the student might simply start subtracting numbers (e.g., $8-2$; $9-4$) without remaining aware that he or she is "subtracting this smaller number (i.e., 48) from this larger number (i.e., 92)."
5. Students with Spina Bifida should be encouraged to "think out loud" when completing a problem. Listening closely as the student "thinks out loud" will allow the teacher to quickly provide immediate error correction so that the student doesn't keep working in the "wrong direction." This will also help the

teacher assess conceptual understanding and awareness, and will help avoid careless “slips” and calculation mistakes. In math, it is very important to kindly correct errors immediately so that wrong procedures do not become habits.

6. Students with Spina Bifida should learn to “work backwards” (i.e., inverse operations) as a way of checking their work for accuracy. For instance, after completing the problem 92-48, the student should add their answer to the number 48 to see if it equals 92.

7. Another way to assess the “reasonableness” of answers to math problems is to generate a second answer using “rounded” values. For instance:

- The student with Spina Bifida calculates an answer to the question $92-48=$ _____.
- The student then rounds each of the numbers of the question to the nearest 10, (e.g., 90 & 50).
- The student calculates an answer to the question using the rounded values (e.g., “ $90-50=40$ ”).
- The student’s answer to the original question is “reasonable” if it is somewhat above or somewhat below 40.

Early and periodic screening of math skills is recommended for students with Spina Bifida. Early problems with the acquisition of math procedures can be identified by 2nd or 3rd grade. However, as new math procedures continue to be learned as students advance in grade, close monitoring of math progress is recommended.

While not the focus of this tip sheet, there are additional intervention strategies for older youth with math difficulties which may also be helpful when they are presented with word problems, geometry, algebra, etc. These interventions and accommodations include direct and explicit instructions, presenting information in a step by step manner, presentation of examples and models, low student:teacher ratio, and using meaningful manipulatives.

ADDITIONAL RESOURCES

illumination.nctm.org
nctm.org
interventioncentral.com
thinkfinity.org
calculationnation.nctm.org
econedlink.org
nlvm.usu.edu/en/nav/vlibrary.html
fun4thebrain.com
superkids.com

TEACHER RESOURCES

Direct Instruction Techniques Found To Be Effective for Math Disability
(Carnine et al 1991)

Explicit Instruction in Procedural Math Skills and Conceptual Math Knowledge
(Fuchs et al 2001, 2002)

Peer Meditated Practice
(Fuchs et al 2001, 2002)

Teacher Modeling To Improve Math Computation and Problem Solving
(Rivera & Smith 1987)

Explicit Instruction in Problem Solving Rules
(Fuchs et al 2003 a&b)

Teaching Word Problems of a Similar Type (e.g., addition word problem with similar syntax) Together To Improve Generalizability
(Quilici & Mayer 1996, Fuchs et al 2003 a&b)

Teaching Word Problem Solving Specifically for Children and Adolescents with Spina Bifida
(Coughlin & Montague 2010)



SPINA BIFIDA
ASSOCIATION

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THE JEFFRAS' PROGRAM THAT PROMOTES
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READING COMPREHENSION DIFFICULTIES & SB

Preschool

Many of the skills that are necessary for reading comprehension begin to develop during the preschool years and earlier. Early skills that support reading comprehension involve many of the same oral language and listening comprehension skills that young children acquire through interactions with parents and peers at home, during play, in preschool settings, and in the community. During preschool, other skills that contribute to the development of language skills will lay the groundwork for reading comprehension once the child acquires the ability to decode words. Early skills that create a foundation for later reading comprehension include:

- Learning the meanings of new words
- Learning to ask and answer questions during conversations, when listening to stories, & during shared book reading times
- Learning to predict or anticipate what might happen next in a social situation or in a story
- Learning to summarize or retell a story or an event to others

There are many opportunities for preschoolers to learn these skills, both at home and in school programs. For instance:

- Ask "why" type questions throughout the day to help teach cause and effect relationships (e.g., Why do you think we need to feed the dog every day?, Why do we have houses?, Why do we have policemen?)

- Give the child the chance to draw conclusions from different pieces of information (e.g., It's snowing outside and a re is roaring in t replace...what time of the year do you think it is?)

- Ask the child to look at pictures and describe what he or she sees. This provides a good opportunity to draw conclusions based upon details (e.g., If the child describes a picture of children playing, ask if the children are getting along or not? How can you tell? What activity are they doing?)

- Provide the pre-school child with simple chores and self-care responsibilities. Help the child learn to think through "what to do if?" situations that may occur during chores or self-care responsibilities (e.g., What should you do if you run out of pet food?, What should you do when it rains?, What should you do if you have a cold?)

Like all children, preschoolers with Spina Bifida benefit greatly from being read to by their parents and teachers. When reading to a preschool child, it is important to talk about the stories and ask questions about it. Stopping to discuss the story or ask questions is a good way to show the child how to think about what he or she is hearing. It also provides a model for how to be an "active" reader. For instance, pause occasionally while reading and have the child "fill in" missing details or make predictions about what will happen next. However, it is also important to not disrupt the flow of the story too often (which can interfere with comprehension and interest). Rereading short parts of the text to maintain flow and coherence can be helpful.

Kindergarten & Elementary School

Children with Spina Bifida are often successful in developing single-word reading skills during early elementary school. However, children with Spina Bifida often have more difficulty understanding what they are reading (i.e., reading comprehension). Because of this, early screening for listening comprehension and reading comprehension are recommended for children with Spina Bifida, particularly around second or third grade.

If mild reading comprehension problems are found, accommodations and interventions for reading comprehension problems should be provided by the teacher in the classroom and used by the parents at home. Teachers should help parents learn reading comprehension approaches they can use with their children.

While some reading comprehension problems can be addressed in the classroom setting, many youth with Spina Bifida have difficulties that require special intervention strategies. Special intervention strategies used by the school should be "evidence-based" approaches. Evidence based approaches are techniques that have been shown to work with children with similar learning disabilities.

An important goal of the interventions should be to make the youth with Spina Bifida an "active reader," rather than letting the youth simply read "on cruise control." It is important to teach the youth to "slow down" while reading, and learn how to "think about reading." One useful way of doing this is to teach and use clear comprehension strategies that can be used before, during, and after reading.

Before Reading:

1. Before starting a book, help the child orient to it by taking a "bookwalk." A bookwalk includes previewing the book by talking about things like its cover, the title, chapter names, the length of the book, pictures, picture captions, the difficulty level of

the words used, etc. Parents and teachers should model this type of bookwalk process for the child so that he or she can learn to do this independently.

2. If unfamiliar words are found in the bookwalk, it will be important for the child to look the words up in an electronic dictionary to help build their reading vocabulary. Efforts should also be focus on helping children learn to identify the meaning of unfamiliar words using the surrounding details of the story.

3. After previewing the book, help the child identify a purpose/goal for reading before starting (e.g., "Why am I reading this text?" Is it for entertainment?, To learn information?, To hear a persuasive argument?, To answer comprehension questions?)

4. If the reading assignment requires the child to answer reading comprehension questions, teach the child to read the comprehension questions before reading the text/story. It is also helpful to assist the child in identifying what type of information they will need to answer each comprehension question (e.g., should he or she be looking for a specific piece of information such as a date or name, or does the question require him or her to draw some type of conclusion from the information in the text?)

5. Help the child learn to make predictions about books and reading passages before reading them. Predictions can be based upon the child's own experiences, things he or she has read before, and information he or she may have heard through TV, computers, etc. For instance, when previewing a book about Babe Ruth, the child may predict that the book will be about baseball ("I've seen a picture of Babe Ruth and he was wearing a baseball uniform"), New York City ("Babe Ruth plays for a team from New York"), or the early 20th century ("The picture on the cover of the book is black and white and the clothes look old-fashioned"). The child should also review any prior knowledge they have about the subject ("What do you already know about Babe Ruth?")

6. Predictions should also include what the child thinks he or she will learn from the book or reading passages ("I think I'll learn about Babe Ruth's baseball career.")

During Reading

1. The child should be taught to highlight important details as they read. Highlighting also facilitates re-reading, which can increase comprehension.

2. Model/teach "thinking out loud strategies" when you read to the child, or when the child is reading aloud to you. Asking and answering questions while reading is an important way of monitoring the child's comprehension of the reading passage and avoiding the practice of "reading on cruise control." When reading with a child, watch to make sure they don't lose focus. Don't be afraid to stop and go back, re-read to improve understanding, and discuss what may be confusing.

3. Much of the "thinking out loud" approach can include asking questions about how accurate the child was regarding the predictions he or she made before reading the story (e.g., "Is this what you expected to happen when you started reading this story?" "We thought this book about Babe Ruth would be about New York and playing baseball there, but the first several chapters have been about Baltimore.") These types of questions can be used to clarify understanding of the reading material, raise new questions about the story ("I wonder what happened that led to Babe Ruth playing in New York?"), and can lead to making new predictions about the story ("Maybe Babe Ruth didn't like playing in other cities.")

4. As the child asks questions and assesses the accuracy of his or her predictions about the story, the child begins to make connections to it and learns important facts and information. To help organize information the child is learning during reading, he or she should be taught to transfer it into learning aids such as graphic organizers (e.g., outlines and "story webs".)

After Reading:

1. After reading the story/text, help the child assess how accurate he or she was with regards to what they predicted would happen in the story. Also, help the child identify any unresolved questions. Many questions about a reading passage have clear answers (Who? What? Where?) that can usually be found directly in the text (e.g., "Babe Ruth was born in Baltimore."). Answers to other questions (Why? How? What if?) are sometimes only indirectly available (e.g., "Did Babe Ruth like growing up in Maryland?"), and must be answered using available clues. Answering these types of questions helps the child learn to summarize the reading passage and make applications/connections to it.

2. Children should be encouraged to go back and review reading passages after they have read them. This is an opportunity to clarify their understanding of the story/text and identify the answers to comprehension questions. Because children with Spina Bifida can be slow but accurate readers, rereading may help their comprehension because their reading will be faster the second time, allowing them to focus more of their mental effort on the meaning of what they are reading.

Additional Ideas

There are now many available intervention curriculums which target reading comprehension.

The goal of reading comprehension intervention for children with Spina Bifida should be to gradually shift the responsibility for "active reading" away from the teacher/parent to the student (e.g., the teacher takes an "I do, you do, we do" approach).

As children sometimes grow weary of re-reading stories or texts, it may be helpful to get a text-to-speech program which can "read" the information to the child several additional times after he or she has read it on their own.

ADDITIONAL RESOURCES

www.readwritethink.org
www.ira.org (International Reading Association)
NTCE (National Council of Teachers of English)
www.thinkfinity.org
www.fccr.org
www.lida.org
www.whatworks.ed.gov

TEACHER RESOURCES

Activation of Background Knowledge During Reading
(Vaughn & Klingner 2004)

Collaborative Strategic Reading
(Vaughn, Klingner & Bryant 2001)

Asking the Student Questions During Reading and the Learning Strategies Curriculum
(Shumaker, Deshler & McKnight 2002)

Explicit Teaching of Vocabulary To Promote Understanding During Reading
(Hughes et al 2002, Swanson 1999, Clark & Uhry 1995; Swanson 1999, NRP 2000)

Use of Graphic Organizers (e.g., semantic maps, world maps)
(Kim, Vaughn, Wanzek & Wei 2004)

Peer Assisted Learning Strategies
(Saenz, Fuchs & Fuchs 2005)

Theme Identification Program that Teaches Text Structure
(Williams, 2002; 2003)

Contributing Editor
Dr. Marcia Barnes



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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> |



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

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 (SB) varies according to level and severity of the deformity, presence of hydrocephalus and other associated conditions.

There is no specific physical education program that can apply to all children with SB.

Consider the following for developing an adapted physical education plan for a student with SB:

- Deformities (hip, knee, foot, 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 SB (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 SB should be permitted to use the bathroom for catheterization, bowel management or to change soiled clothing as needed.

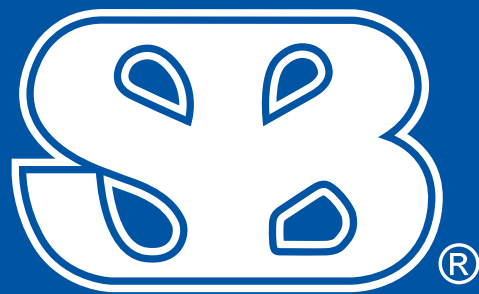
- Abdominal, orthopedic or neurological surgeries are common in children with SB. Postoperative orders should be followed until the child is healthy enough for full participation.
- Avoid using latex products in the physical education environment. (Refer to latex list in schools, courtesy of Latex Allergy Association of America).
- When planning physical education activities, consider that children with SB may have hand-eye limitations and slower response times.
- Cognitive function varies in children with SB. Cognitive function includes: attention span, ability to compete or self advocate, developmental stage in relation to chronological age, the ability to follow instructions, understand rules, use equipment and be safe in the physical environment 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



This information does not constitute medical advice for any individual. As specific cases may vary from the general information presented here, SBA advises readers to consult a qualified medical or other professional on an individual basis.
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Promoting the prevention of Spina Bifida and enhancing the lives of all affected.

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