



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

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.

References

- Lutkenhoff, M. (Ed.). (1999). *Children with Spina Bifida: A parents' guide*. Bethesda, MD: Woodbine.
- National Institute of Neurological Disorders and Stroke (NINDS). (2001). *NINDS Spina Bifida info page*.
- Sandler, A. (1997). *Living with Spina Bifida: A guide for families and professionals*. Chapel Hill, NC: University of North Carolina Press.
- Spina Bifida Association. (2007). *Learning Among Children with Spina Bifida*. Washington, DC.
- Spina Bifida Association. (2007). *Educational Issues Among Children with Spina Bifida*. Washington, DC.

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 coatings (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 neural tube 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 often becomes evident in later childhood or adulthood.

Academic Accommodations

1. BOWEL AND BLADDER

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 addition, it is often important to refer the child for a special education assessment, 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.) 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, miscopy 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 them.
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 said, 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 they are reading to be sure they know what they're reading.
3. Help the child capture "the main idea" of a story, movie or conversation.

HANDWRITING DIFFICULTIES

Children with Spina Bifida often find handwriting a laborious task, with the end product being barely legible. Poor handwriting can stem from poorly developed hand and fine motor control, 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 in 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 students may only be able to remember one word at a time.

Suggestions:

1. Give brief, clear simple instructions to assist with 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, creating frustration, anxiety, and anger among parents, teachers and even the child, at times.

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. Keep the number of items as few as possible 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 they can plug or obstruct, break or come apart, resulting in shunt malfunction. The signs of shunt malfunction are varied and can be confusing for everyone involved. 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. People who have allergic reactions to latex may also have food allergies, including: bananas, tomatoes, potatoes, avocados, and kiwi fruit. The only way to prevent allergic reactions to latex is by avoiding contact with items containing latex or latex contaminated powder.

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, if 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 can not 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.

The school nurse or other personnel, if the school nurse is not available, will provide care to the student as outlined by this 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/information from parents/guardians regarding the student's care.

The student's parents/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. The student must not be treated in a way that discourages the student from participating in school activities, or from progressing in doing his/her own management. 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 decides to openly communicate 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. If unable to reach parent/guardian:
2. Call the parent/guardian's cell or work phone. If unable to reach parent/guardian:
3. Repeat steps with other parent/guardian. If unable to reach the other parent/guardian:
4. 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 Contact:

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: _____



**SPINA BIFIDA
ASSOCIATION**

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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