



Spina Bifida Program
111 Michigan Ave NW Suite 4400
Washington, DC 20010-2916
Phone: (202) 476-SPNA (7762)
Fax: (202) 476-2716
Email: spinabifida@childrensnational.org

Dear school care provider:

Since school is the most important developmental task for a child, it is extremely important that a child with spina bifida attend school in a way that supports their medical, physical, and developmental needs. The purpose of this letter is to provide you with recommendations that will assist you in providing school-based care for children with spina bifida. The key role of the school is to be aware of the student's baseline status and alert the family of any changes.

Spina bifida is a birth defect in which part of the spine does not form normally before birth, leaving an opening in the back. As a result, the spinal cord and nerves may be damaged. There are three types of spina bifida:

Spina bifida occulta is the mildest form. The defect is covered by skin. There is no protrusion of the spinal cord or its coverings. Most children with this type don't have any problems, though some may develop symptoms as they get older.

Meningocele involves the meninges, the membranes that cover and protect the brain and spinal cord. The meninges push through the opening in the back, forming a sac called a meningocele. Since the spinal cord is not involved, there is little or no nerve damage. Some children will have mild disability.

Myelomeningocele is the most severe form of spina bifida. It happens when the meninges and the spinal cord push through the opening in the back. This causes nerve damage and is associated with more severe disabilities.

Children with Spina Bifida may experience any one or combination of the following:

- Hydrocephalus (fluid buildup in and around the brain) that requires a **shunt** to drain the extra fluid. Children experiencing shunt malfunction may present in many ways.



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Symptoms such as headache, decreased cognitive abilities, nausea or vomiting may indicate shunt malfunction. Teachers should report any of these symptoms right away to the family. Please report all concerns to school nurse, parent, and/or feel free to email us spinabifida@childrensnational.org

- Physical mobility challenges, depending on the location of the opening (the higher on the spine, the more severe the paralysis)
- Bowel and bladder control problems resulting in fecal and urine incontinence
- Trouble with writing due to poor eye–hand coordination,
- Learning disabilities such as attention deficit hyperactivity disorder (ADHD) or autism.
- Mental health challenges such as anxiety or depression.

Children with spina bifida may:

- need to use splints, casts, leg braces, canes, crutches, walkers, or wheelchairs
- need extra time moving around classrooms and between classes
- need special seats, desks or tables, as well as assistive technology and extra space for wheelchairs or other equipment
- have learning difficulties and problems with memory, attention, comprehension, and organization, therefore needing extra help and time to do assignments
- miss class time due to medical visits or surgeries
- need frequent bathroom breaks to perform clean intermittent catheterization
- be allergic to products that contain latex
- have specific accommodations listed in an individualized education plan (IEP) or 504 education plan
- receive psychological or neuropsychological testing, even if they are doing well, so that future problems can be addressed right away.



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How teachers can help

Most children with spina bifida have normal intelligence, but some may have learning difficulties. Every child with spina bifida is different, and students' specific abilities can vary widely. Understanding the extent of a student's condition will help you identify strengths and weaknesses in the classroom. You may need to modify the classroom environment to meet your students' needs. Accommodations will depend on the student's impairment and the classroom. The student's specific needs should be listed in an IEP or 504 plan.

Consider a latex free environment

Check for pressure sores that will occur mainly on bottom of students' feet

Clean intermittent catheterization (CIC): It is important that the CIC schedule is consistent. Any deviation may result in urinary incontinence, urinary tract infections and embarrassment and social isolation for the child. Stool and urinary leakage may occur from time to time. Please allow students access to clean bathroom, time to perform CIC or change their pad and/or diaper, and access to a water bottle throughout the day. Please encourage all children to be independent as possible.

School absences: Clinic appointments are necessary to monitor these imaging studies, medications and every effort needs to be made to help keep up with schoolwork when absences occur due to clinic visits, lab appointments or special procedures.

Activity: Developmentally appropriate activity is permitted as tolerated unless otherwise instructed.

Diet: A regular, well-balanced diet is permitted as tolerated. Please encourage drinking water throughout the day.



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Please send all medication and CIC forms to spinabifida@childrensnational.org and allow 5-7 business days for completion.

We look forward to partnering with you.

Children's National Hospital
Spina Bifida Program
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Resources:

What is Spina Bifida? <https://www.spinabifidaassociation.org/what-is-spina-bifida-2/>

Education and Accessibility
<https://www.spinabifidaassociation.org/resource/learning-disabilities/>

<https://www.spinabifidaassociation.org/resource/iep/>