

STUDENTS WITH SPINA BIFIDA

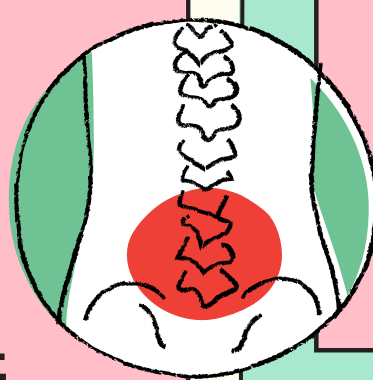


A RESOURCE FOR SCHOOLS AND EDUCATORS ON HELPING STUDENTS WITH SPINA BIFIDA THRIVE IN SCHOOL

What is Spina Bifida?¹

Spina bifida is a condition that affects how the spine develops before a baby is born. It occurs when the neural tube (the part of the body that forms the brain and spinal cord) does not close all the way. Because of this, the bones of the spine do not fully form around the spinal cord, which can lead to nerve damage.

Each year, 1 in every 2,875 babies born has spina bifida



Types of Spina Bifida¹

There are 3 types of Spina Bifida, which have different levels of impact on functioning

Myelomeningocele (most severe):

A sac forms on the baby's back with part of the spinal cord and nerves inside. This can cause serious problems, like difficulty moving the legs.

Meningocele (moderate):

A sac of fluid is present, but the spinal cord is not inside it. Nerve damage is usually mild or not present.

Spina bifida occulta (mildest):

A small gap in the spine with no sac or opening. Most people have no symptoms and may not know they have it.



POSSIBLE COMPLICATIONS/OUTCOMES²

Not all students with Spina Bifida will have all of these complications, and some may have others

Movement and mobility: Weakness or paralysis in the legs can affect a student's ability to walk.

Bowel and bladder control: Some students may have difficulty controlling their bowel and bladder.

Skin concerns: Reduced feeling in parts of the body can lead to sores or injuries that may go unnoticed and become serious.

Learning and attention: Some students may have learning difficulties, including challenges with attention, reading, and math.

Other health concerns: Some students may experience medical issues such as infections, digestive concerns, or depression.

COMMON MYTHS AND MISCONCEPTIONS³



MYTH	FACT
Spina bifida is always fatal	Spina bifida is not usually fatal. While some complications can be serious, many children live long, fulfilling lives with proper care.
Parents cause spina bifida	Spina bifida is caused by a mix of genetic and environmental factors. Some things may increase risk, but parents are not to blame.
All children with Spina Bifida have learning difficulties	Many children have typical learning abilities, though some may have challenges with attention, learning, or problem-solving. With support, many do very well.
All children with Spina Bifida use wheelchairs	Physical abilities vary. Some children use wheelchairs, while others may walk with supports like braces or crutches.

WHAT SCHOOLS CAN DO TO SUPPORT STUDENTS WITH SPINA BIFIDA⁴



Develop a bathroom plan

Toileting and bathroom needs can be a major source of stress for students who have trouble with bowel and bladder control. Each student has different needs, so it is important to work with the student, family, school nurse, and healthcare provider to create a plan that helps the student feel comfortable and confident at school.

For example, a student may visit the nurse every 2 hours to change a catheter or a protective undergarment. Having set times and a regular place to go can make this routine easier and less stressful.

Teachers can also support the student by allowing them to leave class quietly, such as using a pass or signal instead of asking out loud. Some students may feel more comfortable leaving a few minutes early or going with a trusted peer, if they choose.

It is important to include the student in the plan. Let them help choose times, signals, or supports that work best for them. Having a simple, private plan for accidents can also reduce embarrassment and help the student feel supported.



Testing and Educational Services

Students with Spina Bifida should be considered for testing to determine eligibility for educational services. Even if a child appears to be doing well in school, it is important to test them and understand how they think and process things to address problems as early as possible.

Students with Spina Bifida may receive support through a 504 Plan or an IEP based on their needs. These supports may include:

- Scheduled bathroom or nurse visits and extra time as needed
- Extra time on tests and assignments, especially if the student works more slowly
- Help with notes (e.g., teacher-provided notes or guided notes) to reduce writing demands
- Support with organization (e.g., checklists, labeled folders, reminders for assignments)
- Extra time to move between classes, use of an elevator, or seating near the door
- Flexible attendance and make-up work options for medical appointments or absences

Classroom Strategies for Teachers

- Give directions one step at a time and check for understanding
- Provide written directions to support memory and organization
- Use a private signal or pass so the student can leave the room without drawing attention
- Check in quietly if the student seems tired or uncomfortable



ADDITIONAL RESOURCES TO HELP SUPPORT STUDENTS WITH SPINA BIFIDA

Spina Bifida Association- a lot of good information, including an info page directly focused on children with Spina Bifida with a section on education

<https://www.spinabifidaassociation.org/living-with-spina-bifida/children-with-spina-bifida/>

They also have a very comprehensive packet titled Behind the Crayons: Resources to Promote a Healthy School Environment for Students Living With Spina Bifida

<https://www.spinabifidaassociation.org/wp-content/uploads/2025/09/Beyond-Crayons-Workshop-Packet-2016-Digital-Screen-View-Only.pdf>

Also, a one-page reference sheet for educators of individuals with Spina Bifida to understand learning abilities and needs

<https://www.spinabifidaassociation.org/wp-content/uploads/2025/09/Quick-Reference-Sheet-for-Educators1.pdf>

References

1. About spina bifida. Centers for Disease Control and Prevention. Accessed March 5, 2026. <https://www.cdc.gov/spina-bifida/about/index.html>.
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3. Spina bifida: Myths and misconceptions explained | Lurie Children's. Lurie Children's Blog. Accessed March 5, 2026. <https://www.luriechildrens.org/en/blog/spina-bifida-myths-and-misconceptions-explained/>.
4. Beyond Crayons Resource Packet - Spina Bifida Association. Accessed March 5, 2026. <https://www.spinabifidaassociation.org/resource/beyond-crayons-resource-packet/>.

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