

# SPINA BIFIDA

## Background

Spina bifida is a birth defect that occurs when the spinal column does not form properly, leaving a portion of the spinal cord and spinal nerves exposed through an opening along the back. This incomplete development is a neural tube defect that occurs during the first month of pregnancy when the neural tube does not form normally. Nerve damage causing weakness and loss of sensation below the defect is determined by the location of the lesion along the developing spine.

Malformation of the spinal cord and its effects on the central nervous system can cause paralysis and other extensive secondary medical conditions. There are many types of spina bifida ranging from mild to severe forms. Spina bifida occulta is the mildest and most common form of spina bifida. This form rarely causes symptoms and is often detected accidentally by an x-ray or similar test. A meningocele occurs when a sac of spinal fluid protrudes through the spine because of a problem with the bony covering, causing only minor symptoms. A myelomeningocele is the most severe form. A portion of the spinal cord or nerves are exposed through an opening in the spinal cord. When people talk about spina bifida, most often they are referring to myelomeningocele.

Most children born with a myelomeningocele will have changes in brain structure, bowel and bladder dysfunction, and physical mobility. Complications may include Chiari malformation, hydrocephalus, seizures, poor eye hand coordination, incontinence, constipation, and scoliosis. Children with spina bifida commonly experience learning disabilities, especially in attention span, memory, organization, sequencing, and problem solving.

Exposure to latex does remain a concern as many children with spina bifida are allergic to products that contain latex. School staff should be educated on exposure risk and avoidance strategies for latex-containing products.

Treatment options for SB are initially focused on the surgical repair of the lesion (in utero or shortly after birth), then management of co-occurring conditions. Some children with SB will need surgeries for problems with their feet, hip, and spine.



Management in school could also include bowel and bladder support. Students may have a daily bowel regimen that is completed each evening at home. Even in patients that are continent, it would be helpful for school to have supplies readily available for any accidents.

## Top Takeaways for School Considerations

Spina bifida can affect a part of the brain causing neurobehavioral issues. Executive functioning tasks like planning, organizing, and problem-solving may be difficult. Executive function can also affect the student's motivation for things like self-care.

Despite physical mobility needs that may require the use of assistive devices or orthotics, students may appear fidgety and restless in class due to poor impulse control.

Poor eye–hand coordination and depth perception may make tasks like reading, writing, and other fine motor skills difficult (e.g., learning to grasp urinary catheter for self-catheterization).

Reinforcing safe urinary catheterization practice can promote independence such as dictating step-by-step instructions, participating in gathering supplies, or learning to self-cath.

Latex-containing products in a school environment should be avoided. Consider items such as art supplies, erasers, rubber bands, science lab materials, rubber mats, flooring, balls and other gym equipment.

## Kennedy Krieger Institute's Specialized Health Needs Interagency Collaboration

The Specialized Health Needs Interagency Collaboration (SHNIC) program is a collaborative partnership between Kennedy Krieger Institute and the Maryland State Department of Education.



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## Considerations for the Individualized Healthcare Plan (IHP)

- Nursing diagnosis of risk for disturbed sensory perception, impaired physical mobility and impaired thought process
- Current diagnosed health condition including date of diagnosis, progress of disease process and other chronic health conditions
- Current medication and treatment orders (consider schedule, equipment needs and side effects)
- Allergies or food restrictions (latex, latex-containing products)
- Elimination interventions and equipment needs (consider catheterization brand/system, French size, cleaning procedure and frequency of catheterization); note location of procedure
- Assessment of implanted medical device (consider location, date of surgical placement, and device specific information)
- Use of specialized equipment, adaptive equipment, and orthotics
- Activity, positioning, transferring (consider precautions and/or restrictions)
- Skin check, pressure relief techniques
- Equipment troubleshooting (consider equipment/device user manual, battery, charger)
- Consider emergency care plan(s) (ECP) and emergency evacuation plan(s) (EEP) as related to medical needs in the school setting, and staff education/training, as appropriate

## Discussion Starters for Educational Team

1. Has the school staff been trained to implement the student-specific emergency plan?
2. Would the student benefit from evaluations or assessments in any of the following areas: physical therapy, occupational therapy, speech and language therapy, assistive technology, adapted physical education, functional behavior, psychology, hearing and vision?
3. Would the student benefit from additional academic support and/or modified education (e.g., copies of notes, extra time, reduced workload, simplified instructions, alternative formats for presentation of material, 504/IEP)?
4. Can strategies be implemented to assist the student with executive function (e.g., plan, prompts, organizers, agendas)?
5. Does the student need support with gross or fine motor skills in the classroom?
6. Is the physical school environment safely accessible for the student's mobility needs (e.g., entry and exit, ramps, location of classes, access to elevator, doorways)?
7. Does the classroom environment support the student's needs and/or equipment (e.g., desk/seating options, maneuverability space, electrical outlets, flash pass for bathroom or nurse)?

## Resources

Kennedy Krieger Institute: Center for Spina Bifida and Related Conditions  
[kennedykrieger.org](http://kennedykrieger.org)

Spina Bifida Association  
[spinabifidaassociation.org/](http://spinabifidaassociation.org/)

Nationally Consistent Collection of Data on School Students with Disability (NCCD)  
[nccd.edu.au/professional-learning/classroom-adjustments-spina-bifida](http://nccd.edu.au/professional-learning/classroom-adjustments-spina-bifida)



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