



An Educator's Guide to Spina Bifida

This guide on spina bifida is part of a series of briefs that provide basic information about common disabilities, as well as tips for educators as they support children with disabilities.



Overview

Spina bifida is a developmental complication that occurs when the brain, spinal cord, and/or the protective covering around them do not fully develop during early pregnancy. The symptoms of spina bifida can vary greatly, depending on the area and degree to which the brain and/or spine is affected. While nearly all children with spina bifida experience some form of physical disabilities, cognitive impairments are quite rare. A child with spina bifida may experience these symptoms:

- Unusual nerve sensations
- Partial or complete paralysis
- A compressed spinal cord
- Difficulties eating or swallowing
- Difficulties controlling breathing
- Stiffness or weakness in the upper arms
- Allergies
- Skin conditions
- Gastrointestinal conditions
- Depression, as the child gets older and copes with the other symptoms

Spina bifida is the most commonly occurring neural tube defect in the United States, effecting approximately one in every 20,000 babies. Spina bifida is typically diagnosed through routine ultrasounds and screenings during pregnancy, although some mild cases may go unnoticed until the baby is born, and extremely mild cases may go completely undetected. There is no cure for spina bifida, although some kinds of corrective surgery may improve more severe symptoms. In some cases, bladder or bowel interventions or management strategies may be necessary. Physical and occupational therapy from an early age can help with mobility development, and some children with spina bifida may require assistive devices, including braces, crutches, walkers, or wheelchairs. Children with spina bifida can lead active intellectual, personal, and physical lives, especially with the support of early intervention services.

Support Strategies

- If the child already has an Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP), attend the regular team meetings.
- Ask the child's support specialists, such as a physical or occupational therapist, about how you can further their efforts or use strategies in the learning setting to support the specific child's development.
- Check in with the family about what strategies or supports they have at home, such as in-home care assistance or mental health services for the family, and ask how you can support their efforts.



- Examine and make any necessary adjustments to the layout, toys, and activities in the learning setting so that the child can move freely around and access all areas and items.
- Make adaptations to ensure full participation in the learning setting, daily routines, and activities.
- Support the child to engage fully in social interactions and group activities.
- Provide extra time for the child to accomplish developmentally appropriate tasks and activities, as needed.
- Encourage the child to make choices, such as between items or activities in the setting.
- Offer encouragement when the child attempts and/or successfully completes developmentally appropriate tasks or activities that may be challenging.
- Provide adaptive utensils, cups, seating, or other modified devices needed for mealtime.
- Work together with the child's family and other team members to create a simple, effective plan for using the bathroom, if needed.
- When transitioning outdoors, ensure that the child's shoes and clothing layers are adjusted properly to avoid skin irritation.
- Examine and adjust the outdoor play space to ensure the setting, available toys, and activities are accessible and developmentally appropriate for the child.
- Find out if sun-protective clothing, sunscreen, or other products are necessary for the child, and obtain the proper instructions and permissions, if the product needs to be administered while in your care.
- Notify the child's family if you notice any changes to areas of the child's skin, such as redness or sores.

Helpful Resources

- [Center for Disease Control and Prevention \(CDC\) – What is Spina Bifida?](#)
- [National Institute of Neurological Disorders and Stroke – Spina Bifida Fact Sheet](#)
- [Spina Bifida Association – Guidelines of the Care of People with Spina Bifida \(online\)](#)
- [Spina Bifida Association – Guidelines of the Care of People with Spina Bifida \(PDF\)](#)
- [Spina Bifida Association – Infants & Children](#)