

Spina Bifida



Spina bifida is a birth defect in which the spinal cord and spine are not completely formed. The effects of spina bifida vary greatly depending on the severity and location of the spinal cord damage. The most common and severe form is myelomeningocele. Typically, the ability to control movement of the legs is affected the most, resulting in difficulties with balance and walking. The student also may have trouble moving the arms and hands, resulting in difficulty with fine motor activities (e.g., printing, colouring, cutting). Sensation and use of the bladder and bowels often are affected. Most people with spina bifida have an average IQ; however, there can be a broad range of cognitive abilities. The more severe the spinal cord damage, the more learning difficulties the student may have. Students with hydrocephalus (fluid build-up in the brain) tend to have lower cognitive ability and more learning challenges. Latex allergies are common and sometimes life-threatening in people with spina bifida.

Implications for Planning and Awareness

- Meet with the student and parents early in the school year to discuss how the school can support this student's needs related to spina bifida. This could include finding out about:
 - the student's strengths, interests and areas of need
 - the student's specific symptoms
 - successful strategies used at home or in the community that could be used at school.
- In collaboration with parents and health care professionals, develop a written management plan that aligns with related jurisdictional policies and protocols. This should include specific information, such as:
 - symptoms that may affect the student at school and may require monitoring
 - the role of school staff
 - equipment and environmental modifications
 - appropriate physical activities
 - possible complications and responses, including allergic reactions (if present)
 - when and what emergency measures should be taken.
- If the student is taking medications during the school day, discuss with the parents possible side effects. Follow school and/or jurisdictional policies and protocols in storing and administering medication.
- Work with the parents to carry out a risk assessment before field trips to determine potential hazards, and to plan for the student's safe and successful participation.

Your awareness needs to begin with conversations with the student's parents.



- Learn from parents whether the student has a shunt (a tube that runs from the brain down the spinal cord to help remove excess fluid), as extra caution will need to be taken during physical activities.
- Collaborate with the parents and student to consider if, and how, they would like to share specific information on spina bifida with peers. If they wish to do this, consultation with health care providers, such as school or community health nurses, may be helpful.
- Learn as much as you can about how spina bifida may affect learning and social and emotional well-being. Reading, asking questions and talking to qualified professionals will build your understanding and help you make decisions to support the student's success at school.
- Collaborate with the school and/or jurisdictional team to identify and coordinate any needed consultation and services, such as physical or occupational therapy.
- Work with specialists to arrange for any equipment or classroom modifications that might be needed. This may include accommodations for mobility equipment (e.g., wheelchairs, standing frames, walkers), supportive seating, supportive toilet seats and/or mechanical lifts.
- Determine if any changes to school timetables or schedules will have to be made to accommodate the student's equipment and/or travel time from class-to-class.
- Develop a system for sharing information with relevant staff members about the student's condition and successful strategies.

Implications for Instruction

- Be aware that students with severe spina bifida may have numerous absences due to medical appointments or treatments, or fatigue.
- Develop a communication strategy between the home and school to stay informed about absences, and to keep the student and family connected to classroom learning.
- Determine the student's particular pattern of strengths and needs. Students with spina bifida are typically:
 - stronger in language skills
 - weaker in perceptual skills
 - weaker in motor skills
 - weaker in attention, problem solving, organization, sequencing and memory.
- Provide the student with copies of notes and assignments. Provide the student with two copies of books, one for school and one for home.
- Provide adapted tools and materials, such as slant boards, adapted writing paper and pencils and specialized computer software, if weakness in the arms and hands make writing difficult.
- Provide alternative ways for the student to demonstrate learning.



- Provide additional time for transitions between classes, particularly in large schools. A trolley may assist in transporting books, laptop computers or other heavy items from room-to-room, if this is necessary.
- In collaboration with the student and parents, discuss the appropriate level and types of physical activity for the student. Alternatives to regular physical education may need to be considered.
- Take necessary precautions and provide close supervision during physical activities, especially if the student has a shunt. Adapt activities as needed (e.g., one-on-one with peer or assistant).

Implications for Social and Emotional Well-being

- Engage the student and parents in planning for transitions between grade levels and different schools.
- Consider having a “key person” the student can check in with on a weekly (or daily basis) to assist with any goal setting, planning, self-monitoring and problem solving that may arise.
- Recognize that the student’s physical disability, appearance and lack of bowel or bladder control may affect the student’s sense of self and ability to form friendships. Provide emotional and social support in a matter-of-fact way.
- Take steps to ensure the student does not feel left out during recess, intramural or other school activities; for example:
 - provide an alternative role, such as referee during physical education or intramural activities
 - provide alternative activities during recess, such as a friendship bench to sit on and meet with peers.

Parents know their children well and can offer insights on how to support their social and emotional well-being. There is strength in collaborating on strategies that could be used at home, at school and in the community.



As you consider the implications for this medical condition, think about the following questions:

1. Do I need further conversations with the parents to better understand this student's medical needs? Yes No
2. Are further assessments required to assist with planning for this student?
If yes, what questions do I need answered? Yes No
3. Do I need targeted professional learning?
If yes, what specific topics and strategies would I explore? Yes No
4. Is consultation with jurisdictional staff required?
If yes, what issues and questions would we explore? Yes No
5. Is consultation with external service providers required (e.g., Regional Educational Consulting Services, Student Health Partnership, Alberta Children's Hospital, Glenrose Hospital)?
If yes, what issues and questions would we explore? Yes No
6. Is service to the student from an external provider required? Yes No
If yes, what outcomes would be anticipated?

Links for further information:

Spina Bifida Association of America. "Learning Among Children with Spina Bifida."
<http://spinabifidaassociation.org/project/learning-among-children-with-spina-bifida/>

Spina Bifida Association of America. Educators. Health Information Sheets.
<http://spinabifidaassociation.org/educators/>

British Columbia Ministry of Education. *Awareness of Students with Diverse Learning Needs, Volume 1*. <http://www.bced.gov.bc.ca/specialed/awareness/63.htm>

Please note:

These websites are for information only and the user is responsible for evaluating the content and appropriate uses of the information.

