

Prader Willi Syndrome



Prader Willi Syndrome is a genetic disorder. These students may be shorter than other students their age, and they may appear “floppy” due to poor muscle tone. The students may have learning difficulties, problem behaviours and a constant feeling of being hungry that puts them at risk of continual overeating. These students often have a slower metabolism than the general population so they tend to put on weight more quickly and often struggle with obesity.

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 Prader Willi Syndrome. This could include finding out about:
 - the student’s strengths, interests and areas of need
 - successful strategies used at home or in the community
 - any medications the student takes and potential side-effects, including those that may affect learning and behaviour
 - other professionals involved with the student.
- Learn as much as you can about how Prader Willi Syndrome may affect learning and social and emotional well-being. Reading, asking questions and talking to qualified health care professionals will build your understanding and help you make informed decisions to support the student’s success at school.
- In collaboration with parents and health care professionals, develop a written medical management plan that aligns with school and jurisdictional policies and protocols. This plan should include specific information, such as:
 - food and dietary restrictions
 - medical concerns that may affect the student at school
 - any medications the student takes at school, how they are administered and potential side effects that staff should watch for
 - when emergency measures should be taken
 - appropriate physical activities
 - behaviour management strategies.
- Develop a system for sharing information with relevant staff members about the student’s medical conditions and successful strategies. This might include a variety of people working with the student (e.g., bus drivers, custodians, secretaries, volunteers).
- Collaborate with the school and/or jurisdiction team to identify and coordinate any needed consultation and support (e.g., behaviour, dietary, occupational therapy).
- If required, work with the parents to carry out a risk assessment prior to field trips to identify potential challenges, and to plan for the student’s safe and successful participation.

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



- Collaborate with the parents and student to consider if, and how, they would like to share specific information on Prader Willi with peers. If they wish to do so, consultation with other professionals, such as the school psychologist, may be helpful.
- Be aware of the pattern of student's energy and fatigue levels throughout the school day and adjust activities accordingly.
- Develop secure systems for storing snacks and lunch so the student with Prader Willi does not have unsupervised access. These students may never feel full from eating and may constantly crave food. Some students will go to great lengths to obtain food.
- Students with Prader Willi tend to have high pain thresholds and may scratch their skin when they feel stressed. Provide long sleeve T-shirts and fidget toys as a distraction to or replacement for scratching.
- Provide quiet areas where students can retreat if they feel temporarily overwhelmed by a busy, noisy environment. Rehearse when to go to area, what to do (e.g., calming activities, such as looking at books or listening to music on a headset) and when to return.

Implications for Instruction

- Give clear, brief directions. Have the student repeat the directions back to you to monitor comprehension.
- Simplify language and directions.
- Remind students to “stop, think and listen” before responding, acting or making a choice.
- Provide support in transitioning from one activity or place to another. Cues, routines and purposeful activity during transitions may be helpful and can reduce confusion and/or anxiety.
- Provide quiet alternative work spaces during noisy classroom activities and/or provide alternative or adapted quiet activities.
- Provide a warning to the student just before loud, predictable noises (e.g., school bell, announcements over a public announcement system, music in assemblies).
- Teach strategies for self-monitoring, such as making and using daily lists and personal checklists.
- Use low-key cues, such as touching the student's desk to signal the student to return to the task at hand.
- Break task and assignments into short, easy-to-manage steps. Provide each step separately and give feedback along the way.
- Design learning activities that require a high response rate and use concrete learning objects. For example, provide students with individual white boards, chalkboards or manipulatives that allow them to actively respond and “show” their answer.
- Design math tasks and materials that consider spatial organization and fine motor difficulties. For example, reduce the amount of information on a page, provide a “window box” template to view one question at a time, provide graph paper to align numbers correctly.
- Limit the amount of copying and/or writing. Consider the use of assistive technology tools, such as a dedicated word processing software.
- Help the student to organize belongings and work (e.g., label school supplies, colour-code subject notebooks).



Implications for Social and Emotional Well-being

- Explicitly teach social skill, such as how to ask a friend to play, taking turns and sharing, etc. Use modelling, social stories and role-play. Students may not know how to make friends in the classroom even though they want to have friends.
- Partner the student with positive peers so he or she does not feel left out at recess and other less structured times.
- Students may be messy eaters because of low muscle tone in the mouth area. Ensure they have napkins at lunch time and work out a subtle cue (e.g., touching mouth) that positive peers and school staff can use to remind them to wipe their mouths.

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

Links for further information:

British Columbia Prader Willi Syndrome Association <http://www.bcpwsa.com>
Prader Willi Syndrome Association of Alberta <http://www.pwsaa.ca>
Prader Willi Syndrome Association USA. Prader Willi Syndrome School Issues. <https://www.pwsausa.org/school-issues/>
Special Education Support Service. "Prader Willi Syndrome: Tips for Learning and Teaching." <http://www.sess.ie/categories/assessed-syndromes/prader-willi-syndrome/tips-learning-and-teaching>

Please note:

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

