

Supporting Students with Prader-Willi Syndrome: Information and Advice for School Professionals

This handout was created by members of PWSA (USA)'s Adults with PWS Advisory Board. At their January 2015 meeting advisory board members were asked what they would like school professionals to know in order to effectively and appropriately serve students with Prader-Willi syndrome (PWS) based on their school experiences. We thank the following advisory board members for their contributions to this handout: Shawn Cooper, Brooke Fuller, Conor Heybach, Kate Kane, Lauren Lange, and Abbott Philson.

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What Works Best For Students With PWS

- Adaptive Physical Education is important for students with PWS. It helps with weight management and improves low muscle tone.
- A positive response to behavioral meltdowns including the following:
 - Give the student time to recover.
 - Limit verbal interaction to simple directions.
 - Allow space.
 - Avoid restraint and seclusion.
 - Never making fun of a student in distress.
- Plan for food security – especially managing lunch and any other food-related activities.
- Eliminate easy access to vending machines.
- Provide 1:1 paraprofessional supervision with food security and support during academic activities and transitions. A paraprofessional working with a student with PWS should:
 - Receive training on how to appropriately and effectively support a student with PWS.
 - Enforce food security protocol – including not eating lunch or any other food in front of a student with PWS.
 - Have a sense of humor.
 - Have a coaching or teaching background.
 - Know how to provide support without hovering.

What Accommodations Can Help Students With PWS

- Extend time for tests and assignments.
- Read questions on tests to the student instead of having the student read them.
- Use of assistive technology.
- Utilize fun strategies and teaching methods.
- Adaptive Physical Education
- Supervision as needed to promote academic success and safety.

What School Professionals Should Do To Better Serve Students With PWS

- Instruct other students to put food away so it is not visible or accessible in the classroom or other school environments.
- Remember that students with PWS can't help asking for food especially when it is visible.
- Don't take advantage of a student. Listen so you can understand their point of view.
- Make every effort to put the interests and needs of student with PWS first.
- Don't use food as a reward for any activity at school.
- Understand there is no cure for PWS and it is life threatening.
- Be aware that skin picking is a problem for many. Don't invite embarrassment or shame to this challenging behavior.
- When possible show a student what to do rather than just tell them.
- Communicate with parents regarding holiday activities at school and create a plan for students with PWS to participate in a safe and appropriate way.
- Know that tantrums can be part of PWS. When we are upset, please do not punish us - help us.

What Students With PWS Did Not Like About School

- Other students not putting food away.
- Vending machines were a constant temptation.
- Use of detention and punishment for seeking food.
- Teachers using food rewards for classroom activities.
- Being bullied, picked on and called names.
- Teachers and classmates not understanding PWS.
- Isolation from peers.
- Being bullied by teachers and staff.

What Students With PWS Liked About School

- Spending time with friends.
- Learning.
- Using a computer.
- Special Olympics.
- Gym class/adaptive PE.
- Graduating with class and participating in graduation activities.
- Special celebrations with classmates and family.
- Senior Prom and other extracurricular activities.
- Learning photography.
- Helping other people/classmates.
- Freedom to have new experiences while meeting new people.
- Changing classes in high school.
- Participating in mainstream and general education classes.
- Working on the school newspaper.
- Graduating from high school.

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