



Food Security in the Education Environment for Students with Prader-Willi Syndrome

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We all want positive, successful educational experiences for all students. Students with Prader-Willi syndrome face some unique challenges that require understanding, planning and support so they can learn, socialize and remain healthy and safe in any education environment. Food security is important. In the early years, the educational environment may be limited to actual school buildings. However, in the later years, this environment expands in to the community as well as the vocational work areas.

What is Prader-Willi Syndrome (PWS)?

PWS is a complex developmental disability that results from a defect on the 15th chromosome. Because of an abnormality in the area of the brain called the hypothalamus, these students face challenges in learning, behavior and controlling their appetite. The message of fullness never reaches their brain and they are always hungry. The intensity of their food drive can vary but all students require support and understanding if/when they are exposed to food or they attempt to seek food. Food security must be considered and provided in all environments and at all times.

Health and Safety Concerns

There are 2 major health risks associated with food seeking behavior; these include choking and severe gastric illness that could result in rupturing of the stomach. Over eating and binge eating can cause life threatening situations for these students. All staff should be trained in the Heimlich maneuver. It is rare for a student with PWS to vomit and if this occurs could indicate a serious medical situation. All cases of binge eating or vomiting should be reported to the students' parents or guardians immediately. Immediate medical attention may be needed.

Goals

The student with PWS will:

1. Remain healthy, safe and successful around food in all educational environments.
2. Receive supports and assistance that will help him/her to make good choices in situations where food, and/or money may be present in a least restrictive environment as possible.
3. Follow the prescribed diet for all meals and food he/she receives in educational environments.

Suggested Supports:

1. The student will have supervision in all environments where food is present during his/her school day. This may include: while receiving transportation services; walking in hallways, near classrooms, vending machines, lounges, break rooms, stores, secretary/teacher food sources (candy dishes, visible food ...) or where access to food and/or money may be possible.
2. The student will receive supervision and/or support in the cafeteria or other lunch room environments. Some students may require:
 - Minimal assistance - possibly only oversight and reminders that food should not be traded or shared by others (usually by other classmates).
 - 1:1 assistance in obtaining prescribed food items to meet their dietary needs and may need someone to obtain their food and deliver it to them.
 - No participation in the school hot lunch program. However this may not be used for students who qualify for free or reduced meal programs.
 - Eating their food in a smaller, less stimulating environment (a classroom, outside, private office).
3. The student will be provided low calorie meals and snacks as dictated by a written prescription from the student's physician and is included in the IEP.
4. Create a "food free" learning environment. Remove food from sight. Do not use food as a manipulative, in art projects or as an incentive.
5. Develop a plan between the parent and educator/vocational coach on how to handle special events and holidays where higher calorie or unplanned food items may be present.
6. All staff of the school or work environment should receive written and/or onsite training about Prader-Willi syndrome.
7. Discuss any changes in routine with the student – especially ones that may impact or be perceived to impact the timing of snacks or meals. A visual representation of changes including the new/changed time for food is often helpful.
8. The student will have a behavior support plan that teaches and emphasizes appropriate behavior stated in a positive, supportive way. In the event that the student steals food and/or money, non-confrontational strategies should be used.
 - Encourage "good choices". Strategies such as trading, sharing (ask him/her to share ½), and/or returning the stolen items should be used. Avoid threats.
 - Do not use physical force to retrieve the items. It is safer to report what was eaten or taken and have the parent adjust calories or assist in obtaining item(s).
9. In cases where the student's food drive is very strong, staff may be asked to provide extra security measures and be more diligent – remove all visible food; lock classroom doors while not in the classroom; lock teacher lounge door or keep food out of site when a door may be opened.
10. Staff may need to provide supervision around all sources of garbage where discarded food is present. If possible, garbage cans should be emptied prior to the students' arrival in that classroom.
11. When going out in to the community or on a field trip, plan the timing and choices for all food items ahead of time. If no food will be purchased or eaten, discuss this as well. For many students with PWS, it is helpful to put this "agreement" in writing.
12. Food security in the work environment must be evaluated for food sources and it must be determined how it is impacted by food.

- a. Is food an integral part of the company's culture? Is staff able to eat at their work site?
- b. Is food left out and to what degree?
- c. Will the employer be willing to be supportive of the needs of the person with PWS?
- d. Where is the break room in relation to the worker's job site?
- e. What are the smells?

Students with PWS of all ages with want to be successful. They want to learn; have friends; be a part of their school community; and learn to work cooperatively. They need your help to learn and live successfully.