



What is Prader-Willi Syndrome?

PRADER-WILLI SYNDROME (PWS) is a complex developmental disability that results from a defect on the 15th chromosome. It causes a malfunction in the area of the brain called the hypothalamus.

Common Characteristics:

Hypotonia (low muscle tone), Low Stamina, Developmental Delays, Cognitive or Learning Disabilities, Speech and Language Delays/ Problems, Behavior Challenges, Complex Health Issues and the Inability to Control his/her Appetite

Students with PWS require services and support from many educational professionals. Most qualify for the following related services:

Early Intervention Assessment and Services Birth to 3 and Early Childhood services address motor, speech and developmental delays.

Speech and Language Varying degrees of speech and language problems.

Occupational and Physical Therapy Fine and gross motor weakness, trunk/core muscle weakness which impacts endurance, breathing and spine problems.

Psychological and Counseling Services Cognitive assessments and behavior management issues.

School Health Services Unique health needs and issues require ongoing assessment and oversight.

Parent Counseling and Training Help in management of global learning, behavior and health issues.

Transportation Safety, hypotonia, behavior, cognitive, and food seeking issues often necessitate services.

Special Health Concerns:

High Pain Threshold Diminished pain response. All injuries and illnesses must be carefully evaluated.

Altered Temperature Regulation Little or no fever present with illness. Low tolerance to external heat or cold temperatures.

Severe Stomach Illness Life-threatening situation often seen after binge episode. Abdominal bloating and/or pain, vomiting, a general feeling of illness. Must urgently seek medical care.

Choking Often eat very fast. If successful in stealing food, will ingest food quickly and risk choking.

Skin Picking Common to see open sores; may pick at various openings of body.

Excessive Daytime Sleepiness Low endurance. Sleep apnea and hypoventilation common. Some require rest periods; others may need increase in activity.

Strabismus Cross-eye often detected in visual screenings. May require referral to eye specialist for patching and/or surgery.

Scoliosis May require bracing and/or surgery if severe.

Each student's individual needs must be closely evaluated, and an educational plan developed.

Prader-Willi Syndrome is:

A non-hereditary birth defect resulting from a disorder of chromosome 15

A serious, life-long, and life-threatening medical condition

Occurs in 1:12,000 to 1:15,000 births, both sexes, all races

Characterized by

- Hypotonia (*low tone*)
- Hypogonadism (*underdeveloped sex organs*)
- Hyperphagia (*uncontrollable hunger*)
- Cognitive impairment
- Challenging behaviors

One of the most common conditions seen in genetic clinics

The most commonly known genetic cause of life-threatening obesity

A major medical concern is morbid obesity, however with early diagnosis and early intervention, many children can maintain a healthy weight.

For more information on how to successfully support the student with PWS, contact:

Prader-Willi Syndrome Association | USA

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What Educators Should Know



Students with PWS are very caring, loving, sensitive and conscientious. They want very much to be successful, have friends and be a part of their school community.

Although faced with some unique challenges, students with PWS can play, learn, work and live successful in our communities.

A team of knowledgeable educational staff help to make this possible.



Common Issues and/or Behavior Challenges that Impact Learning:

Strong Food Seeking Behavior

The message of fullness never reaches their brain. Can gain weight on ½ calories of others their age. Must be on low calorie diet. Can become irrational when it comes to food-related issues. May steal or fight to obtain food.

Recommendations:

Create a “food-free” learning environment. Remove food from sight.

Avoid using food as a manipulative, incentive, or reward.

Supervise in all areas where food or money can be accessed – lunchroom, hallways, break rooms, vending machines, offices, and special events.

Follow calorie restricted diet as prescribed by a health care professional.

Work with parents in developing a plan to handle birthday and other special events where treats may be present.

Create a positive behavior support plan that emphasizes appropriate, supported behavior in the event that the student steals food or money.

- Encourage “good choices” – avoid trading or sharing; practice returning item.
- Avoid threats.
- Do NOT use physical force to take it away.
- Communicate with parents so calories can be adjusted.

Monitor weight. Include exercise.

Tenuous Emotional Control

Can lose control of emotions and become over-stimulated easily.

Have knowledge and skill deficit in handling frustration and anger.

May yell, cry, swear, destroy property and/or do self-injury.

Recommendations:

Be aware of over-stimulating situations – especially in hallways. Carefully plan transitions, arrivals and dismissals.

Develop a behavior support plan that includes teaching the student what **to do** if he/she feels angry or frustrated.

Encourage communication of feelings – using words. Listen to what is said.

Don't try reasoning if out of control. Limit discussion.

Rigid, Perseverative Thinking

Common to receive and store information in very orderly manner. Strong need for structure & routine.

Do not handle changes well.

Often want to finish what is started. Transitioning to new things is difficult.

Can get caught on one idea or issue to the point where it overshadows learning. Can lead to loss of emotional control.

Recommendations:

Foreshadow schedule for the day. Put any changes in writing.

Keep instructions simple.

Provide praise when being flexible.

Use reflection – have student restate what was just said.

Limit repetitions – by number or time.

Less is best – give fewer amounts to do and “add on” for extra credit.

Elopement

Some students with PWS like to run away when faced with situations they feel they cannot handle.

Recommendations:

Teach, practice, and encourage other ways for the student to handle feelings associated with these situations.

Provide close supervision.

Incentive programs for positive behavior.

Difficulty with Peer Interactions

Many are very friendly and outgoing but lack age-appropriate social skills.

Can get caught up on the idea of “fairness” and compare themselves to others.

Want friends and to be able to participate in social and extra-curricular events.

Recommendations:

Include in social skill classes and coaching to assist in developing appropriate skills – sharing, taking turns, losing appropriately.

Have the student role play and practice different social situations.

Create supported play groups, recess, and other social outings.

Clearly communicate “dos and don'ts” for dating and social interactions. Visual format helpful.

Provide support and modifications so the student can participate in social and extra-curricular events.

Learn the Student's Strengths:

Most love to be “helpers”. Put them in leadership roles where they can succeed.

Many are visual learners. Put things in writing or in another visual format.

Some are very social. Teach appropriate times and ways for them to maximize this skill.

Build up their self-esteem. Most love rewards and awards. Certificates and other acknowledgments can be a great way to celebrate success.

Practice during times where there is no stress. Use their obsessive-compulsive tendency to help them learn and develop more appropriate strategies.

Talk with the parents to learn other areas of interests and strengths.

Communication is Key!

It is very important to keep the lines of communication open when educating and working with the student with PWS and his/her family. This can be done in a number of different ways – e-mail, voice mail, notebooks and/or in-person.

Report and celebrate successes. Share important events and/or assignments. Problem solve around issues ahead of time. Identify concerns and, if needed, set up monthly meetings to keep the lines of communication open.

Look for our other great PWSA (USA) resource titled: **How Does a Person with PWS Think?**