

## PWS Behavior Management Strategies for the School Professional



Presented by  
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### Physiological Symptoms That Impact the Student

<ul style="list-style-type: none"> <li>• <b>Hypotonia</b> - Weak muscle tone</li> <li>• <b>Problems with Strength, Balance, Coordination, Motor Planning</b></li> <li>• <b>Abnormal Growth</b> (short stature, small hands &amp; feet)</li> <li>• <b>Respiratory Issues</b></li> <li>• <b>Cognitive Limitations, Impaired Judgment</b></li> <li>• <b>Hyperphagia</b> - Dysfunctional appetite regulating system</li> <li>• <b>Metabolic Issues</b></li> <li>• <b>Gastrointestinal Issues</b> – Gastroparesis (slow emptying stomach), slow emptying bowel, lack of vomit reflex</li> <li>• <b>Temperature Regulation Dysfunction</b> – Students may become too hot (hyperthermia) or too cold (hypothermia) quickly. Internal body temperature often runs low; serious illness or infection may be present without fever.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>High Pain Threshold</b></li> <li>• <b>Self-Injurious behaviors</b> most often skin picking</li> <li>• <b>Hypopigmentation</b> in Deletion – very fair hair, skin and eye color</li> <li>• <b>Dental Problems</b></li> <li>• <b>Speech and Language Problems</b> increase frustration</li> <li>• <b>Scoliosis and other orthopedic abnormalities</b></li> <li>• <b>Incomplete Sexual Development</b></li> <li>• <b>Disordered Sleep</b> causes daytime sleepiness, irritability</li> <li>• <b>Temperament and Behavior Issues</b></li> <li>• <b>Social / Psychological / Psychiatric problems</b> Anxiety, OCD-like behaviors, perseveration, impulse control disorder, intermittent explosive disorder, depression, ODD, <b>lying/confabulation</b>, psychosis</li> <li>• <b>Other common characteristics</b> include: eye abnormalities, gall bladder problems, medication sensitivities</li> </ul>
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PWS Hyperphagia

**Dysfunctional appetite regulating system:** physiological, neurological drive to eat or obtain food that lasts throughout the lifetime.

**The brain functions as if the body is starving:**

- The brain drives the individual to eat/find as much food as possible.
- The brain does not experience satiety (fullness)
- The brain tells the body to store consumed food as fat
- The brain lowers the metabolic rate to almost half to conserve energy

**Vomit reflex is absent.** The body does not expel consumed poisons, rotten food, too much food. Syrup of Epicac may *not* induce vomiting and repeated doses may be toxic. If vomiting occurs it could signal a life-threatening situation; parents should be notified immediately.

Unmanaged hyperphagia + slow metabolic rate causes rapid weight gain, potential for premature death from stomach and/or bowel perforation or necrosis, poisoning, choking, complications of morbid obesity, and behavior problems. **Death can occur from a single overeating episode.**

PWS is *not* an eating disorder. PWS is a medical disorder.

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### PWS Hyperphagia con't

- No known medication treats PWS' hyperphagia food drive. There is no learning to control food intake. **Current management is 24/7/365 supervision and adherence to the Principles of Food Security throughout the individual's lifetime.**
- **No one known to be diagnosed with PWS can successfully live independently.** Those who have tried have either become morbidly obese and returned to a supported residential environment, or died. For the duration of the lifetime, life is lived in the family home or a PWS-designated residential setting.
- The goal of educating the student with PWS is NOT to teach independent life skills that could lead to serious consequences:
  - No independent transportation. Do not teach the student to ride a public bus or take an Uber independently. Independent Transportation = Access to food
  - No independent use of money or credit cards. Money = Access to food
  - Students should NOT be subjected to cooking classes, purchasing food at the mall, etc. because these create an enormous amount of anxiety and potential for a dangerous food-related incident.
- **PWS's hyperphagia food drive underlies many maladaptive behaviors** but there are a multitude of neurological issues that contribute to unwanted behaviors as well.

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**PWS Anxiousness**

- **Almost everyone with PWS has a high level of anxiousness**  
– excessive worry, fear, unrealistic view of problems, feeling out of control – that lurks just below the surface, ready to react to the next real or *perceived* stressor
- **Anxiety can *cause* of maladaptive behaviors:**
  - ✓ Arguing and defiance
  - ✓ Verbal and physical aggression
  - ✓ Elopement
  - ✓ Repeated questions
  - ✓ Excessive talking
  - ✓ Skin picking

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Anything -- or anyone -- that raises anxiety  
has the potential to cause a behavior problem

Which means that YOU have the potential to cause a behavior problem...



And YOU have the potential to reduce that behavior problem...

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Top 10

## PWS Behavior Management Strategies Toolkit

1. PWS Environmental Basics
2. Empathy as Intervention
3. Paint the Picture
4. Fix a Past Goof
5. Preferred Choices
6. Disguise The No's
7. Allow for the Possibility of Rightness
8. Use Egocentrism to Your Advantage
9. Motivate Externally
10. Use Transition Prompts to Increase Flexibility

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#1

## PWS Environmental Basics

- A. Food Security
- B. Routines
- C. Rules
- D. Boundaries
- E. Calm Responses



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**Environmental Basic A: Food Security**

**NO DOUBT**

No doubt when the next meal or snack will be served  
*Consistent routines for food consumption*

+

**NO HOPE or CHANCE**

No hope or chance to obtain extra/ unauthorized food  
*Eliminate access to food to reduce anxiety and behavior problems*

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**NO DISAPPOINTMENT**

No disappointment that extra food is not available  
*No disappointment means no behavior problems!*

The Principles of Food Security is a term coined by Janice Forster, MD and Linda Gourash, MD of The Pittsburgh Partnership Specialists in PWS. [www.pittsburghpartnership.com](http://www.pittsburghpartnership.com)

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**No Doubt**

**No doubt when the next meal or snack will be served**

Establish consistent routines for food consumption. Determine when snack and lunch will be served during the school day.

- Write the food schedule on a notebook until it's learned.
- Inform the student if there are to be any changes to the food plan.

**Scheduled food should be as reliable as breathing air.**

**NEVER use food as a reward  
NEVER use food as a bribe  
NEVER withhold food for poor behavior**

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**No Hope or Chance**

**No hope or chance to obtain extra food**

Access to food creates hope. Hope creates anxiety. Anxiety creates the potential for unwanted behaviors. If food is available, the individual can do little else but anxiously think of ways to get that food.



**Eliminate access to food to reduce anxiety and behavior problems**

- Remove all visible foods from classroom. Lock food in cupboard if possible.
- Put away students' snack bags, backpacks, etc.
- No one should eat in front of the individual with PWS if food is not also available to the person with PWS.
- Establish rules for type and quantity of food *before* attending field trips or outings.

**Put a lock on the thought that unauthorized food is available.  
NEVER Give In to a Tantrum -- Especially for Food**

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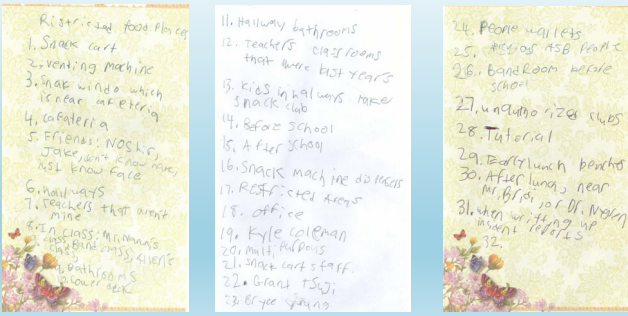
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**Where does Hope or Chance lie within the school setting?**




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**If Unauthorized Food is Known or Suspected:**

1. Do not question the consumption: "Did you eat those chips?"
2. Rather, presume food was eaten and state as a fact: "I see the chips are gone."
3. Take responsibility for the individual gaining access to the food: "I'll make sure it doesn't happen again so you stay safe."
4. Secure the food source.
5. Without the individual knowing, advise parents/caretaker about what was eaten so they can reduce calories in future meals to compensate for additional consumed calories.

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**Food Security Insights**

- Higher cognitive abilities and verbal skills do not mean the individual can override the brain's insatiable drive to obtain food.
- People with limited intellectual functioning can be brilliant at obtaining food.
- The ability to plan and execute complicated arrangements to obtain food may not generalize to abilities in other areas of life.
- Even the most honest person with PWS may lie, fib, or steal when it comes to food. This is simply a symptom of PWS.
- Behavior problems are often related to unsecured food sources *somewhere*. Once all food sources are locked, anxiety is reduced and behavior problems are often reduced in *all* areas.
- Do not remove food – or *any* item – from the hands of someone (unless dangerous or poisonous) as this will almost always create a behavioral outburst.

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### Environmental Basic B: Routines

Consistency and routines help people feel safe and secure. When people know what to expect they don't have to worry. Routines reduce anxiety. Persons with PWS have a high need for routine, predictability, consistency, and sameness in the environment.



#### Create routines to reduce anxiety

- Create daily routines for every activity
- Create written or visual schedules or charts
- Refer to the written schedule or chart to avoid arguments
- Provide advance notice about changes in plans as appropriate to the individual

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### Environmental Basic C: Rules

Knowing the rules makes it easier to obtain success. Knowing the rules reduces anxiety. Persons with PWS are rule followers.



#### Establish the rules to reduce anxiety

- Rules are not intended to be nor should they be punitive. Rules are simply the structure for behavior and activities.
- Establish rules for the classroom, lunch room, library, recess yard, accessing the school nurse, accessing the principal... everything!
- When something is understood as a rule, it's more likely be followed, especially if the individual had input to create the rule. Involve the individual to the extent possible in the creation of the rules.
- Post the rules so they're visible or easily seen.
- Be sure to establish the rule that teachers can change a rule if necessary.

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### Environmental Basic D: Boundaries

Boundaries define limits and provide structure to relationships. Boundaries establish what behavior is and is not acceptable. Firm boundaries reduce anxiety and help people feel safe. Boundaries are critically important to persons with PWS.



Boundaries feel like buoys that keep the individual feeling safe and free from anxiety

#### Create clear and firm boundaries to reduce anxiety

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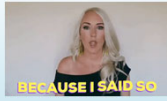
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### Boundaries continued

Goal is to be the Authority: "We need to do it" Not Authoritarian: "Do it because I said so" because Authoritarian-styles cause behavior problems by inherently removing control from the individual and activating oppositional thinking and behaviors.



Providers must be experienced as a Fair Authority so that students in your care can feel safe and supported

- Define and uphold your boundaries with gentle but firm authority and empathy.
- Say what you mean and mean what you say. Don't promise anything you don't intend to follow through on. You must be the reliable authority.
- Don't threaten to remove a privilege. Removing privileges or taking something away does not teach cooperation but rather tends to lead to more behavior problems. If a privilege or item is revoked, immediately provide the opportunity to earn it right back.
- Don't allow yourself to be manipulated. When the individual believes they have manipulated you, they no longer feel safe, their anxiety increases, and the potential for a behavior problem increases. Use *The Day Stops Here* strategy to manage refusal behaviors (tantrum, sit down strike). Progress through the day's schedule proceeds when the current task is finished (or at least attempted and partially finished).

\*Term coined by Drs. Janice Forster and Linda Gourash that addresses avoidance tantrums.

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### Environmental Basic E: Calm Responses

Anxiety is significantly increased by raised, critical, accusatory, or angry-sounding voices.

**Always speak calmly despite how you feel on the inside, especially during emotionally charged exchanges.**

- No matter how upset the individual with PWS is, a calm response from YOU reduces their anxiety and potential for increased behavior problems. Use self-calming strategies to reduce your reactivity. Breathe!
- Listen to the individual who says, 'Leave me alone.' Don't say anything else, don't look directly at them, don't stand close. Monitor with peripheral vision and let them cool down.

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### Calm Responses Continued

- Respond to a tantrum or unwanted behavior with indifference, boredom.
- Ignore unwanted behaviors, while monitoring for safety, to extinguish them as quickly as possible.
- Persons with PWS typically like "drama." Some people are "pot stirrers." Don't engage. Supervise and monitor for "drama" and "gossip" and intervene as needed.
- Lying to avoid blame or gain an audience, and confabulation (making up stories) are common symptoms of PWS.



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## Don't Give In To A Tantrum

If you give in to a tantrum you have taught the individual all they need to do to get what they want is yell louder, be more aggressive, wait you out longer, and eventually you will give in.

Giving in today over a "little thing" will lead to a larger tantrum tomorrow. The peacefulness and overall quality of the classroom depends upon upholding the established limits and boundaries. Think long term! Don't give in to a tantrum.

### Don't Give In To A Tantrum

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#2

Empathy  
as  
Intervention



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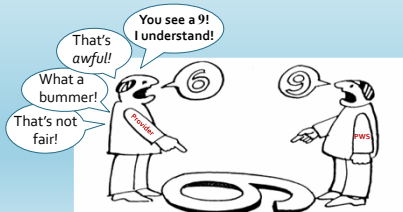
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## Empathy is a Powerful and Critical Intervention

- Empathy is the ability to see another's perspective, understand and share the feelings of another.
- Most persons with PWS do not possess the ability to see things from another's perspective.
- We have to see things from *their* perspective to manage interactions

Empathy is a **powerful and critical** intervention for PWS



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## Empathy is Successful Because...

Empathy gets to the core of anxiety, disappointment, or frustration, gets you *out* of a power struggle, and puts you and the individual with PWS *on the same side of the same team*.



At its most basic form, an empathetic response can simply be repeating the *exact* words used by the individual. Other words that can convey your empathy or understanding:

- "You think x. I understand that you think x."
- "I get it. You want to xyz."
- "It sounds like you would like to xyz. Is that right?"
- "Xyz won't work. No, xyz won't work."
- "What a bummer!"
- "What a disappointment."
- "That's not fair!"

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## Empathy Continued

- Empathy is neither agreeing nor disagreeing, and it's definitely not giving in; it is simply communicating that you understand the perspective, want, need, or concern of the individual.
- When someone feels listened to and understood they typically don't need to "turn up the volume" to get you to understand them – get louder, more aggressive, or escalate their upset.
- Get into the mindset of the individual. Look at things from *their* perspective and reflect that you *understand* things from *their* perspective. Don't be afraid to reflect the intensity of how *awful* it must feel to the individual. "*This is just awful! Just terrible!*" Genuine empathy will not make things worse!
- Only after you are *certain* the individual with PWS knows you *completely understand their concern* should you begin to share *your* concern or begin to problem solve.
- Empathy is a critical fundamental intervention to reduce anxiety, disappointment, and frustration.
- Empathy may be the only healthy intervention that can stop an escalating behavior.

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## Empathy Tips

- **Don't try to talk someone out of their upset;** they'll just feel they need to express *more* upset so that you understand. If your offer of comfort is not effective, **go immediately to Empathy.**
- **Don't use logic and reasoning,** especially when the person is upset or "stuck" on an idea or position. Give up trying to think of brilliant ways to convince the individual that you are right... *all they hear is you telling them they are wrong which will increase their upset.* **Use Empathy.**
- **Don't engage in a Power Struggle.** Learn when to disengage. Disagreements can often be ended if you allow the individual with PWS to have the last word. "*I'll say one more thing, and then you can say one more thing, and then let's talk about something different.*" **Don't say another word!**
- **Don't argue. You can't win.** You are constrained by logic; the individual with PWS is not. **Use Empathy.**
- **Distraction after empathy** can be effective.



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#3  
Preferred Choices



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### Preferred Choices

**PWS causes oppositionalism.** The brain's automatic reaction is typically to respond with "NO!" This looks like oppositional, defiant, argumentative behavior.

- **Avoid "Yes/No" questions. Offer Win-Win Preferred Choices** to reduce oppositionalism and improve cooperation. Make *everything* the individual's choice within the preferred win-win options you present to give the *experience* of control but not too much *actual* control.
  - *Do you want to put your backpack under your chair or on the hook?" "Do you want to work on this project for another 5 minutes or 7 minutes?" "Do you want to watch me set the timer or no?"*
- Avoid open-ended questions as they can be difficult to process and create anxiety.
- Avoid ambiguity. "We'll see" or "Maybe later" are vague and may create anxiety. If you don't know, say, "I don't know, and I'll let you know as soon as I do."
- Avoid hurrying with your words. Instead, use music and games to motivate or hurry.
- Allow lots of time to process past the brain's oppositionalism. Build in extra time *everywhere* you go.

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### Preferred Choices to Manage Obsessive-Compulsive Tendencies

**The brain believes 'if 1 is good, 100 is better.'** Many people with PWS collect or "hoard" items. Sorting, pulling, tearing, stealing, and skin picking can be associated with the brain's obsessive and compulsive tendencies.

If the obsessive thoughts or compulsive behaviors don't interfere with the flow of the day or anyone, ignore them. Otherwise:

- **Offer preferred choices and empathy to help manage excessive collecting or hoarding.**
  - *"I can see you really like the purple paper. Purple is such a beautiful color. I like purple too! Do you want to take 3 pages or 5 pages?" Or, "Do you want to put 5 or 7 of those papers back?"*

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#4

Paint  
the  
Picture



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### Paint the Picture

Knowing what to expect reduces anxiety and reduces the potential for unwanted behavior

**Paint the Picture** before entering *any* situation, explain in detail what will happen, what things will look like, expectations for behavior, what the plan is if unwanted behavior occurs, etc.

**Paint the Picture** especially before field trips, community outings, *everything!*



- Giving *too much* advance notice creates anxiety for some people. Not giving *enough* advance notice creates anxiety for others. Finding the right timing for the student in your care is critical... though not always easy.
- Anticipate that what you do or what happens *this* time will be expected to occur *next* time. Disappointment will result if it *doesn't* occur, if not fixed first.

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#5

Fix  
A  
Past  
Goof



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## FIX A PAST GOOF

Anything that has occurred in the past is expected to occur in the future. If something that occurred in the past needs to change, it is important to provide advance notice for the change and what that will look like. **Fix a Past Goof** and paint a *new* picture to create appropriate future expectations.

### Fix a Past Goof Guidelines

1. **Bring up issue that needs fixing.**  
*"Remember last time when we went to the library and got a lollipop on the way out?"*
2. **Incorporate empathy.** Remind individual how wonderful (or bad) it was for individual last time.  
*"That was a nice, unexpected treat, wasn't it?"*
3. **Preface fix with reminding individual of benefit to them.**  
*"We always want to do what's best for you because we care about you."*
4. **Introduce the fix.**  
*"This time when we leave the library no one will get a lollipop on the way out because that's much healthier for you and the other students."*

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## #6 Disguise Your "No's"



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## Disguise "No" as a Positive

Anything that looks, sounds, or smells like a frustrator could lead to a behavior problem. The word "No" is a frustrator. The word "but" is a frustrator.

**Use "No" and "But" sparingly and disguise them whenever possible!**

- o Individual: "I want to go to lunch now."
- o Provider: "Me too! I love lunch hour! Did you bring a good lunch? As soon as we finish Math it will be lunch time and we'll leave for lunch with the class!"

- **Use Empathy.** Be gently and compassionately unswerving.
- **Use the broken record technique.** "Yes! As soon as we finish Math we'll leave for lunch with the class!"
- **Schedule non-preferred tasks/activities before preferred tasks/activities.** Lunch after Math.
- **Keep the individual "thinking" versus spiraling deeper into the negative feeling.** "What do you think we should do about that, maybe x or y?" "What options do you think we might have...?"

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#7

Allow for the Possibility of Their Rightness



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### Need to be Right | Good | Competent

Most people with PWS have a strong need to be right at all times and at all costs. Disagreements can quickly turn into power struggles that have a "life or death" feel to them because being "wrong" to the person with PWS feels deathly intolerable.

**Allow for the possibility of the individual's "rightness" to avoid power struggle arguments**

- "You might be right."      "I like how you think!"
- "Interesting thought."      "Isn't that interesting. You think x and I think y"
- "I never thought of that!"      "So you think x and I think y. I wonder why?"

- Anticipate denying guilt or lying to get out of trouble. Acknowledge simply or ignore self-defending statements. E.g., Person with PWS: "Don't blame me!" You: "I heard you."
- Many people with PWS believe they should already know something not yet learned so their response may be to fake or argue. **Teach as if you believe they know what you're teaching.** "You know the routine at the end of the day, right? You look at your schedule to see what books and papers you need and then you put those items inside your backpack. Great job!"
- Role model that it's ok to make a mistake: "I goofed!"

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#8

Use Their Egocentrism to Your Advantage



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## Egocentric Thinking

PWS neurochemistry typically interferes with the ability to see things from another person's perspective which can look like self-centeredness and egocentrism. **People with PWS generally think about themselves first and foremost.**

**Use PWS' egocentrism as a strategy to increase cooperation.**

- Don't say, "If you don't hurry the whole class will be late to the Library." Do say, "If we get to the Library on time, we get back to the classroom for Snack on time!"
- Don't say, "Your yelling is disturbing the other students." Do say, "I hear you want xyz. When you speak softly and calm your body we can talk about what you want."
- Teach the other's perspective. "What do you think they're thinking?" "What do you think they meant?" Teach "on purpose" vs "on accident."
- Utilize egocentric thinking to your advantage! "Now that you're 16 years old, I wonder if you're mature enough to lead the class to the Library. I'm not sure though... Do you think you're mature enough?"

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#9

Motivate Externally



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## Motivate Externally

Most persons with PWS typically have low internal motivation. **Motivate externally using:**

- Verbal praise, encouragement, high-fives
- Earning privilege to be a 'special helper'
- Special time earned with someone
- Token rewards, stickers, collectibles, reward system
- Participate in activities alongside the individual
- Lead Like a Momma Duck\*<sup>1</sup> Use your body movements to "pull" your student to follow you.
- **Do NOT use food as a motivator, incentive, reward, or punishment!**

Remember that Executive Functioning deficits are common. Individuals will need support throughout the lifetime with planning, prioritizing, organizing, problem-solving, self-monitoring, self-regulating, paying attention, beginning tasks, multi-tasking, meeting deadlines, time management, and short-term memory.

- Remember that "common sense" and judgment are typically impaired
- Guide to conclusions rather than solving problems for the individual
- Remain vigilant "delusional grandiosity"<sup>2</sup> and monitor for safety

\*1 Strategy applied to PWS by Katherine Crawford

\*2 Term coined by Janice Forster, M.D. and Linda Gourash, M.D.

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#10

Use  
Transition  
Prompts  
to  
Increase  
Flexibility



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### Transition Prompts

Many people with PWS have attentional deficits. At the same time, they often exhibit hyper-focus on what they're doing *in the moment* which makes it difficult to move to the next activity. This looks like extreme difficulty stopping one task or activity to transition to the next, even if moving to a preferred activity. Common challenges include non-stop writing, torn paper from continuous erasures, etc.

- Use limited, Preferred Choices
  - "Do you want to stop in 3 minutes or 5 minutes?"
- Use Transition Prompts to help the brain prepare to move to the next task or activity.
  - "We're moving to our next activity in 5 minutes. Start finishing what you're working on. OK, 3 minutes until we need to stop. Start putting your things away."
- Praise, Praise, Praise when the student makes *any* movement toward cooperating!!
- Provide lots of empathy
  - "I know it's really, really hard to stop. You don't want to stop. I understand. And you chose 5 minutes so it's time to stop."

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### Excessive Talking, Repeated Questions?

**Determine the function.**

**May reflect short-term memory deficit:** Answer question 2-3 times then ask student what he thinks answer is. Confirm then let him know the question is all done being asked and answered.

**May reflect anxiety:** Work to reduce stressors.

**May reflect desire to connect:** Engage the individual in conversation, steer from monologue to dialogue, to another topic. Help student engage/play with peers.

**May reflect a learning style or disability (NLD):** The student may need to talk out loud in order to better understand their situation or environment. Gently guide their understanding with reflections, clarifying questions or statements.

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## Use of Consequences and Punishment with Persons with PWS

- Punishment does not change future behavior or teach a new skill. Instead it escalates unwanted behaviors and creates potential for a meltdown.
- Persons with PWS are often predisposed to react stubbornly to negative consequences and can shut down completely in response to a negative consequence.
- A person with PWS often has the ability to adjust to unpleasant situations. Some care providers perceive this as the need to apply more and more severe consequences.
- Most persons with PWS lack impulse control.

**NEVER utilize food to punish or incentivize.**



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## Final Thoughts

Remember, as the professional provider, YOU are absolutely *critical* to the health, safety, and overall quality of life of the student with PWS in your care.

Bear in mind that *everyone* has a bad day now and again, including persons with PWS, and that even the most brilliantly managed intervention won't be successful *all* of the time. That's just PWS... and that's just life!

When you incorporate the strategies you've learned today, however, you will create an environment that inspires greater overall cooperation, increased fun with your student with PWS, and reduced stress for *everyone!*

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On behalf of your student with PWS and his or her family, we thank you for your time, attention, and expertise.



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Contact Information

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Questions



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