

Prader-Willi syndrome (PWS) is a spectrum disorder so not everyone will exhibit the same degree of behavioral symptoms. The strategies presented here, however, can help with almost everyone with PWS! Always keep in mind that anything that raises anxiety has the potential to create an unwanted behavior, so when you reduce/eliminate the source of anxiety you'll reduce/eliminate the potential for a behavior problem! For more information about PWS or to request a PWS Training contact PWCF.

- **Respond with calm empathy at all times.** When there is an upset, listen to and repeat the individual's concern. Repeat the concern using their words again, and again, and again. Do not problem-solve; empathetically repeat their concern. When someone feels listened to and understood they typically don't need to "turn up the volume" of their upset. Logic and reasoning generally don't work so **don't try to talk someone out of their upset because they'll likely express more upset to get you to understand.** If upset remains after you've expressed *massive* amounts of empathy respond with steadfast indifference to the tantrum.
- **Anxiety:** Anxiety, the feeling of being out of control, typically lurks just below the surface at all times. Work to reduce or eliminate the *cause* of the anxiety to reduce or eliminate the potential for an unwanted behavior.
- **Frustrators:** Anything that looks, sounds or smells like a frustrator could lead to a behavior problem. Use "No" infrequently and disguise all "No's." Don't say, "No, we can't go outside." Do say, "Yes! As soon as we finish homework/chores we'll go outside!" Preemptively check in: "You look upset. What's up?" Provide empathy!
- **Oppositionalism:** The brain's automatic reaction is often to respond with "NO!" This looks like oppositional, stubborn, defiant, argumentative behavior. Avoid "Yes/No" questions. Give limited, preferred choices and as much perceived control as possible: "Do you want to wear your jacket or carry it?" Avoid open-ended questions which can be difficult to process and create anxiety. Allow lots of time to process past the brain's natural oppositionalism. Build in extra time everywhere you go.
- **Egocentrism:** People with PWS generally think about themselves first and foremost. This can make it difficult to see things from someone else's perspective. Don't say, "Grandma will be late to her appointment if we don't hurry." Do say, "If we get Grandma to her appointment on time we'll be able to watch the movie you want to see!" Don't say, "Your yelling is bothering people." Do say, "When you speak softly we can talk about what you want."
- **Impulsivity:** Persons with PWS generally want what they want, when they want it, which is right now. Before entering a setting/situation, reduce anxiety by 'painting the picture' of what the individual can expect: what things will look like, what will happen, your expectations for behavior, what will occur if there is an unwanted behavior. Reward for patience/self-control. Know that what occurred in the past will be expected to occur in the future so "fix" the picture if it needs fixing to avoid a behavior problem.
- **Need to be Seen as Right/Good:** Most people have a *strong need to be right at all times and at all costs.* Avoid power struggles by allowing for the possibility of the individual's "rightness." Use phrases like, "You might be right" or "That's interesting. You think x and I think y."
- **Inflexibility:** Persons with PWS often have difficulty with transitions and changes in routine. Provide verbal or visual countdown prompts, "5 minutes until we leave. 3 minutes 'til we go so let's put your shoes on. 1 minute till we leave so let's stand up. Great job getting ready on time!" Avoid using *words* to "hurry" the person; use excitement, music, praise. Give advance notice of change whenever possible. Provide empathy when there is upset.
- **Obsessions:** The brain believes 'if 1 is good, 100 is better.' Collecting, hoarding, sorting, pulling, and tearing can be associated with the brain's obsessive-compulsive tendencies. Give limited, preferred choices. Use empathy. Supplements like NAC or medication like Topamax can be helpful to reduce obsessive skin-picking behavior.
- **Self-Monitoring:** The ability to monitor one's self and accurately evaluate one's performance is often impaired. Continuously remind to speak softly; slow down eating, etc. and monitor for safety.
- **Concrete Thinking:** Abstract concepts are often challenging. The concept of time can be especially difficult. Make things as "concrete" as possible by using visual or auditory timers or alarms. Use written schedules, charts. Specifically teach metaphors and slang. Until taught, terms like, "Hop to it!" may not be understood to mean "Begin the task immediately." Teach meanings to reduce anxiety and increase social competence.
- **Planning, Prioritizing & Problem Solving:** These skills are typically poor and require a lifetime of support. Keep the individual thinking and guide them to solutions rather than solving a problem for them.
- **Low Internal Motivation; Higher External Motivation:** Use external motivators such as praise, token rewards (points, stickers, etc), visual reward system, earning special time, asking individual to be your 'special helper.'
- **Don't give in to a temper tantrum.** Stay strong and remember that if you give in today, tomorrow's tantrum will be worse.

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