

Prader-Willi syndrome is a spectrum disorder; not everyone with PWS will exhibit the same degree of behavioral symptoms. The following strategies and techniques can, however, help with almost everyone with PWS. Keep in mind that anything that raises anxiety has the potential for a behavior problem, so if you reduce/eliminate the source of anxiety you'll reduce/eliminate the behavior problem! For more information about PWS or to request a PWS Training, contact the Prader-Willi California Foundation.

- **Respond calmly at all times.** Logic and reasoning don't work when the person with PWS is upset. *Don't try to talk someone out of their upset because they'll just feel they need to express more upset so that you understand.* Listen, repeat their concern. Listen, express your concern. Listen, repeat their concern. After empathy, respond to an escalation or temper tantrum with indifference. Ignore unwanted behaviors as much as possible.
- **Oppositionalism: The brain's automatic reaction is often to respond with "NO!"** This looks like oppositional, defiant, argumentative behavior. Avoid "Yes/No" questions. Allow lots of time to process past the brain's oppositionalism. Build in extra time everywhere you go. Give limited, preferred choices and as much control as possible: "Do you want to wear the red jacket or the blue jacket?" "Wear your jacket or carry it?" "Do you want to clean up in 5 minutes or 8?" Avoid open-ended questions which can be difficult to process and may create anxiety.
- **Egocentrism: People with PWS generally think about themselves first and foremost:** This can also make it difficult for them to see things from someone else's perspective. Don't say, "If we don't hurry, Grandma will be late to her appointment." Do say, "If we get Grandma to her appointment on time you and I will have time to watch the movie!" Don't say, "Your yelling is disturbing the class/residents/workplace." Do say, "When you speak softly we can talk about your concern."
- **Impulsivity: Persons with PWS generally want what they want, when they want it, which is right now.** Before entering a situation or environment, 'paint the picture' of what things will look like, what will happen, your expectations for behavior, what will occur if there is unwanted behavior, etc. Reward for patience/self-control.
- **Inflexibility: Persons with PWS may have difficulty transitioning, changes in routine, or expectations.** Provide verbal and/or visual countdowns, "Five minutes until we leave. Three minutes 'til we go so let's put shoes on. One minute until we leave, good job for getting ready to leave on time." Don't use words to "hurry" individual; instead use excitement, music, natural incentives, praise. Provide advance notice of change when possible. Provide empathy when there is an upset.
- **Frustrators: Anything that looks, sounds, or smells like a frustrator could lead to a behavior problem.** Use "No" as infrequently as possible. Disguise No's: don't say, "No, we can't go outside now." Do say, "I'd love to go outside too! As soon as we finish homework/chores let's go outside!" Provide empathy: repeat individual's words. Observe individual's actions: "You look like you're feeling upset. What's up?"
- **Obsessions: The brain believes 'if 1 is good, 100 is better.'** Collecting, hoarding, picking, sorting, pulling, tearing can be associated with the brain's obsessive or compulsive tendencies. Give limited, preferred choices. Use empathy. Medications may be necessary.
- **Self-Monitoring: The ability to monitor self and accurately evaluate one's own performance is often impaired.** Continuously remind to speak softly; slow down eating, etc.
- **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 interesting. You think x and I think y."
- **Planning, Prioritizing & Problem Solving:** These skills are typically poor. Continuously provide assistance and guidance. Keep the individual thinking and guide them to solutions rather than solving the problem for them.
- **Low Internal Motivation; Higher External Motivation:** Use external motivators such as praise, token rewards, visual reward system, special time, asking individual to be your 'special helper.'
- **Persons with PWS are generally concrete thinkers.** The concept of time can be especially difficult. Make things as concrete as possible. Use visuals, timers, alarms, etc. Specifically teach metaphors, idioms, slang. Until taught, terms like, "Hop to it!" may not be understood to mean "Begin the task immediately." Teach to reduce anxiety and increase social competence.
- **Don't give in to a temper tantrum.** Stay strong and remember that if you give in today, tomorrow's tantrum will be worse.