Principles of PWS Behavior Management

- Create Consistent Routines
- Create Clear Rules
- Create Clear Boundaries
- Create a Calm Environment
- Create positive consequences
- Follow the Principles of Food Security
- Apply the Principles of Food Security to every area of life to create the Principles of Life Security

Lower Anxiety + Increased Boundaries + Increased Consistency = Decreased Behavior Problems

Create Consistent Routines

- Consistency and routines help people feel safe and secure. When people know what’s happening next and what to expect, they don’t have to worry about it. **Routines reduce anxiety.**

- Create routines around wake up time, meals and snacks, chores, bedtime rituals… everything! Have a consistent schedule at home and school. Having a menu or picture menu for the days of the week that is on a bulletin board can be helpful. Have consistent meal and snack times. This helps the child with asking when they can eat again, it also reinforces and helps with the concept of time.

- Before entering a new or unknown situation, paint the picture of what will happen and talk about your expectations for behavior. Try to do this in small steps, and not a lot of words. **Creating a picture of what to expect will help reduce anxiety.**

Create Clear Rules

- Parents must be Top Dog. Parents must establish and maintain the rules. Parents are not friends to their kids. Parents need to be parents so their kids can feel safe. Best parental match for a person with PWS is one who is an authority figure but NOT authoritarian. Anger and being ridged do not work.
• People with PWS are rule followers. Rules provide guidelines for understanding what is expected and how to behave. If something is understood and processed as a rule or a contract, it will be adhered to.

• Establish household rules (make bed in the morning), hygiene rules (wash hands after using restroom), chores rules (set the table before supper), exercise rules (walk first, then snack), social rules (greetings, sharing, turn-taking, reciprocal play), shopping rules (no whining), and food rules (Principles of Food Security). Practice social conversations. “When you meet someone, say, “Hi how are you?”.

• Be sure to establish the rule that Parents can change a rule if necessary! But remember children with PWS count on fairness.

Create Clear Boundaries

• Establish boundaries around what behavior is acceptable and what behavior is not acceptable.

• Say what you mean and mean what you say. Don’t threaten something you don’t intend to follow through on. Remember positive reinforcement goes much further than negative reinforcement. Praise the good choices, however small.

• Give limited, all preferential choices. “Do you want to wear the red jacket or the blue jacket?” “Do you want to take your bath/shower in 5 minutes or in 10 minutes?”

• Be clear, avoid ambiguity. “We’ll see” or “Maybe later” are too vague and may create anxiety which could lead to an unwanted behavior.

If you give in to a tantrum, you have taught the person with PWS all they need to do to get what they want is to cry louder, wait you out longer, and that eventually you will give in.

Uh Oh. Already Given In to a Tantrum?

Don’t be too hard on yourself.

We all goof every now and again!

• Explain that your past giving in has not been helpful. Talk about something you gave into and how it was not helpful for the child.

• Apologize for your foible.
• Explain that from now on, for the child’s/adult’s benefit, you won’t give in and you’ll work harder to keep him/her safe.

• When a tantrum for something begins, calmly remind the individual that you will not be giving in because that’s unfair to him/her.

• Stay strong and don’t give in!

• When changing a behavior the child will try and push even harder to get you to go back to the old ways.

Create a Calm Environment

• Persons with PWS are typically “Hyper-Reactive.” The best environment for someone with PWS is one where everyone responds calmly.

• Always speak calmly during emotionally charged exchanges. The global sense of anxiety people with PWS feel is significantly increased by raised, critical or angry-sounding voices. Tone is often more critical than the words used.

• The person with PWS knows how you really feel and will respond to that. If you can respond with compassion the person will feel more calm.

• Some people with PWS like to “stir the pot” to elicit a reaction, but when they receive a negative reaction it can cause them to feel anxious, which can turn into an unwanted behavior.

• Respond to an escalation with indifference, boredom. Ignore unwanted behaviors as much as possible to extinguish them as quickly as possible.

• Respond calmly on the outside, despite how you feel on the inside. Be patient. Be gently firm. Be encouraging.

• Don’t argue. Don’t engage in a power struggle. It’s ok to matter-of-factly explain, “It’s this or nothing. What would you like?” Walk away for the moment and allow the individual time to process their situation and come around to doing what you’re asking.

• 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. The time it takes to listen and express genuine empathy is worth it. Listen, repeat their concern. Listen, repeat their concern. Listen, express your concern. Listen…. 