

Positive Behavior Strategies: Tips For Educators of Students with Prader-Willi Syndrome

We can become frustrated when the student with Prader-Willi syndrome (PWS) does not seem to hear what we are saying and does not stop when we ask them to do so. So often, educators, therapists and others who work with these individuals get caught using phrases and instructions which emphasize the negative – “don’t statements”. When a person with Prader-Willi syndrome is starting to become anxious and frustrated, in most cases he/she is incapable of taking a “don’t request” and turning it around to a “do action.” With their frustration and anger escalating, we come to a point where we have lost our opportunity to teach and for them to hear what we are saying.

The most effective way to address negative behavior and to change these into more socially appropriate responses is to teach, and ask for the behavior you want to see. Sounds simple right? Well, it can be a challenging change for many of us.

Communication—The Key

Below are some examples of positive ways to communicate behavior requests and/or expectations.

IF the child or adult with PWS is:

Yelling, whining ... You can say “I need to hear a quiet voice”.

Hitting, pushing, kicking ... You can say, “I need you to keep your hands to yourself. I need quiet hands/feet”.

Misbehaving on the bus ... You can say, “You must sit in your seat with a soft voice while you ride on the bus.” (Instead of yelling at him because he is getting up and jumping and yelling on the bus.)

Be specific in your requests:

“I need you to put your book into your backpack” (Instead of “Get ready for the bell!”)

“I need you to put your math book away.” (Instead of “Get ready for your next class.”)

“I need you to get your jacket and put it on”. (Instead of saying, “Get dressed for recess”)

Give choices it often empowers the person with PWS. It gives them a sense of control and it allows us the ability direct those choices.

“When you want to ask a question, you can either raise your hand or hold up your question card.”

“You can have a snack – your choices are string cheese or a small container of yogurt”.

“You need to wear a jacket – do you want to have the zipper open or the zipper closed.”

Make the student your “special helper”. If you want him/her to get ready for the next topic or activity and you need him/her to cooperate you can say, “TJ will you be my special helper? I need you to help me find the special paper we will need for this activity –

I can’t seem to find it.” No matter the age; most like to please and help.

Teach the child or adult with PWS what they CAN do when they are frustrated or angry. So often, we tell them what “not to do” but we must teach, practice and re-teach strategies that they CAN do to deal with these feelings. The best time to teach these is when the person is calm and can hear what you are saying. Often times, when the person with PWS starts practicing strategies, the strategies themselves become a diversion when it comes time to use them.

Some students may be able to control some emotions using a diversion strategy utilizing an activity that is known to be calming. For some, they can de-escalate by being removed from an area and listening to music, doing a puzzle, or going for a walk. Other students with PWS may feel a need to utilize behaviors that allow them to release some of their pent up emotions. These students may want to go to a “safe area” to tear paper or hit a pillow when they are upset. This strategy can be easily used at school as well as in the home and other environments. Once again, the important part is talking about the plan ahead of time and having the person with PWS “buy” into it and practice it before it is needed.

If the student with PWS is found with food he should not have; do NOT attempt to physically take it away from him/her. Try to negotiate or trade. “Let’s make a deal. If you give me that cupcake, I will make sure to call your mom and tell her what a great job you did. I will let you have a piece of candy (sugar-free) from my special drawer. (Locked drawer).” Don’t threaten the student; you will only make him/her angry and make the situation worse. It is NOT a good idea to say things like: “If you don’t give me that cupcake, you won’t be able to have any supper tonight. I am going to call your mother.” Do let the parent know about the incident so appropriate diet and calorie changes can be made. However do it in a non-threatening way.

An important part of any behavior management plan is to evaluate and correct the cause of frustration and/or anger. If we can problem-solve around the causative issue, we may be able to prevent future escalations from reoccurring. How did they get the food? What can we do to prevent this from happening again?

The student with PWS can make educators use skills they may not have had to use in a long time. These students can make you more organized; more creative and more positive in order to get cooperation. They can challenge your imagination in mastering behavior management and motivation. Asking the person with PWS to demonstrate the behavior you want to see; as well as providing choices and teaching ways to exhibit anger and frustration are just a few strategies or ideas of how to assist the child or adult with PWS to use behaviors that are more socially appropriate and less dangerous for themselves and those who support them.