

## PWCF General Education Meeting Session

### "Behavior-Behavior-Behavior-Everybody is Talking About Behavior"

Excerpted from Barbara "BJ" Goff's, Ed.D. Presentation

All behavior is either adaptive/helpful or maladaptive/not helpful. And just when we're about to label a behavior "maladaptive," BJ Goff, Ed.D. advises us to examine our perceptions and think again...

Of course children and adults with PWS have many assets, including being bright or clever, friendly, loving, have good visual processing strengths, having strong maternal or paternal instincts, etc. As parents and care providers, we can build upon our child's or adult child's strengths by helping to empower them through education and by providing them choices within limits. It is important to teach our kids about nutrition, healthy eating habits, and how to make healthy food choices. By asking our child to make decisions within limits, we provide them a greater degree or perception of independence and strengthen their problem-solving skills. Examples of choices within limits include, "Do you want to wear the red shirt or the blue shirt with your pants?" or "Do you want strawberry or grape jelly with your peanut butter sandwich?" Dr. Goff advises parents and care providers to create and maintain routines and schedules. Predictability helps reduce anxiety, and lowered anxiety reduces maladaptive behavior. She further advises to create a plan for special occasions that fall outside of regular routines - such as holiday parties! This plan can include rehearsals with our child about what they can expect to occur during a particular setting and what we, as the parent or care provider, would like to see happen. Rehearsals can be helpful with other events as well, such as going to the grocery store, a restaurant, on a field trip, etc.

As we all know, people with PWS have a preoccupation with food. Dr. Goff asserts that never feeling full (satiety) is different from always feeling hungry, and that the underlying physiological problem probably involves an impaired satiety response. She reminds us that overeating or searching for food is not a function of the person's lack of self-control, and that when this concept is *truly* understood we can better address the preoccupation by developing realistic expectations and plans that are more effective. Some of the ways Dr. Goff suggests to help reduce temptations to food include controlling the environment (lock kitchen cupboards, fridge; control access to money); maintain a meal and snack schedule; have "emergency snacks" in the car should a schedule change unexpectedly; educate and enlist the help of family, neighbors, and friends; and don't assume that control around food in one setting will carry over to control in another setting. Dr. Goff encourages us to make exercise a

family affair, fun, and highly praised. She reminds us that weight management is our job, not *our* child's.

In addition to never feeling full, many people with PWS have a significant degree of maladaptive or unhelpful behaviors such as skin picking, being stubborn, having tantrums, being disobedient, being impulsive, stealing, having labile (up and down) emotions, or talking too much. Individuals with PWS show higher rates of obsessions (recurrent and persistent thoughts, impulses, or images that feel intrusive and inappropriate and are difficult to ignore) and compulsions (repetitive behaviors or mental acts that the person feels driven to perform in response to an obsession) compared to those with other types of developmental disabilities, not all of which are about food. Examples of common obsessions include hoarding (cards, pens, paper, etc.); ordering and arranging items (by color, shape, size, etc.); needing to tell or say things, repeating questions or statements (also called perseveration); being concerned with symmetry, exactness, neatness; redoing things (cutting until perfect, shoe tying/ untying, homework, etc.).

How do we respond to our child's obsessions and compulsions? First, advises Dr. Goff, we must recognize them as obsessive/compulsive behaviors and realize that their underlying cause may well be anxiety; individuals with PWS are often overly anxious or worried. Intervention is probably only necessary if obsessive/compulsive behaviors are truly interfering in everyday life; if so then behavioral intervention and/or medication may be required. Behavioral interventions might include helping the individual talk about their concern or fear, or ask them to write down or draw what they are obsessing about. This helps to get it out of their head and into a concrete form, where it can be more manageable. She advises us to help our child look for a solution to their concern, help them problem solve. Accommodation may be helpful when it comes to compulsive behaviors. Dr. Goff suggests allowing extra time for the behavior to be performed, or acknowledge what your child is saying up to three times and then let him or her know you will not talk about it anymore. If it still needs to be repeated have them write it down (or color/draw it) and place it in a visible place.

Skin picking, says Dr. Goff, occurs in approximately 80-84% of individuals, and ranges from very mild to severe. Other forms of self-injurious behavior include nose-picking, hand biting, and head banging. We don't yet know why people pick, but when/if it occurs she advises us not to focus on it, keep hands

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and mind busy, keep the skin and lips as moist and "bump-free" as possible, apply insect repellent before going outside to reduce bug bites, teach basic first aid, monitor frequent and/or lengthy trips to the bathroom and place time limits and provide supervision if necessary, and consider medication if it's severe and associated with a high degree of other obsessive-compulsive behaviors. She reminds us that every person is different and in order to develop successful interventions, we must have specific information about where, when, and under what circumstances our child picks most often. Dr. Goff relayed one successful intervention used with a gentleman who had a severe, chronic problem picking. The man's care providers rolled a massager on his back ten minutes before he went to sleep each night and five minutes in the morning upon awakening. For whatever reason, this sensory input continues to help this man successfully manage his skin picking.

Stubbornness, a common characteristic of PWS, is appropriate at age two or three years. Older than this, stubbornness is often a big problem. Dr. Goff suggests that some underlying causes of stubbornness might be that the assignment/task/activity is perceived as too difficult; the person is not finished with their current activity; they have their mind set on doing something else; or the activity is simply not interesting, fun, or rewarding.

Dr. Goff believes that unless someone is having a psychotic episode, there is an identifiable 'cause behind each and every temper outburst. She believes that most tantrums or outbursts can be traced back to a food related issue, a perceived sense of unfairness, or a misunderstanding during the conversation. She offers some helpful rhymes to help parents and care providers reduce the likelihood of temper outbursts: • You've heard it before - try and ignore • The more words spoken - the more things broken • Instead of talking - do some walk-ing • Reviewing the fight will make it ignite • When it ends - just be friends. Important caveats

regarding temper outbursts include the following: if the individual is being aggressive, focus on safety issues and leave the scene; if we think we may need to restrain (hold) the person, we should get trained in using appropriate techniques; and depending on the nature, severity, and precipitants to the aggression, we should consider a psychiatric evaluation for medication.

Dr. Goff maintains that if we can see the positive aspects of a "problem" behavior, it ultimately helps us cope better. She offers some wonderful ways of re-thinking or refraining our child's behavior in ways that are a bit more positive:

<b><u>Problem Behavior</u></b>	<b><u>Reframed Behavior</u></b>
<i>Runs Away</i>	Brave, curious, independent
<i>Dependence on Mom</i>	Good judge of character!
<i>Verbal Challenges</i>	Can advocate for self
<i>Compulsive Behaviors</i>	Can stick with an activity for a long time
<i>Trouble Transitioning</i>	Won't leave until the job is finished
<i>Impulsive</i>	Spontaneous
<i>Cognitive Rigidity</i>	Knows one's own aid. Not wishy-washy
<i>Grandiose</i>	Vivid imagination
<i>Argumentative</i>	Committed and passionate about beliefs

Acquiring the skill to positively reframe "negative" behaviors can be most helpful. Responding to someone who is "committed and passionate about his beliefs" as opposed to "argumentative" may make it just that much easier to manage our own emotions and respond to our child - as well as others! - in more positive, adaptive ways.