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Behavior Plans: WHAT'S WRONG WITH FOOD REWARDS IN PWS?

ALL FOOD IS HIGHLY REWARDING FOR PERSONS WITH PWS

Behavior observation, parent and caregiver observations and neuro-imaging research tell us that food is extremely rewarding to people with PWS. They are especially sensitive to foods that are intrinsically rewarding to other people: sweets and concentrated carbohydrates. We are increasingly advising parents to eliminate ALL sweets as these are highly likely to be contributing to the heightened food drive.

FOOD is *STRESS*

People with PWS are stress sensitive; stress and anxiety are at the heart of most of their behavioral problems, especially disruptive and aggressive behaviors and shutdowns. Because food is so rewarding to persons with PWS, in our DVD released by PWSA and IPWSO in 2005, we emphasized the importance of **FOOD SECURITY**. Behavior plans which use food rewards on a contingency basis, create *FOOD INSECURITY* which *by definition is* anxiety about food. The target behavior *may improve* but at the cost of increased anxiety and stress which may be manifest by other problem behaviors.

REWARDS ARE NOT EASILY FADED

Generally speaking, PWS patients are not subject to *Behavior Modification*, rather we use *Behavior Management*. This means that unless the desired behavior can become its own reward, the reward used to "modify" the behavior cannot be withdrawn. Behaviors which are driven by strong impulses (e.g. disruptive behaviors) or which are rewarding in and of themselves (e.g. food stealing, making inappropriate phone calls, excessive use of social media) do not appear to be subject to modification and other means to prevent these behaviors must be employed.

SWEETS OF ALL KINDS ARE TOO REWARDING for PWS

There is a serious risk that highly rewarding food (e.g. candy) when paired with a desired behavior, **WILL NOT EVER BE FORGOTTEN** and will motivate a person with PWS to return to the undesired behavior in order to reinstate the candy reward. Unless the behavior is well

understood and an alternative reason for avoiding the behavior can be effective in motivating the person, fading a food reward, *especially a highly rewarding food*, is not likely to be successful. If an alternative motivator could be found, then food reward would not be needed in the first place. Food rewards introduced for intractable behavior problems should be assumed to be a *permanent* part of the individual's life plan and not a temporary measure. A very low calorie, mildly rewarding food that can be continued indefinitely is preferred, e.g., tabasco sauce (for those who like it) with the next meal, pickles or sugarless gum. The individual does not learn from NOT earning the reward, therefore the bar for success must be set low and raised gradually and opportunities to earn the reward should be frequent enough so that the very occasional event of losing the reward is not devastating. For this reason non-food rewards and calorie-free rewards are preferred.

There is no formal research in this area. One very small study cites the use of 100 calorie yogurt reserved from the daily diet to reward exercise. This situation is unique as follows:

- 1) The food was part of the daily diet plan and no more rewarding than the individuals' other food.
- 2) The behavior of exercising was already established as well within the reach of the subjects.
- 3) The researcher had no plan to fade the reward (with good reason!)

Finally, using food rewards (and withholding them) for behaviors which may be the result of stress or anxiety [e.g. refusals, tantrums, shutdowns] may worsen the situation. Using contingency plans of any kind for toileting problems or disruptive behaviors must be accompanied with supports which virtually guarantee success.