Challenging behaviors are a feature of Prader-Willi syndrome (PWS). When responding to these behaviors, it is important to remember that negative consequences (which include responses such as shaming, threatening to take things away, etc.) are not typically effective in helping a person with PWS to manage their behavior more appropriately. The cognitive and impulse control deficits caused by PWS inhibit the ability to understand what a negative consequence is trying to teach so it does not alter future behavior. And most often it leads to a power struggle which rarely helps to improve a challenging behavior. So what does work?

People with PWS are successful behaviorally when a positive behavioral strategy is developed and consistently employed. This is a tried and true strategy that is effective for people with PWS of all ages. A positive behavioral strategy uses incentives and rewards to move a person successfully through the day by mixing preferred and non-preferred activities. For example:

If Tommy, who has had a problem getting up and ready for school in the morning, is able to accomplish this task in the designated half hour time period he will receive a sticker. If he earns 10 stickers during the week, he will be able to pick a movie he wants to watch.

In this example, Tommy’s desire to watch a movie of his choice is used to motivate him to successfully accomplish a non-preferred activity – getting ready for school on time.

How to get started?

1. Create a list of challenging behaviors. These are the behaviors you want your plan to help change.
2. Prioritize the list by identifying one or two behaviors to be addressed first. Behaviors that are most disruptive could be at the top of the list or you could start with behaviors that will improve more quickly so the person begins to earn rewards and feel successful more quickly which can increase ongoing commitment to the plan.
3. Create a list of rewards or incentives that will motivate the person. When possible, invite the person with PWS to help you create this list. This creates a good opportunity also for you to begin to explain the purpose of the new plan you are creating in a positive way.
4. Create the plan for the initial behaviors you want to target. As with the example above, create a strategy for each challenging behavior that includes the preferred behavior you want to encourage and how and when the reward will be applied to motivate the behavioral change you want to help create. Pay attention to how often the reward is applied. For some people a weekly reward works well but for others the positive reinforcement might need to be daily or even hourly. Find what works for the person you are supporting!

Tip: Before beginning step three, do some research. You can find many helpful resources on positive behavioral strategies by searching online. If you are working with a counselor, social worker, or school professional they also might be able to assist you with ideas. And don’t forget to contact PWSA (USA) for helpful behavioral resources (video and written) for supporting people with PWS. The more you know the better your plan will be!

Once you have a written plan designed, share it with the person with PWS and others involved in their life so they understand the expectations of the plan and how it works, post it where you both can see it every day, and use it consistently. A good positive behavioral plan is an essential foundation for diminishing challenging behaviors experienced by a person with PWS.