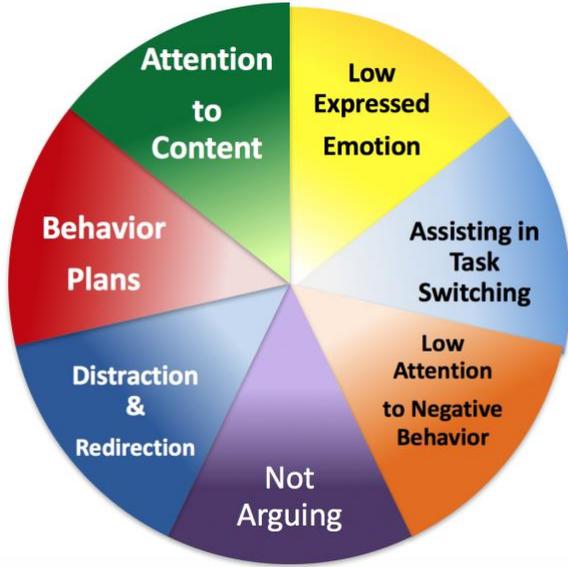


The Behavior Beachball : Skills for Families and Aides



Skills needed for working with noncompliant and disruptive behavior; they are predominantly preventative but *all come into play* at times when de-escalation is needed during an outburst.

Low Expressed Emotion:

All of us are quite sensitive to the emotion in other persons' voices, especially *anger* (annoyance, frustration, exasperation, impatience etc.) Emotion in another person's voice immediately evokes emotion in us! When talking to a person with PWS it is especially important to keep emotion out of your voice for 2 major reasons 1) they are very likely to over-react to your emotion 2) they will cease processing your words as they react to your emotion.

This skill is called **Low Expressed Emotion** because it is not what you feel but what gets expressed that counts. **But** what you feel has a great influence with how much emotion you express.

Our (negative) feelings are usually triggered by some degree of disappointment; that is when expectations are not met. If caregivers understand PWS they will feel less objective disappointment. It helps if parents and aides anticipate that the person with PWS may not to comply immediately with a request; he may argue; he may manipulate or lie. If he or she has done any of these things in the past it is best for the caregiver to assume that these things will happen in the near future. This understanding helps the parent or aide to respond with less emotion.

But emotions will be triggered and then it is crucial for the parent or caregiver to be practiced in the art of *concealing* his negative emotions. **Emotions** are mainly **expressed** in the voice but facial expression and body language are also important to modulate.

Tone rather than volume is what needs the most attention. Your goal is a flat, matter-of fact or upbeat tone as if nothing provocative has happened. Start practicing this art today in ALL of your conversations and other relationships will go smoother.

Assisting in Task Switching

Many conflicts arise out of the failure of persons with PWS to do what they are asked. Many of these events have to do with the desire, even the need, to continue what they are already doing. They may have very little objection or opposition to what you want them to do only difficulty in making the switch. If you help them, you will get more cooperation.

- Begin a request with a pleasant upbeat tone.
- Wait 8-10 seconds
- Expect to have to repeat request
- Move in close; repeat request in same tone with same inflection.

When you know from experience that a certain transition is going to be difficult you may add a step and expect to take more time:

- Move in close;
- Ask child about what he is doing. Engage him on what he is doing before asking him to stop.
- Begin a request to end the activity with a pleasant upbeat tone.
- Wait
- Expect to have to repeat request
- Repeat request in same tone with same inflection.

You may have to cycle through the last 3 steps multiple times.

What does not work:

- Making a request from another room
- Scolding the person who “ought to know” it is time for a new activity
- Making the request and then going away before the person has made the switch or
- telling the person that a switch will be expected “in 10 minutes” and then expecting him to remember that and make the switch on his own in 10 minutes.

Low Attention To “Negative” Behavior

“Negative” behavior is any unwanted behavior. It is a natural impulse to comment on negative behavior, scold or threaten with consequences but these tactics generally make matters worse. PWS in particular seems to be strongly reinforced by attention to undesirable behavior.

This skill can take some real acting talent. You must pretend that you do not notice or do not care about the behavior. Rather your comments and your movements are all directly pointed toward **the behavior that you want the person to be doing instead.**

Therefore, as in the prior skill of **Assisting in Task Switching**, you will NOT comment on the fact that the person is not doing as requested nor threaten consequences to try to speed him along. You will talk about anything else except the negative behavior or remain silent.

Distraction and Redirection

These are the things you are doing when the person with PWS is not doing what you want him to do. They are what you are doing while you are giving **Low Attention** to his negative behavior as above. You may **distract** by talking about something you know interests him or about a preferred activity coming up in his schedule. You may redirect his attention to what you want him to do. Most of your verbal content will be devoted to what you want him to do with no remarks on the fact that he is not doing it. You may also talk about the incentives and rewards built into his daily plan. This is how to make the most use of **Behavior Plans** (below).



NOT Arguing

- What is Arguing?
 - Arguing is point-counter point. Arguing gives reasons and support for your position.
- Why avoid Arguing?
 - Arguing back validates the child's arguing
 - Arguing pulls you off message
 - Arguing empowers the child and allows him to set the agenda.

Having witnessed families and caregivers fall into the trap of arguing with a person with PWS, it is very clear that for some people, this skill is very difficult to exercise. It may help to point out that you can virtually never “win” an argument with a person with PWS. For 3 reasons:

- Arguing encourages more arguing.
- People with PWS often LOVE arguing
- The person with PWS is not bound by logic or facts.

By not arguing, you are giving **Low Attention To Negative Behavior**. Instead of Arguing you will use other skills discussed here, especially **Distraction** and **Redirection**.

Behavior Plans



Building behavior plans is a separate topic covered in another handout. But supporting a child's behavior plan, schedule is very much a skill needed by caregivers and families. One of the benefits of the *existence* of a behavior plan is that you have something to talk about when you are giving low attention to negative behavior

The verbal support that you give a behavior plan is crucial. The *single most common mistake* is to think that talking about consequences will be helpful. Rather, your verbal content should be focused on what you want him to do and the incentives he will receive for doing

it. Primarily you will talk about the incentives he will receive on the same day rather than a long-term reward. The behavior plan is an opportunity for you to be a cheerleader for the child rather than his opponent. How you talk about behavior plans can completely sabotage the effectiveness of the plan. Upbeat statements such as,

“I want you to earn your points for the afternoon! Let’s do it!”

are far more likely to aid compliance than any threats or reminders of consequences. If any caregiver has the mindset that a Behavior Plan functions by “*teaching him a lesson*” is likely to render the plan ineffective with inappropriate and negative remarks.

Attention to Content

In addition to HOW you speak to someone with PWS, experienced caregivers generally recognize that one must be selective and thoughtful about WHAT one says to a person with PWS and WHEN one says it. Caregivers are trying to avoid talking about events until they are certain of the plan and that there will be no surprises or disruptions to the plan. Outright lying is risky but withholding information is essential and sometimes saying you do not know when you do know is necessary.

The reasons for filtering your content is that too much information can cause anxiety and intense perseveration while at the same time not enough information can have the same effect. People with PWS are stressed by uncertainties/possibilities and disappointments. Experienced parents are constantly on the lookout for these in their conversations. The more important the issue is to the person with PWS, the more important it is to manage the uncertainties and disappointments in his life. With respect to what he is going to eat, we call this **FOOD SECURITY**. We avoid saying anything (or situations) that will introduce **DOUBTS, UNREALISTIC POSSIBILITIES OR DISAPPOINTMENTS**.

We generally think that MOST people with PWS do better if they know the plan for their immediate (today’s) needs, their food, their schedule, their activities and their caregivers.

Beyond that, talk of the future often backfires and most families and caregivers postpone discussions of future events as long as feasible. Medical professionals or educators who do not know the syndrome are likely to make errors in this regard and need cautions and time alone with the caregiver since even professionals usually are not aware of this delicate balance and naturally fall into talk of possibilities and future events.

Tolerance for some amount of uncertainty increases with age but this issue remains in adult life.