

Prader-Willi Syndrome Behavior and the Collaborative Problem-Solving Approach

Probably the single most troublesome aspect of Prader-Willi syndrome, aside from the hyperphagia symptom (insatiable appetite), is the behavioral component. This article is the first in a series intended to provide a brief introduction to and overview of Collaborative Problem Solving (CPS), an approach developed by Ross W. Greene, Ph.D. (author of the *The Explosive Child*) and his associates at the Collaborative Problem-Solving Institute (Department of Psychiatry, Massachusetts General Hospital, Harvard Medical School, to help individuals of all ages who are easily frustrated, chronically inflexible and often explosive. CPS techniques are currently being used successfully by families of children with PWS throughout the country.

Two overriding principles of Collaborative Problem-Solving are that "Children do well if they can..." and "Your explanation [of the child's behavior] guides your intervention." This means that if a child/adult is not doing well it's not because he doesn't want to do well, it's because he can't do well yet, and that how we think about our child/adult child's behavior will directly impact how we respond/react to any given situation.

Meltdowns, like all disadvantageous behaviors, occur when the cognitive demands placed on the person overwhelm the person's ability to respond adaptively or appropriately. Explosive or noncompliant behavior occurs when the characteristics of the child are incompatible with the environment at the time. The goal of CPS is not to "fix" or change the child, but rather to improve the compatibility between the child and his environment.

Dr. Greene defines seven characteristics of the easily frustrated, chronically inflexible, "explosive" child. These include many characteristics which are strikingly similar to those of the typical individual with PWS:

- **Temperament:** The natural, inborn style of behavior of each individual (Stanley Turecki, M.D.). For the easily frustrated or "explosive" child, temperament may include "distractibility, high intensity, withdrawal, or poor reaction to new or unfamiliar stimuli, poor adaptability (reacting badly to changes in routine), negative persistence (strong-willed, whiny, rigid), low sensory threshold (itchy clothes, etc.), and negative mood (irritable).
- **Executive Skills:** Thinking skills necessary for organizing thoughts, processing information, and responding adaptively. These skills include the ability to shift mind set (transition from one thing to another); organize and plan (not get stuck on the first unsuccessful solution); having a working memory (needed for multitasking, hindsight and forethought which teach us how we handled similar problem in past and potential consequences of current actions on future outcome). Many of these skills are difficult or lacking in persons with PWS.
- **Social Skills:** The ability to attend to relevant social cues; accurately interpret social cues; consider potential response options and potential outcome of each option; choose and enact upon one option, gauge the outcome, and make any necessary adjustments. Social skills are especially difficult to develop for those persons with PWS who also have

Nonverbal Learning Disorder (difficulty or inability to process or benefit from nonverbal communication (body language, facial expressions, tone of voice, etc. Persons with NLD are often unable to intuit or read between the lines (impacting both conversation and reading comprehension), learn by watching others, or generalize a previously learned experience to another.

- **Language Processing Skills:** The ability to accurately understand and process/sort out verbal communication. Without adequate language processing skills, people have an impaired ability to label and manage their emotions, identify problems, and communicate about them with other people, and solve problems. Many individuals with PWS have a problem with language processing skills.
- **Emotional Regulation:** The ability to manage our emotions and choose an appropriate behavioral response. According to Dr. Greene, "Some children... react to even minor problems and frustrations as if they were major obstacles. Others are extremely anxious and/or obsessive, which have the potential to make rational thought and engagement in activities problematic. Such children will need someone (perhaps many someone's) to understand their difficulties and help them cope." Emotional dysregulation is a hallmark symptom of PWS which is believed to be a result of a deficiency in the hypothalamus.
- **Cognitive Flexibility:** Includes the ability to consider another's or multiple points of view, incorporate new information to something previously learned, change one's mind, etc. "Social interactions, problem solving, and many learning tasks require a high level of flexibility and adaptability." Children with PWS are often concrete, "black and white" thinkers who lack cognitive flexibility.
- **Sensory/Motor Skills:** Children with PWS often have difficulty integrating sensory information (touch, movement, body awareness, sight, sound, pull of gravity) received from the environment and as such may underreact, overreact or fluctuate between under- and over-responsiveness to a stimulus.

The key points of CPS are that explosive and noncompliant behavior may be understood as a learning disability (a failure to progress developmentally) not as a goal-oriented form of behavior; that compliance (i.e., doing what one is asked/told to do) is a cognitive skill; and those meltdowns occur when the cognitive demands being placed upon the person overwhelm the person's ability to respond appropriately. Most persons with PWS experience problems in all the above pathways to explosive/noncompliant behavior. Add to these the brain's relentless and distracting focus upon obtaining food along with the heightened level of anxiety most feel, and we can begin to see why persons with PWS melt down so easily and/or may be so oppositional and rigid.

The crux of Collaborative Problem Solving work is to 1) identify what's going on in the individual's head that we wish wasn't (cognitive distortions) and/or what's not going on in their head that we wish was (cognitive deficiencies); 2) manage the environment to the extent possible; 3) help the individual develop a greater capacity for tolerating frustration; and finally, 4) help the individual develop the skills they need to better communicate their wants, needs, thoughts and feelings in more socially appropriate ways.

Dr. Greene asserts that 99.9% of meltdowns are predictable. And if meltdowns are almost always predictable, then they might also almost always be avoided. But how? Stay tuned for Part II in a future edition of PWCF News where we'll outline some specific strategies and techniques used in Collaborative Problem Solving. Or pick up a copy of the book, *The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children* by Ross W. Greene, Ph.D., or purchase the DVD *Parenting the Explosive*

Child: The Collaborative Problem-Solving Approach or visit the website of the Center for Collaborative Problem Solving at www.ccps.info.

Part II

The Baskets

All things a care provider does in response to someone with PWS can be placed into one of three “Baskets.” Basket A is where the care provider imposes his will on the person with PWS. Basket A can be thought of as those things, which are non-negotiable and worthy of inducing a meltdown. All too frequently the mere whiff of a negative response or a clear “No” from the care provider will elicit a negative behavioral outcome (temper tantrum, meltdown, sit down, etc.) from the person with PWS. Issues regarding safety are a good example of the care provider’s response being in Basket A. For example, the person with PWS asks to or begins to cross the street unsafely. Without hesitation, the care provider physically pulls the person safely back onto the sidewalk, ignoring the person’s sensory pathway deficit and risking the meltdown this physical grab may elicit.

Basket B is where the person with PWS wants something but what they want is not exactly ok with the care provider, but some sort of compromise or resolution is obtainable. Basket B is where we “work it out,” where each of us is satisfied with the result, and where listening, empathy, and compromise lead to improved skills and emotional growth. For example, the person with PWS wants to play a video game. The care provider wants homework or chores completed. After careful listening, empathy, reassurance, definition of the problem and invitations to compromise are exchanged, a resolution is mutually agreed upon. One compromise might look something like the person with PWS will play the video game for five more minutes, then do homework or chores until completion, then play the video games for another fifteen minutes.

Basket C is for those things that can be dropped, at least for now. These are the things that we really don’t care about or can easily agree to or ignore because there are no undesirable consequences. Using our example above where the person with PWS asks to play video games, the care provider may prefer they read a book or play outside, there’s no real harm in responding positively. Using Basket C responses as frequently as possible, especially in the beginning of incorporating Collaborative Problem-Solving strategies into daily life, creates a positive atmosphere and makes life less stressful for everyone.

Things that are uncompromisable and hence fall into Basket A are almost certainly going to induce a meltdown. Dr. Ross’ experience is that caretakers too frequently behave as if something is uncompromisable when in fact there very well could be a resolution that would avoid the meltdown and get both parties what they want. While especially difficult for caretakers whose personality style leans more toward the authoritarian-dictatorial-controlling mode, it is important to train ourselves to look for the potential compromise in order to avoid the meltdown and teach the person with PWS to better develop the frontal lobe skills that they have not yet learned.

Implementing Basket B Responses

Basket B responses are where growth occurs – not only for the person with PWS but for us care providers as well! The first step to Basket B is to have an understanding of and empathy for the want/problem of the person with PWS and provide reassurance that you understand and

empathize with their want/problem. The Expression of Empathy helps keep the person with PWS calm and assures him that you hear and understand his concern. Empathy can be expressed by repeating what you understand the person with PWS to be communicating, whether verbally or non-verbally. Often, simply repeating back what the person has said has a calming effect; since they feel heard there's no need to "kick things up a notch." Because speech and language skills are often challenged, it can sometimes be difficult to determine what the person's concern or problem is, and so it is important to calmly work toward determining "What's Up?" while providing continuous reassurance that helps the person stay as calm as possible.

The second step is to Define the Problem. Defining the problem ensures that the concern of the person with PWS is understood and "on the table" for discussion and resolution. And what is the definition of a "problem"? Simple: two concerns that have yet to be reconciled.

The final step in the Collaborative Problem-Solving process is the Invitation to find a mutually agreeable solution.

Dr. Greene asserts that "The hardest part about doing Basket B is remembering to do Basket B" and that "95% of meltdowns are caused by adults being in Basket A when they didn't have to be." There are many "traps" that care providers can fall into when learning to differentiate which situation belongs in which Basket, including using Basket B as a last resort, agreeing to solutions that the person with PWS can't actually do, or believing that Basket A + Logic = Basket B. He advises, "Even if you handle a problem/unmet expectation in Basket A the first time you deal with it, you'll probably need to put it in Basket B if the problem persists."

A very simple example of a collaboratively solved process might look something like this:

Care provider: announces, "It's just about time to take a shower."

Person with PWS: anxiously responds either verbally or non-verbally, "But I don't want to stop playing now and take a shower!"

Care provider: calmly, "Oh, you want to keep playing. You don't want to take your shower right now. Ok. How much longer do you want to play before taking your shower?" Person with PWS: "Fifteen minutes."

Care provider: "Ok, fifteen more minutes of play and then you'll stop to take a shower. That sounds great to me! I'll set the timer for fourteen minutes and give you a minute to finish up." If no mutually acceptable solution is made at this point, the process continues and might look something like this: Caretaker: "Oh, you want fifteen more minutes to play. My concern is if we wait too long, your hair won't be dry in time. How can we work it out?"

Person with PWS: "I don't know."

Care provider: "Hmmm, let's see. Your concern is you want to play more video game. My concern is I'd like your hair dry before we go out. Hmmm, any suggestions as to how we can work this out?"

Person with PWS: "I know! I'll take a shower in fifteen minutes and use the blow dryer on my hair."

Care provider: “Oh, so your suggestion is to stop playing in fifteen minutes, take your shower, and use the blow dryer. Sounds like a good plan to me. Great job. Let’s shake on it!”

In the beginning, care providers may need to suggest or prompt for potential solutions, but after the process is learned it is almost always preferable for the person with PWS to develop their own ideas for solutions because they are more likely to stick to the mutually agreed upon solution.

Care Provider Serving as Surrogate Frontal Lobe

A large part of the Collaborative Problem-Solving approach is to have the care provider serve as the Surrogate Frontal Lobe for the person with PWS while they practice, practice, practice and begin to improve their skills in each of the seven pathways.

Serving as a Surrogate Frontal Lobe means helping the person develop and continue to build upon the skills they currently lack. Of course, it goes without saying that the care provider must always remain calm, reassuring, honest, fair, and soothing.

Surrogate Frontal Lobe in the Executive Skills Pathway

Care providers who serve as the Surrogate Frontal Lobe in the area of Executive Skills help the person to be more flexible in their thinking, less “reflexively” negative, and have a more stable affect (mood) allowing them to stay calm enough to think. Fewer automatic negative responses provide opportunity for the person with PWS to come up with their own suggestions for solutions, predict likely outcomes of potential solutions, increase their problem-solving vocabulary, increase the likelihood they’ll ask for help, compromise or give a little, and/or be able to do something in a little different way.

Improved Executive Skills means that the person with PWS is able to tolerate their emotional reaction just a tad more so as to stay calm enough to think.

Surrogate Frontal Lobe in the Language Processing Skills Pathway

The care provider’s role is to help the person with PWS label, categorize and express their emotions (happy, sad, mad, glad, frustrated, scared, etc.), identify problems and communicate about them. For example, it would be important for the care provider to teach the person with PWS to say, for example, “The music is bothering me,” “I need a break,” “I can’t talk about that right now,” or “I don’t know what to do.”

Surrogate Frontal Lobe in the Emotion Regulation Pathway

One of the most difficult things for a person with PWS to do is to remain calm in the midst of frustration and keep the problem in perspective. The role of the care provider is to help the person with PWS develop the ability to better tolerate frustration and stay calmer. Knowing when the person with PWS is more likely to feel overwhelmed or frustrated – when overtired, in a highly stimulating environment, where there is access to food, etc. – prepares us to either avoid these potentially problematic situations or be more proactive with helping the person with PWS identify and appropriately express their anxiety or mounting frustration. For example, if parties or other large gatherings tend to induce anxiety, care providers should prepare the person with PWS for the anticipated anxiety (“There is probably going to be a lot of noise and disorder”), watch for signs of anxiety (“I notice you’re picking at your nails, honey.”), identify the

behavioral manifestation of this anxiety (“I see by your picking at your nails that you may be feeling a bit nervous. Are you aware of feeling nervous?”), provide options for the person with PWS to manage their anxiety (“Take a deep breath, honey, you’re just fine. Would you like to find a quieter spot? What else might help you feel better? Can you please hold this item/hold my hand/squeeze your hands together to keep from picking your nails.”)?

While the strategies and techniques used in Collaborative Problem-Solving were not created specifically for persons with Prader-Willi syndrome, you’d think they were! There is no age limit to implementing these strategies. There is no environment where these strategies cannot work – home, school, supported living setting, vocational work setting – you name it, it’ll work. The benefits of incorporating Collaborative Problem Solving into daily life are numerous: increased calmer responses, decreased arguing, decreased behavior problems, and overall improved relationships. And while all meltdowns cannot be eliminated, many, many, many meltdowns, and other behavioral problems can be avoided by incorporating these important and useful problem-solving strategies.

Easy to read and understand, Collaborative Problem-Solving strategies are discussed in the book, *The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children* by Ross W. Greene, Ph.D. and are also available on DVD *Parenting the Explosive Child: The Collaborative Problem-Solving Approach*. Visit the website of the Center for Collaborative Problem Solving at www.ccps.info.

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