

Managing Behavioral Issues of the Child with Prader-Willi Syndrome in School

by

Larry Genstil, Ph.D.

Psychologist



The Issues Involved in Managing Behaviors of a Child with PWS in School

1. Social Skills
2. Behavioral Issues
3. Food Security
4. Visual vs. Auditory Learning



Social and Behavioral Skills

- The PWS child learns social and behavioral skills differently than many other children
- These skills must be taught to many special education pupils. This is especially so for the PWS child.



Social and Behavioral Skills (Continued)

- Social and Behavioral Skills Training:
 - Discussion of the skill to be learned
 - Demonstration of the skill via role playing
 - Asking the child to role play the skill back with filming via video if possible
 - Feedback on the child's performance
 - Behavior rehearsal
 - Reinforcing the continued use of the new behavior



Behavioral Issues

- Food Stealing
 - Limit access to food as much as possible and with maximum supervision
 - Have children's backpacks or bags out of sight
 - Empty garbage cans frequently
 - Playground supervision
 - Never leave the child alone
 - The child should be aware that he has no access (Food security)
 - Guided Imagery
 - Role playing with video feedback



Rigidity and Inflexibility

- A part of the syndrome is a high degree of stubbornness, rigidity and inflexibility. Once a PWS child begins to be inflexible:
 - Coaxing, persuading, demanding will almost never help
 - Distracting often helps
 - Humor and sometimes tickling often helps
 - Sometimes, nothing helps and the best thing is to proceed in class without the PWS child's participation, especially when food is involved. This may help him re-join the group.



Food Security

Linda Gourash, M.D. and Janice Forster, M.D.

- "Food is STRESS"
- Food Security includes:
 - 1. NO DOUBTS about what will be provided and when
 - 2. NO HOPES of obtaining food outside the plan
 - 3. NO DISAPPOINTMENTS concerning food



Food Security (Continued)

- **NO DOUBTS**

- Any possible uncertainty about food must be eliminated as much as possible.:
 - Advance planning of meals
 - A schedule of all the days' events with the place of meals clearly identified
 - Visual schedule posted for the children to see
 - Verbal reminders of these plans
 - Never use food as a reward or a punishment.



Food Security (Continued)

- **NO HOPES**

- No opportunity/no chance
- • Food control
- Well-trained school staff
- • Caregivers must avoid saying anything that could create doubts or hopes
- • Matter-of-fact adherence to the plan in the face of manipulation, pestering and whining is an essential skill.
- The presence of these behaviors indicates that FOOD SECURITY is not yet achieved.



Food Security (Continued)

- **No Disappointments**
 - Managing Expectations prevents DISAPPOINTMENTS
 - Disappointments are a major source of behavior problems



Food Security (Continued)

- FOOD CONTROL
 - All food needs to be locked, such that there is no access to food or money; supervision mandatory
 - Management of the physical environment is needed to achieve “no hopes” and to maintain weight.
 - FOOD SECURITY is the psychological state of the individual.
- It is FOOD SECURITY that improves behavior



Visual vs. Auditory Processing

- Auditory processing is usually weak in the PWS child. Thus, any communication that is all verbal will result in partial processing and often will lead to behavioral issues.
 - The PWS child is often very verbal.
 - Verbal conversations have limited use
 - Only part of any verbal conversation is processed. Often the child's imagination fills in the missed content of the conversation
 - Often compulsive questioning is a result of only partial understanding of what was said
 - Verbal memory is less acute than visual memory



Visual vs. Auditory Processing (Continued)

- Visual processing in the PWS child is often above the average of a normal child
- All classroom activities should have a visual component so that the PWS child can comprehend everything. Other special children also may be better visually than auditorily, and thus for all pupils, having a visual component to all learning is helpful
- All communication and learning need to have a visual component
- A visual component to communication can prevent behavioral problems, as the child processes everything



Visual vs. Auditory Processing (Continued)

- Examples of visual components to communication:
 - Sign language
 - Gestures
 - Facial expressions
 - Written communication
 - Pictures
 - Communication via puppets
 - Role playing, especially with video feedback



Basic Principles of Behavior Management

- **Basic Principles of Behavior Management**

- ▶ Behaviors can be observed (seen, heard, etc.)
- ▶ Behaviors can be counted or measured
- ▶ Non behaviors cannot be treated in the same way
- ▶ Feelings, thoughts, ideas, etc. are not behaviors and do not respond to behavioral treatment



Functional Analysis of Behaviors

- ▶ All behaviors may be understood via a functional analysis (ABC):
 - ▶ 1. The Antecedent of the behavior needs to be defined - usually precedes the behavior and often causes it. There are some behaviors for which no antecedent can be identified, but most behaviors have an identified antecedent



Functional Analysis (Continued)

- ▶ 2. The **Behavior** itself usually follows the antecedent and is often caused by the antecedent - the behavior needs to be measured (in order to establish its frequency)
- ▶ 3. The **Consequence** of the behavior - usually follows the behavior and is our response to the behavior



Measuring Frequency/Baseline

- ▶ Frequency (referred to in professional jargon as the Baseline of each particular behavior) is the measure of the behavior before beginning any treatment program. It is important in order to ascertain whether the behavioral frequency changes as the result of treatment. It may be accomplished in various ways:
 - ▶ 1. Simple counting the number of times the behavior occurs per hour, per day, per week, etc.
 - ▶ 2. For behaviors that occur only around certain times of the day, then counting only at those times.
 - ▶ 3. For behaviors with very high frequencies, measuring the time during which the behavior occurs.



Choosing Reinforcers

- ▶ Reinforcers increase the frequency of behaviors.
- ▶ Positive reinforcers increase the frequency by its addition.
- ▶ Negative reinforcers increase the frequency by its removal.
- ▶ Punishers decrease the frequency of behaviors (the word punisher is no longer considered acceptable. A more acceptable term is “cost.”)



Reinforcers (Continued)

- ▶ I recommend choosing 5 different reinforcers if possible.
- ▶ All reinforcers have to be attractive to the person, so that he can expend effort to earn them.
- ▶ One of them is always verbal or visual.
- ▶ Some people want only one or two specific things and then it is not practical to use 5.
- ▶ When there are 5, then the reinforcers can be used non-consecutively so that no one reinforcer loses its attractiveness to the person.



The Basis of the Behavioral Plan

The Behavioral Objectives

- ▶ State the expected or desired change in each behavior
- ▶ State the measured baseline for each behavior
- ▶ State the frequency of each behavior that is desired
- ▶ State the time frame in which to achieve each goal



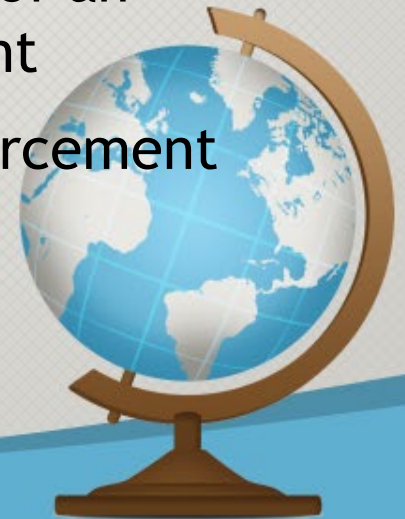
The Basis of the Behavioral Plan: Each Step in the Plan

- ▶ 1. Intervention at the Antecedent level
- ▶ 2. Consistent, structured, frequent reinforcement when the problem behavior is not exhibited, based on the attention span of the person
- ▶ 3. Structured, non-reinforcing response when the behavior does occur
- ▶ 4. 3 X more positive reinforcement than criticism
- ▶ 5. Consistency by all those involved in implementing the plan
- ▶ 6. Via role playing, giving each person alternative, pro-social behaviors in his/her behavioral repertoire



Development of a Behavioral Plan

- ▶ **1. Intervention at the Antecedent level:**
- ▶ When the antecedent to the behavior is identified, then its occurrence should elicit a response by staff that may prevent or lessen the severity of the behavior.
- ▶ Usually, there are some frequent ways to do this:
 - ▶ Set up contingencies so that non-appearance of an undesired behavior will result in reinforcement
 - ▶ Distraction from the issue at hand with reinforcement
 - ▶ Try humor with reinforcement



Ongoing Reinforcement When the Problem Behavior does not Occur

- ▶ When the problem behavior does not occur:
 - ▶ Ongoing, structured reinforcement
 - ▶ Unless the person prefers only one or two specific reinforcers, use the reinforcers consecutively to prevent burn-out to that specific reinforcer
 - ▶ Always use a verbal reinforcer immediately before the concrete reinforcer



Ongoing Reinforcement When the Problem Behavior does not Occur (Continued)

- ▶ The reinforcers need to be given based on the attention span of the person. For example, if the person has a 5-minute attention span in a given activity, then he/she needs to be reinforced every 4 - 4.5 minutes in order for him/her not to lose concentration on the task at hand. There is a need to not allow the person to go beyond his ability to attend to the task.
- ▶ If there is no reinforcer before the attention span has gone over one's ability to attend, that is when behavioral problems are expected to occur



The Occurrence of the Behavior

- ▶ Give as little attention to the behavior as is possible. Of course, when possible danger is present, the behavior cannot be ignored.
- ▶ Use low expressed emotion. Often expressions of stress, anger, etc., may exacerbate a behavior.
- ▶ When possible to intervene without causing harm, then it must be done carefully in order not to increase the intensity and/or duration of the behavior.



3 x More Attention

- ▶ Each person with PWS needs at least 3 x more positive attention than negative (at least 3 times more “Great,” “Good for you,” than “Stop,” “Enough,” etc.
- ▶ Sometimes this alone improves behavior
- ▶ With our more problem people, they often hear “Stop it!!” 20 times more than “Great!”
- ▶ Behavior changes occur more easily and frequently with more positive attention.
- ▶ Sometimes it is difficult to find behaviors to reinforce. But every effort must be made because this is one way to improve behaviors



Consistency

- ▶ The limits have to be consistent.
- ▶ People with PWS have a sixth sense about the weak link in the person's life (a pitying grandparent, a school secretary, etc.).
- ▶ When everyone in the person's life is consistent with all the limits that have been established, then progress in the treatment plan is quickest.



Video Role Playing

- ▶ Many behaviors occur to the person with PWS based on the syndrome, on his personality, on the structured program, etc. The low tolerance to frustration is a part of the syndrome.
- ▶ More pro-social behaviors are often not a part of his/her behavioral repertoire.
- ▶ Therefore, in order to allow his learning of new, pro-social behaviors, the best way is via role playing with video feedback



Video Role Playing (Continued)

- ▶ 1. Ask the person with PWS to role play a situation that was problematic, while video-recording
- ▶ 2. Ask the person to think of a better way of responding in the same situation, while video-recording
- ▶ 3. Have the person view himself in both situations and give his/her own evaluation (“Which Johnny would you choose as a friend?”, or “Which Johnny would you want the world to see”?)



Video Role Playing (Continued)

- ▶ They almost invariably choose the more pro-social role.
- ▶ Then, the person needs to “behavior rehearse” the new behavior many, many times over the next period of time in order for him to include it in his repertoire of behaviors.
- ▶ He/she needs to be reinforced every time he/she exhibits the new behavior instead of the old one.

