Program Modifications

** These modifications should be adapted to fit your child.

Add or remove things as you see fit. **

Program Modifications, supports for school personnel and/or supplementary aides and services in regular and special education programs.

General Modifications:

1. (Child's Name) has been diagnosed with Prader-Willi Syndrome.

2. Emergency Medical Alert Brochures (provided by the parents) are on file in designated locations in the school office and classroom.

3. Parents will provide a thirty minute in-service training for all teachers, therapists, and staff members who will have contact with (Child's Name) during the school year. Date for in-service will be agreed upon by teacher, parents, and staff before the beginning of the school year. The school will inform other school employees about the syndrome and its implications. If (Child's Name) starts with a new teacher during the year, the teacher will receive a thirty minute training within two weeks of him/her starting the class.

4. No food items will be used as rewards or manipulatives in the classroom or worksite unless approved by (Child's Name) parents beforehand. It is less stressful and important to his/her health and well-being to have no food in the classroom.

5. (Child's Name) will have constant one-on-one supervision throughout the day.

6. (Child's Name) will not be allowed to take food items from other peers during lunch time or any other food event. (Child's Name) parents will be notified if he/she is starting to take food from others. (Child's Name) will be redirected to another activity as soon as he/she is finished with her lunch (or other food-related event), to reduce the possibility that he/she can take food from other children. Other peers having contact with (Child's Name) should be informed as often as necessary that they should never give food to (Child's Name).

7. If a student has food in the class, the student will be asked to put the food away by the teacher. If a teacher is going to have food in the classroom, his/her aide and parents should be notified in advance so an appropriate plan can be made.

8. Should the lunch setting prove too stressful for (Child's Name), he/she will eat her lunch in a location approved by both his/her parents and the school.

9. (Child's Name) should only eat what she brings for his/her snack and lunch. (Child's Name) should not consume any other food at school or at a worksite unless his/her parents are informed. This can be through a text or email, including what the food is that is being offered and the calorie amount. These extra snacks or treats should be infrequent and should amount to no more

than 100 calories, including the beverage. If for some reason (Child's Name) consumes more than 100 calories, his/her parents should be also be informed of this so they can reduce his/her dinner calories accordingly. (Child's Name) daily intake of calories is about 1,000 per day and highly nutritious foods are always preferred. (Child's Name) metabolic rate is very low and she will gain weight rapidly if allowed to eat even a few more calories per day than the set amount.

10. Garbage cans in the classrooms will not contain any food.

11. All food will be out of sight and will be behind cupboards at all times unless there is a pre approved snack or party time. If (Child's Name) ever gains access to the cupboards or refrigerator, from that time forward they will be locked. Also, if (Child's Name) becomes aware of food in the in the class or worksite or is overly obsessed with it, it must be removed.

12. (Child's Name) "sleepiness" is a direct manifestation of her disability. If (Child's Name) becomes drowsy during school time, the teacher or aide will conduct activities that will alert or re-energize him/her. For example, the aide can run an errand with (Child's Name) or have (Child's Name) get up and sharpen her pencil. If after consistently trying several different strategies, (Child's Name) is still nodding off, he/she can take a 10-15 minute nap with his/her head down. (Child's Name) should never be allowed to sleep more than 15 minutes. Parents will be notified if he/she takes a nap at school or at a worksite.

13. If (Child's Name) leaves the school, the aide will inform his/her parents immediately. Police will be involved if necessary to find him/her. (Child's Name) phone has a tracking device in it so (Child's Name) should keep his/her backpack (with his/her phone in it), rather than putting it in his/her locker. He/She should not be told the phone has tracking capabilities.

14. If (Child's Name) is observed skin picking, the aide will notify his/her parents. (Child's Name) parents will provide Polysporin Ointment to rub on the sores. If (Child's Name) persists in picking, his/her activity will be changed to take his/her attention from picking. (Child's Name) generally picks when he/she is very stressed, bored or has nothing to do with his/her hands. If picking becomes a big problem, (Child's Name) will be given fidget toys (provided by his/her parents) to keep his/her hands occupied.

15. No physical force will be used to make (Child's Name) comply with requests. If (Child's Name) is not complying with verbal cues 95% of the time, a behavior strategist from the district will be called in, consulted with, and strategies agreed upon to accomplish compliance. (Child's Name) generally responds well to such verbal cues as "please put your paper in the basket (the undesired task at hand), and then you will be able to play with the puzzles" (the next desired activity).

16. Avoid teaching 911 emergency phone procedures to (Child's Name). He/She can be taught about safety and the role of community helpers, but specific teaching of contacting emergency workers for assistance is not in the best interest of an individual with PWS. Their view of what constitutes an "emergency" is very different from that of others.

17. (Child's Name) has low muscle tone, hyper-flexibility, joint instability, weakness, decreased balance and coordination, atypical posturing, and severe scoliosis, all of which impacts his/her mobility and functional skills at school. (Child's Name) should be monitored for possible injuries.

18. (Child's Name) is toilet trained but does not wipe himself/herself or wipes himself/herself very poorly. The aide or another person designated by the school will wipe (Child's Name) if he/she has a bowel movement. Baby wipes are best for the final clean up if he/she has had a bowel movement. All supplies have been provided and are in his/her locker along with an extra set of clothes.

19. (Child's Name) will often have a hard time transitioning from one activity to the next. He/She has obsessive/compulsive tendencies and "needs" to finish the task he/she has begun. (For example, if a dot needs to be placed on every box, he/she has a very hard time moving to another activity if he/she has not put a dot in every box.) The aide or teacher will work directly with (Child's Name) during transition times to help facilitate a smooth transition. The aide or teacher will work with the parents to incorporate signals for (Child's Name) that will let him/her know that a transition is imminent and will help (Child's Name) through the transition so he/she will not disrupt the class and so he/she will be able to move from activity to activity throughout his/her time at school. (For example, an announcement of the next activity would be helpful, or the lights in the room could be turned on and off with a general announcement that the activity will change in 2 minutes). Care will be taken to design tasks that do not have lots of objects that will cause (Child's Name) to "need" to organize them unnecessarily or to take an extra-long time to complete the task. (For example, rather than giving him/her 5 markers, give him/her 1).

20. (Child's Name) will take all the help that is offered to him/her and act like he/she needs it. The teacher and aide will provide instruction and a small amount of help but then will let (Child's Name) try to do things on his/her own. For example, a hand over hand demonstration one or two times will be enough. Several hand over hand demonstrations do not help (Child's Name) learn to write. These demonstrations should scale back help each time until perhaps just a cue to his/her elbow is enough.

21. (Child's Name) needs frequent motor breaks. Physical activity should follow each stretch of about 10 minutes of seat work. If (Child's Name) is allowed to sit for long periods of time, he/she will lose focus and will become sleepy. His/Her sensory input becomes very low and he/she will not be productive if he/she does not intersperse his/her work day with many physical activities.

22. If (Child's Name) handwriting is illegible, he/she should be encouraged to use the computer or his/her tablet for an assignment.

23. If (Child's Name) improperly gains access to food, physical force will not be used to retrieve the food. Strategies such as trading, sharing (ask him/her to share ½) and or returning the food should be used. If he/she will not comply, then allow her to have the food and notify the parents.

24. If (Child's Name) is feeling stressed in class and needs to take a break, he/she should signal the teacher and his/her aide and walk the halls for a few minutes. If he/she is angry at his/her aide or is more than a little anxious, (Child's Name) has been told and he/she should be reminded that he/she can go to various safe places in the school. The goal is to have her not leave the school. When he/she is frustrated and wants to get away from a situation, make sure (Child's Name) knows beforehand the safe spots he/she can go. Someone will always have eyes on (Child's Name) so he/she doesn't leave the school unattended. (Child's Name) should have something to do when he/she goes to those locations as he/she usually has adrenaline going and may not be willing to sit there without a plan for something to do. Just some simple options like listening to music on her phone, doing research on the computer, possibly playing war or a card game he/she likes with the aide. A balance should be struck with making it appealing enough that he/she wants to do it and it can help calm him/her down, but not so appealing that he/she would find a reason to leave class for it.

25. (Child's Name) will make up stories or confabulate, especially when in a new or stressful situation.

Managing this Confabulation behavior is challenging. Here are some helpful tips from Dr. Forster, PWS Expert:

1. Reduce his/her degree of freedom. He/she may have access to too many people and too much information. This may enable him/her in a negative way. If the information for the stories is coming from the computer, leisure time can be limited or supervised.

2. Take away the audience. This means that you have to alert every one that he/she comes in contact with, that he/she is a storyteller. They should listen but always react in a neutral way. Although the truth should be doubted, there is always the possibility that a story could be real. Then, try to redirect the person to a safe topic that everyone knows is true, like "Tell me about your Power Ranger's collection" or "Tell me about the last time you went to St. George." Or, if in a day program or school environment, teach staff an intervention "That's an interesting story, but I'll have to check with your parent," or, "It must make you feel important to think that you're related to a sports star." It's not helpful to ignore, and it's not helpful to attempt to dissuade. Helping him or her to save face is important.

3. Turn the content of the story into an asset. If he/she wants to be a sports star, or he/she wants to be a film star, then they need to live the life-style, including weight loss and exercise. (Special Olympics can be a wonderful way to provide an appropriate level of competition, together with appropriate exercise.)

4. Use social stories. Social stories are a helpful tool for teaching morality like why it's a good thing to always tell the truth and why there are consequences for lying. Most confabulators are creative people, so maybe they can write some social stories with you.

5. Alert the police. Be proactive with the police. Tell them that storytelling is part of your child's repertoire. Give them your telephone number so they can call you if they become involved. If your son or daughter already has experienced the police, I would strongly advise you to obtain guardianship, or advocate for them. As intelligent as they may appear, they will not be able to advocate for themselves, although the court may find them competent.

6. Consider therapy. If your person with PWS is high functioning, he/she may be dealing with feelings of inadequacy due to having PWS, so their stories are all about being someone else who doesn't have the syndrome.

7. Adjust medications if they are contributing to the situation.

8. Punishment never works. When a person with PWS truly believes their thoughts are based on reality we must remember to be aware of their sensitivity to “blame.” Overreacting to their stories, ridiculing their confabulation or blaming them for “causing trouble” will not help the situation, no matter how embarrassing or far reaching the implications of the story have become. Remaining calm and supportive while providing the person with PWS the security they need to express his/her thoughts, then gently redirecting the conversation allows them to be heard without enhancement.