

Supporting Adults with Prader-Willi Syndrome in Residential Settings

An Expert's Recommendations



Compiled by B.J. Goff, Ed.D.





SUPPORTING ADULTS WITH PRADER-WILLI SYNDROME IN RESIDENTIAL SETTINGS

*Working Together
To Change Lives!*

Book design and graphics by Carrie Larsen and Paige Jackson

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As a residential caregiver for individuals with Prader-Willi syndrome, you are a member of a select group of individuals.

As a member of this group you are engaged in some of the most important work of your life. You are involved in saving the lives of people who, prior to residential programs such as the one in which you are now employed, often died in early adulthood due to complications related to obesity. The individuals you work with may not always express their appreciation, but be assured that their families and friends are deeply grateful for the commitment you are making to ensure their long term health and happiness.

I wish you all the best on this journey. I encourage you to collect stories, share them, and get to know more professionals in the Prader-Willi syndrome community. And, please, if we're ever in the same place at the same time, introduce yourself, give me some feedback on this manual, and be sure to tell me a funny story or two.

B. J.

About the Author

Barbara J. (“B.J.”) Goff, Ed.D is an Associate Professor of Education at Westfield State College in Massachusetts, USA. She has 35 years of experience working with individuals with developmental disabilities in residential, educational, vocational, and home settings.

In 1999, while employed by Family Residences and Essential Enterprises (FREE, Inc), BJ opened an Intermediate Care facility for eight individuals with Prader-Willi syndrome in Hempstead, Long Island, NY after being convinced that they, indeed, had unique characteristics and living requirements. At that time there were only a handful of residential programs for individuals with PWS in the United States. Today, most states have at least one dedicated residence for individuals with PWS, and many large states have several.

At present, B.J. is a consultant and trainer for schools and providers serving individuals with Prader-Willi syndrome throughout the US. Her work includes the development of residential, vocational, and crisis intervention programs; advocacy; providing expert testimony; program evaluations; educational program design and behavior management programs.

She is co-author of a handbook on PWS for Educators, entitled *The Student with Prader-Willi Syndrome: Information for Educators* with Barbara Dorn, RN, BSN. She authored two chapters on educational issues and co-authored one chapter on sexuality in the third edition of *Management of Prader-Willi Syndrome* (2006). Dr. Goff serves as an educational crisis consultant for PWSA (USA), assisting families and schools to successfully collaborate on behalf of students with PWS. She is a frequent presenter at national, state, and local conferences and represents the United States at international conferences as well.

Foreword

From B.J. Goff

Although this manual is focused primarily on group homes (residential programs supporting three or more individuals), the same principles, and most practices, apply to any size or type of residential setting.

It can be used as part of a specialized training program in Prader-Willi syndrome which would include descriptions of the clinical features and concerns associated with PWS.

I want to thank my friends and colleagues from the Prader-Willi Alliance of New York, Inc. for inspiring and insisting that I undertake this project initially. I would also like to gratefully acknowledge the faith, support, and patience of my friends and colleagues at Prader-Willi Syndrome Association (USA) for continuing to prod me to bring this manual to a larger audience. A special thanks to my friend and colleague, Lota Mitchell, who persisted in moving me along in her caring, yet insistent way.

Thank you all.

About This Book

By Diane Spencer

I want to give an explanation how the book design and colors were chosen. The turquoise coloring was chosen because turquoise is the color of communication and also a calming color. For those of you who care for our loved ones, you may upon occasion require an extra measure of calmness and creative communication skills.

Researchers have frequently been interested and done studies in the excellent puzzle working abilities displayed by many of our people with PWS.

No answers have been found, but this continues to be a strength that can sometimes be utilized in the education process. Shape memorization certainly aids in the recognition of word shapes and leads to the mastery of reading.

The puzzle piece has a second and more profound meaning... each person with PWS has a unique makeup. There are no formulas or list of instructions that come with the syndrome, thus you must find each solution and fit it together with other solutions to help define the person with PWS and their needs. The author has given you many pieces of the puzzle but it is up to you, to find the ones that fit and will work for you and your client.

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I. Introduction

Welcome. Whether you are new to the field of developmental disabilities or an “old pro”, you will find working with individuals diagnosed with Prader-Willi syndrome (PWS) not only to be unique and challenging, but also more deeply rewarding than almost anything else you may undertake in your professional life.

One of the key factors in working effectively with those with PWS is recognizing the uniqueness of this syndrome. This manual focuses on “Life in the Residence” with persons with PWS and how that differs from residences serving people with other disabilities. Even if you come to this job with prior experience, you will find working here a different and probably more challenging experience. But first, you have to open your mind to a different way of thinking about people with developmental disabilities and understand that strategies that may be effective with others most likely will not work here. However, there are some notable exceptions, such as treating them with respect, dignity, understanding, and providing opportunities for growth and change.

I would like to highlight these qualities — since they should be the main focus of your work with people with any kind of disability, yet take on a special meaning for individuals with PWS.

A. Respect and Dignity

All adults with disabilities want to be respected by the people who assist them. They are not helpless children and should not be treated as such. It’s difficult sometimes to remember this when a 35-year-old man is having a “tantrum” in public, but responding in a parental rather than adult fashion will only fuel the fire. Respect means acknowledging that this same 35-year-old man, who in one instance can act like a two-year-old, also has 35 years of experience in the world and has adult feelings, dreams, hopes, and ambitions. Your quickest route to establishing a good relationship with the residents you serve is demonstrating respect for each one as an individual—not just one of the group to be “looked after.”

Dignity is about acknowledging each person’s individuality, supporting and enhancing their status in the world, and building on strengths rather than harping on deficits.

- Yes, these individuals have been diagnosed with Prader-Willi syndrome. But they are far more than their diagnosis. It is inappropriate to refer to them as “Praders” or “PWs”. Doing so denies them their full human status. Prader-Willi syndrome is what they have, not who they are.
- Yes, these individuals require some degree of lifelong supervision. But that doesn’t mean that they should be treated like inmates and opportunities for reasonable risks be avoided.
- Yes, many need prompting to accomplish tasks we may take for granted. But

instead of giving directives, encourage the individuals to self-manage their responsibilities to the greatest extent possible.

- Yes, they often obsess over some question or problem and are unable to let go of certain thoughts. But that doesn't mean we should ignore their concerns or worries.
- Yes, they engage in some behaviors that are embarrassing and difficult to manage and sometimes dangerous, but that doesn't mean we should write them off as hopeless and stop searching for ways to teach them coping strategies.

The degree to which you demonstrate respect and dignity for the individuals you support is the degree to which they will experience themselves as worthy of such respect and act accordingly. A main function of your job is to facilitate acceptance of individuals with disabilities into the larger community, so how you act toward them is how others will perceive them.

B. Understanding and Acknowledgement

All It is critical that you develop a good understanding of Prader-Willi syndrome early on in your work. Without this understanding you deny yourself and the residents the maximum opportunity to establish positive and respectful relationships. If you are perceived as someone who doesn't understand the syndrome, you will be tested continually by the residents and inadvertently be feeding into their less desirable qualities. With understanding, you easily can create situations where the residents begin to develop and focus on their positive qualities, which in turn enhances their self-esteem.

Part of this understanding is acknowledging what PWS is. Often, someone without experience with PWS will simply not accept that many of the characteristics of PWS are truly outside of the person's ability to control. A note of clarification: while many of the characteristics of PWS may forever be part of a person's repertoire, that does not mean that certain behaviors cannot change, over time, and quality of life cannot be achieved.

Individuals with PWS have been described in many negative ways, including; manipulative, stubborn, sneaky, irritable, mood labile, angry, prone to tantrums and rage attacks, verbally and physically aggressive, ego-centered, perseverative, demanding, liars, thieves, and generally hard to get along with much of the time.

While they may display these characteristics now and again, there is much more to be considered. Individuals with PWS may also be; quite interesting, sociable, creative, intelligent, hardworking, helpful, considerate, loving, and just plain good company.

I believe that anyone who wants to work effectively with individuals with PWS has to be curious, forgiving, have a good sense of humor, observant, and be one step ahead

of situations that could have a negative outcome. If you focus on the problematic characteristics of PWS, you'll miss all the challenge, fun and rewards of truly making a difference in someone's life.

Knowing that PWS doesn't go away and that it's your job to try and make life a little easier will increase the person's chances of having a successful day. So will believing that persons with PWS, even those who seem so angry and destructive, do not choose to be that way and are not really enjoying that part of themselves. This requires us, as providers, to try continually to come up with new ideas and strategies to help that person learn to manage feelings positively.

Understanding and acknowledgement means being proactive, not reactive. Understanding is knowing that you don't have all the answers. How could you? No one does.

C. Empathy

In the case of individuals with PWS, it is important that your understanding of the syndrome includes empathy (i.e., the ability to enter into the feelings of others). Having the characteristics of PWS is not easy, and many of those with the syndrome suffer greatly in their efforts to be an active and accepted member of their community while struggling against the daily obstacles PWS presents.

You must first accept that these individuals have minimal to no control over their drive for food. If you can accept that, then you can begin to understand your role in supporting them in a truly helpful fashion. Knowing that persons with PWS may not learn from their mistakes or be affected by negative consequences, especially when it comes to food-related issues or their perception of fairness, means you have to try other ways of teaching life lessons. It begins with structuring the environment in such a way that success is likely. A safe and therapeutic environment does not set the person up to lie, steal, or become enraged over small matters—followed by the caregiver responding punitively when the person does just what could have been predicted that he or she would do.

Not only does the drive for food affect most daily activities, but some of the individuals also struggle daily with severe skin picking. This self-injurious behavior may require routine first aid treatment or, on occasion, treatment by a nurse or physician. This behavior may be viewed as quite repugnant to others, causing both staff and housemates to consciously or unconsciously avoid interaction with this person.

Picking may also make obtaining meaningful work impossible regardless of the person's skills. I worked for a time with just such a woman. In her early twenties, she had an IQ in the borderline range, and had graduated from high school with a regular diploma.

Unfortunately, she had an incredibly strong drive for food, a severe skin-picking problem, and was verbally perseverative, all of which required a great deal of monitoring and intervention. As a result, she was living in a group home with seven other adults with PWS and was the most sophisticated intellectually and academically. She had been unsuccessful in a variety of vocational programs as well and was placed in a day treatment program where she engaged in some schoolwork, home living, and arts and crafts type activities. She was, and is, quite depressed. I recall her telling me one day that she wished she “had been born more retarded, because then it wouldn’t hurt so much.”

Empathy does not mean pity. Rather, empathy means understanding their experience in the world and creating a home environment that is designed to promote personal strengths and success—an environment where failure and rejection are not options.

D. Opportunities for Growth and Change

There is no one “right” way to operate a residence for adults with PWS. In fact, in those residential programs that have maintained their original rules and structure over the years, you will find low weights, but high levels of discontent. It is crucial that you understand that people with PWS need much more than reaching an Ideal Body Weight Range. Indeed, that’s the easy part in a group home. The real challenge is to go beyond health issues and address personal needs and desires.

Now that residential services have been available for individuals with PWS for several years, we are seeing more and more variation in how these programs are run, such as how challenging behaviors are managed, how decisionmaking occurs, and how access and control over food and money is addressed. With all this variation, individuals are healthier and happier because they are offered more choices and opportunities. These choices and opportunities promote growth and change and allow individuals to make decisions based on personal preference and need. Even though choices involve some degree of risk, it is important to remember that taking risks creates growth.

What’s important is to not get “stuck” on a particular strategy or approach or procedure. You must change your program to meet the needs of the individuals as they grow, and the individuals can only grow if your program allows and encourages them to do so. This is a special challenge in programs supporting those with PWS for two reasons: they generally require a high degree of supervision in many situations, and they fare best with a high degree of consistency in all areas of their lives. Here is where the staff needs to know the residents well and become extremely creative in meeting the challenge of change.

In residential programs serving adults with mild mental retardation without PWS, there seems to be a natural progression toward independence when proper teaching and

support is provided. Not so with people with PWS. In spite of mastery in many different areas of their lives such as personal care, homemaking, community skills and work, the drive for food and related behaviors keep getting in the way of complete independence.

So, what do we do? First, know that each person is unique, so you must individualize your program activities. You'll find that some can handle making their own lunch, while others can't. You'll find that some can go to their work site and control the temptation to steal a coworker's lunch, and some can't. If an evaluation determines that they are able to successfully complete a task, then they should be allowed the opportunity. For some, an opportunity for growth may be the option to mix the drink for the evening meal, or to walk to the corner mailbox alone, or to pick up the Sunday newspaper at the local deli.

The point is to assess their strengths and abilities to see what steps can be taken to help them achieve their goals. You have to be especially creative—there is no formula, no steady progression from point A to point B. You may encounter regular setbacks or “slips”. That doesn't mean that you should not continue to go forward. Just as with addicts or alcoholics, we encourage “one day at a time”, and we do not give up on a person when they falter. We help and support them as they begin again. The progress toward independence usually entails “baby steps”, rather than the leaps that others with developmental disabilities may take.

Keep in mind that individuals with PWS have hopes and dreams just as you do. Your job is to try to help them to achieve those hopes and dreams.

We don't have to dismiss the goal of independence—just move in a more calculated manner towards it. If we get there, great; if not, that's OK because the important thing is to keep moving.

II. So What's Really So Special About Prader-Willi Syndrome?

What exactly distinguishes individuals diagnosed with Prader-Willi syndrome from individuals with other types of developmental disabilities? And what are the implications for treatment? Following are some of the most critical and challenging characteristics of Prader-Willi syndrome with some thoughts on how these characteristics affect services and interventions.

UNIQUE CHARACTERISTIC OF PEOPLE WITH PWS

A. They Generally Have a High IQ

The average IQ for a person with PWS is around 70, which places them in the mild range of mental retardation. Most IQ data is from adolescents and young adults in their 20s. The younger or older the individual, the less reliable is the score. No hard evidence exists that scores change based on age.

Since 70 is only an average, many individuals have an even higher IQ, indicating close to normal intellectual abilities. Yet their IQ is deceptive and can fool us into thinking that someone with such a high IQ must understand what he is doing and must have some ability to control his actions.

Even those individuals with borderline or normal IQs tend to have severe learning problems. The consequences include poor academic skills in some areas and a general immaturity in social interactions due to missing the “social cues” needed to gauge human contact. On the plus side, it often means that the person is capable of fairly sophisticated academic or vocational tasks. Some are capable of taking college classes or performing the responsibilities of a full-time employee. They may be able to use public transportation, including handling changeovers and delays. In short, they have what it takes to make a living and enjoy adult status in the world.

So, what's the problem?

Behaviorally speaking, a high IQ often means only that an individual is more adept at obtaining desired outcomes—food or money. It does not necessarily mean that they are better able to manage emotions and behaviors, even though they may be able to articulate understanding, even insight. Some may manipulate others and lie more effectively, or find increasingly creative ways to “cover their tracks”, blame others, and escape consequences.

What's missing is the ability to withstand the constant temptation of food, which can result in serious weight gain. For many, a low frustration tolerance and inability to tolerate criticism are major obstacles to the greater independence that their IQs suggest.

Unfortunately, a high IQ also means that the individuals can see that they are different from others and therefore may be more susceptible to depression. Don't forget that people with PWS experience emotional suffering for the same reasons we do. However, it is compounded by knowing that they are "different" and may never experience the freedom and independence they, like all of us, so desire.

B. Hyperphagia

Not all individuals have the same food-seeking drive. They may or may not pick gum off a bus floor, may or may not go into trash for food, may or may not eat pet food, may or may not complain of a physical ailment to obtain medicine, may or may not treat toothpaste and mouthwash as food, may or may not steal candy from the drug store, may or may not approach strangers and ask them to give them some of what they are eating.

You should get to know the individual over time and in different settings. You must monitor weight very closely and frequently in order to figure out what the individual does to obtain food. Most likely, you'll never know all of a person's food sources, and most are smart enough to make sure you don't find out. If a resident on a 1,000 calorie diet who is watched closely at home and at day program is gaining weight or not losing as expected, then there is a food source and it's your job to find it. I've heard more times than I can count, from parents and staff alike, that so-and-so "would never do that" (e.g., go into a dumpster for food, steal from a store, eat pet food). But given the right circumstances, so-and-so may be doing just that—and it's not because the individual wasn't brought up right—it's because of the genetic drive to seek and eat food.

Remember, food to a person with PWS can mean anything that is ingestible, including garbage, pet food or, in extreme cases, feces.

Here are some food-related behaviors to watch for. You'll find yourself adding to this list as you work in the residence.

- *A resident comes home and hands you a bag with half a sandwich in it, saying "I found this on the bus and I know I shouldn't have it, so I'm giving it to you."*
Translation: *The guy sitting next to her on the bus left it on the seat that afternoon and she ate the apple and cookies and the other half of the sandwich.*
- *A resident volunteers to take out the trash, help with kitchen chores, or be on the cleanup committee at work/day program.*
Translation: *Where there is trash, there is food.*
- *A resident comes home from work and goes straight to the bathroom.*
Translation: *She's got food that must be eaten before getting caught and the*

bathroom has a lock on the door.

- *Of all the goals the resident wants to work on, the main one he asks for (after helping with meal preparation) is going for a walk by himself.*

Translation: *Between home and the corner are several trash cans, kids who have snacks, empty (or not so empty) soda cans/bottles that can be turned into cash for food, a corner deli. Or he needs time to eat something that he had pocketed at some point during the day.*

- *A resident routinely complains of a cough and asks for cough drops, or acid indigestion and asks for Tums, or constipation and asks for Mylanta.*

Translation: *These medicines are food.*

- *A resident seems to be quite zealous in his oral hygiene.*

Translation: *Toothpaste and mouthwash are food.*

- *A resident goes the long way or chooses a different path, to get on and off the bus he takes to work/program.*

Translation: *He has food stashed somewhere, possibly behind a bush or under a rock and he's just waiting for a good opportunity to eat it. (This could also apply to non-edible items that the person has lifted from someone or somewhere.)*

- *A resident is suddenly quite friendly with another much less capable resident in whom he had previously shown no interest.*

Translation: *This "new friend" has something the resident wants and/or is an easy mark to get things from (overtly or covertly), or the resident is stashing stuff in his "friend's" room instead of his own so he won't get caught.*

There are a million more examples, but this list should get you started. I repeat: Not every person with Prader-Willi syndrome engages in the same food seeking behaviors. Indeed, I do know of some individuals who will ask to be allowed to leave a situation where food is available, knowing that they can't withstand the temptation. However, this is not the norm. The way you know for sure whether or not someone has a food source is through weigh-ins. If there is a weight gain, or no weight loss when there should be, there is a food source. This is when you begin your detective work.

The most dangerous position you can take is to deny the lengths to which an individual will go to obtain food.

Persons with PWS are good planners with regard to getting food.

Even individuals with very low IQs can be masterminds when it comes to obtaining food. Most are able to pick even the best of locks, and their patience in learning that skill is amazing—if only it would transfer to other areas!

I guarantee you that the residents know which of you carry gum, breath mints or cough drops in your purse; which desk has candy stashed in the drawers; exactly how the condiments are set up in the cafeteria; which coworker never finishes his lunch; which one is easy to talk out of his dessert or money; and with whom a pencil can be traded for a cookie. They know which of the staff is diligent about locking drawers and even which staff usually has a bag of chips in their unlocked car. With all this information, the next step is to “plan” a way to get to the goodies.

Contrary to popular belief, people with PWS are capable of rather extravagant planning and can, under certain circumstances, postpone immediate gratification for a much more desirable outcome later on. There is evidence that individuals with PWS will wait for a larger quantity of a less preferred food over an immediately available more preferred food. This finding supports the possibility that the residents can plan and stick to a healthy dietary regimen with staff coaching and intervention.

However, one should be highly suspicious when a person with PWS refuses food legitimately available to him or easily gives up a food item they “found” and know they shouldn’t have. It’s a sure bet there is a better stash somewhere else! It is this “missing the forest for the trees” that distinguishes experienced staff from novices. Many staff members don’t believe that a person’s developmental disability would allow him to plot and plan so carefully for a future reward. Just ask a veteran staffer or parent, and you’ll hear some amazing stories!

Here are some examples:

A woman “ran away” from her residential placement, changed her name, became “homeless”, and then used her diabetic condition to be hospitalized (where food is much more available). Since she was quite bright and articulate, she knew once hospitalized that she could present herself to the hospital social worker as a homeless person in need of shelter rather than someone with a disability. Furthermore, she knew that she would invariably be referred to an adult residence without the restrictions of a PWS-designated placement, as she had had this experience in the past. On one occasion, she got very close to achieving her goal and was discovered just as the hospital social worker was in the process of making referrals. She had given herself an alias, but neglected to provide a fake social security number!

Another individual quite cleverly planned a shopping trip in her community. She went to her favorite clothing store where she removed a blouse from the rack, then went to the exchange counter insisting that she had recently purchased the blouse and now wanted to return it although she had no receipt. She raised such a stink and was so convincing that the clerks gave in to her. She then treated herself to a feast with the money she obtained. She might have simply attempted to steal some snacks from a local establishment, but she wanted something more, so she actively planned and pursued her goal.

I knew a man in his forties with a pacemaker who would claim, now and again, that it wasn't working properly, necessitating a trip to the Emergency Room which led in some instances to hospitalization.

Hospitals are notorious for allowing easy access to food, are often the source of substantial weight gain and should be avoided at all costs. This man was well aware of the benefits of a hospital stay and knew that claiming a problem with his pacemaker was a sure fire way to get there.

This next story cracks me up. *The players are Michael and John from the Central Avenue Residence and Sara from the Manor Residence. They all go to the same day program. Goodness knows how long they had planned their escapade. Michael had gone home for Easter holiday and stolen \$50.00 from his mother, unbeknown to the residential staff. Monday evening, Randy, a Central Avenue resident with a history of suicide attempts, went to therapy leaving two staff on duty when there are typically three. Sara (from Manor) calls Central Avenue crying and claiming that she was all alone in the house as the staff and other residents were not there (which turned out to be not true). While Sara has one staff person engaged on the phone, John opens his window setting off the alarm and the other staff person comes running to his room. John tells him that he is going to jump out his window because he wants to die. With both staff engaged, Michael runs out the front door (since the alarm was already going off from John's window, no one noticed), goes to the corner store, buys \$50.00 worth of food, and returns without anyone realizing that he had been missing. Can you guess how they got caught? Michael didn't share the loot with John and Sara as planned, so they ratted him out! Now that's planning!*

If so much energy goes into thinking about and obtaining food, what can I do to change that?

Your job is to create an environment that allows the residents to feel safe, that is, free from the constant struggle that food presents. This means making food a "non-issue." Here are some strategies:

- Food and money are inaccessible except in prescribed situations.
- Meals are prepared according to individual nutritional and caloric needs.
- Menus are posted or available to the residents to provide reassurance about what is to come.
- Questions about food and meals are addressed, without dwelling on food as a constant topic of conversation.
- When a resident questions his/her food portion, the food is simply re-measured or re-weighed so that the individual is reassured.
- Staff sits down and shares the meals the residents are having, and enjoys both

the food and the conversation so that the residents don't feel ostracized with their "special diet".

- Staff does not bring in food that the residents can't have, especially the strong smelling ones, like fast food burgers, fries, Chinese, fried chicken, and such. If special meals are necessary, they should be eaten in a private area away from the residents.
- The nutritionist or dietician builds treats into the menu, and special occasions include favorite food items.
- Residents have nutritional information and counseling available to them, ideally from the nutritionist or dietician but also from well-trained staff.
- Recreational and social events are designed to be activity, not food, focused, so that the individuals can attend to and enjoy the event, rather than spending the entire time trying to figure out how to get to the food table.
- Where events do include food, staff prepares the residents by discussing how they can enjoy the food available by making dietary exchanges within their caloric allotment.

All of these strategies take planning and extra effort. And it's difficult, sometimes, not to slack off or lose patience, or to remember that food is an all-consuming theme in their lives. Try to imagine it. Think of all the places you go within one week. How many have food available? (Indeed, are there any that do not?) What would you need to help you be in those situations, many of which cannot be avoided? What about at home? What would you need in your home to help you relax and enjoy other activities, rather than obsessing about the next meal?

A final note: The residents will come up with ways to obtain food that you can't even imagine. Don't be discouraged. Log the attempts with sufficient detail for others to appreciate the effort, and put a plan in place to avoid the same thing from happening again. You need to acknowledge (even admire) and learn from their ingenuity all the while coming up with proactive strategies for reducing food seeking. There may be different ideas and activities that work for different residents. As always, get to know them as individuals.

C. Lying and Stealing

No matter how close you believe your relationship to be with the person with PWS, they may steal from you or a best friend. They may lie about it even when the evidence is overwhelming. You need to remember that they have been developing surreptitious ways to get things since they were very young. It is not personal, and it does not mean that they are bad people who really know better and just keep doing the same bad things over and over.

I have witnessed individuals deny the obvious chocolate on their face to the point of hysteria. They will say they don't know how the chocolate got there. They may even admit to eating the chocolate, but say that another person planted the candy bar in their room or gave it to them.

One of the boldest instances of lying about food consumption I've ever heard came from a father of a 14-year-old boy, Paul. One day the boy made his lunch with his dad looking on. He then went into the dining room and ate it. The dad was in another room watching TV but could see Paul through the doorway. Paul finished his lunch, put his dishes in the dishwasher, went back into the dining room and sat down. Several minutes later Paul's mother came downstairs. She went into the dining room where her son informed her that he hadn't had lunch yet. The father, overhearing this, came into the dining room and said the boy had just eaten his lunch. Paul denied it. The father listed exactly what the boy had eaten. Paul continued to deny it and went so far as to call his father a liar. The mother, in the meantime, was thinking that perhaps her son had not eaten after all. She knew her husband had been ill and was sometimes forgetful, so perhaps this was one of those times. She spoke up in support of her son. Well, you can imagine how enraged the father became and the parents wound up in quite a big fight. The end result was that Paul was given a second lunch and the parents had a big rift between them. When the father told this story to me a few weeks after it had occurred, he admitted that for a moment or two during the incident he actually questioned himself. His son was that adamant and convincing!

There's a humorous but also tragic side to this story. This boy had found the crack between his parents and was putting a wedge between them to widen that crack. This happens with staff, too. There are two lessons here:

- 1) You need a thick skin to fend off the emotions that may come up with the lies and the sometimes cruel verbal attacks.
- 2) You must communicate with your coworkers in very concrete and specific ways. A daily journal is ideal. Informal, on-the-run comments will not do. You must also communicate with those parents who are routinely involved in their child's life. It's not unusual for an individual to create rifts between parents and staff.

Individuals with PWS have also been known to steal tangible items that they later use to exchange for money or food. This can involve plotting to procure specific desired items from staff or housemates, or much more extravagant plans. Most individuals with PWS will take food or money if it is fairly accessible. If you leave your purse on the dining room table, it is likely your money and/or gum will be taken. If you run to the bathroom while preparing dinner and forget to lock the kitchen door, the food will be eaten. If you leave a person with PWS unsupervised to travel throughout a building to run an errand or deliver a message; any food discovered along the way will be consumed.

For a staff person who feels they have a good, even special relationship with a resident, having him or her steal money from your knapsack or coat pocket can be very hurtful. You mustn't connect stealing from you with his/her feelings about you as a person; these are totally separate.

Having access to a purse with money in it is just an opportunity to get food and has nothing to do with the ownership of the purse. The person with PWS isn't thinking beyond the moment and the possibility of food. This is very much like the behavior of an addict. Husbands steal from wives, fathers and mothers steal from their children, children steal from their parents, and then lie about it. Painful to those family members? YES. Is it personal? NO. So, keep this in mind: do not assume that a particular resident would never take anything from you because he really likes you. This belief will only lead you to let your guard down, creating the very opportunity for stealing that you did not believe would happen in the first place.

Is the lying and stealing always food related?

No. You will find that some individuals steal CDs, clothing and word puzzle books from others and have no intention of exchanging these articles for food. It's not necessarily related to being deprived of such items, and it's very possible that an individual has plenty of money to purchase whatever it is they want. Perhaps it's related to a hoarding compulsion, or a need to acquire "things". Or it may have to do with a sense of competition with housemates, not wanting someone to have something they don't. I don't know the answer and haven't heard of anything definitive as to why a person may have a generalized stealing behavior. However, I can tell you that the same vehemence in denying that they stole food is expressed in these instances as well.

I know a fellow, Pete, who took a sweatshirt from another resident, Sam, whose name was written on the inside collar. Pete, discovered with the sweatshirt, insisted that his sister had given it to him and said that he didn't know how Sam's name got there. When questioned, he said that the other resident must have taken the sweatshirt from him and put his name on the collar. When confronted with the fact that Sam didn't know how to write, he replied, "He must have had someone else do it." When asked why the sweatshirt was much too small for him, he said that it had shrunk in the dryer. So, in spite of the fact that it was two sizes too small and had Sam's name written on it, Pete was adamant that the item was his and everyone else was lying and unjustly accusing him. It was a very emotional scene with Sam in a full-blown anxiety attack without a satisfactory resolution in sight. But, like Paul's dad, if I didn't know better, I might have believed him. It was a great example of why confrontation and pursuing logical explanations is frequently a poor use of time and energy—for everyone concerned. If you know the truth about something, don't torment yourself and others involved with having to prove it. That's engaging in a power struggle and, as this story exemplifies, there are no winners. Sometimes, you just have to let things go. The sweatshirt clearly belonged to Sam. Give it back to him. Period. End of story.

On a much more serious note, often allegations made by persons with PWS against staff, family members, or other residents are false. Now this isn't always the case; however, frequently it is. I always caution male staff to be vigilant in their interaction with both female and male residents. All staff should be sensitive to those individuals who may perceive "horseplay" or a friendly pat on the back as being intrusive in some way. Never enter into a physical restraint alone unless it's a dire emergency. If a resident seems to be particularly angry with you or you just don't get along, be especially aware of your interactions and any possibility of your behavior being misconstrued. A good practice for any program is to maintain a log of informal and formal allegations, including the outcomes of the investigation, in order to have supporting documentation of the event. Such a record can be very helpful in cutting down on the number of full-scale investigations that typically follow an allegation.

I'm not suggesting that allegations made by persons with PWS are always unfounded, because they certainly deserve the right to due process. However, if you see a pattern of in-house, informal accusations or allegations related to a particular resident, it is wise to note them and the outcome of your investigations. In doing so, when a really serious allegation is made, you have the person's "allegation" history on record.

What do I do when a resident is lying about something?

The challenge here is to avoid putting the individuals in a situation where they are likely to lie in the first place. This means not asking questions that you already know the answer to. If you found a wrapper in her room, you don't ask, "Did you eat that candy bar?" Or, in the case of the sweatshirt example, you don't pursue the issue "logically" which then forces the individual to make up additional lies about how the other guy's name got there and why it's too small for him, etc.

People with PWS will steal. It's not about knowing the difference between right and wrong. It's about needing outside support to control the behavior. Yes, you should provide appropriate consequences when someone steals, and they should be held accountable. Just don't set yourself up to think that this response will change the behavior—no matter how severe the consequences may be. Most likely, it will have a very short-term effect.

When I first became involved in working with individuals with PWS, I traveled around the country to learn more about the people, their needs, and how to develop a residence for them. I had the opportunity to speak directly with many individuals with PWS and to ask for their advice on designing a group home.

They assured me that the kitchen should be locked and, in some cases, all means of egress alarmed for those who might leave the residence to get food from trash cans. Most of them readily admitted that, as a group, they steal (although the speaker was always exempt from that charge) and recommended individual bedrooms with locks. They admitted that if food or money were available, they would take it even knowing

that it didn't belong to them. These admissions weren't made with any degree of pride, rather embarrassment and shame.

As such, it was made it clear to me that lying and stealing was, indeed, part and parcel of the syndrome and it was my responsibility to reduce or eliminate opportunities for such behavior. So, before you lose your temper or judge the person, remember their personal struggles.

D. Obsessive-Compulsive Behaviors

Obsessive-Compulsive Disorder (OCD), as the name implies, is made up of two parts: (1) obsessions (when people are plagued by persistent ideas, thoughts, impulses, or images that are unwanted, inappropriate and cause anxiety or distress) and (2) compulsions (feeling they must carry out some repetitive behavior or behaviors, e.g., checking, ordering, washing, or mental acts like counting, repeating words silently, praying). Most people experience some degree of obsessive thinking or compulsive behavior at different points in their lives. For example, haven't we all obsessed about whether or not we actually turned the iron off before we left on vacation? Or haven't we all double, even triple, checked that our windows and doors were locked before going to work, especially following news of break-ins in the neighborhood? However, for a person who is diagnosed with OCD, these obsessions and compulsions can be highly disruptive and interfere with most, if not all, daily activities.

For individuals with PWS, researchers have found that a key characteristic of the syndrome relative to people with non-specific mental retardation is how they are motivated by orderliness. They are more apt to need to do things in a precise manner and to put things in a particular order. They invariably obsess about food. Yet they also have a variety of non-food obsessive-compulsive behaviors, such as ordering and arranging, hoarding, skin picking, and being concerned with cleanliness, symmetry, and exactness.

What is important with regard to PWS is that these compulsive symptoms go beyond the need for sameness in routine often shown by people with mental retardation. In fact, individuals with PWS have an increased risk of obsessive-compulsive disorders as compared to other groups of people with mental retardation. As staff, we must consider how necessary schedules and routines might affect individuals with such obsessive-compulsive behaviors.

Are we inadvertently causing them a great deal of stress when we interfere with their drives? Perhaps this is the cause of many of those unforeseen and unexplained behavioral outbursts, even aggressions. Are these stubborn and perseverative characteristics connected to the obsessive-compulsive behavior in some? Perhaps they repeat questions or stay on a particular topic (obsess or perseverate) because they

must be absolutely certain that something is going to happen as planned. Perhaps the stubbornness is a response to too much change around them. So they stand firm on an issue to keep things the same and/or stable.

It's essential that we don't treat these characteristics as maladaptive behaviors which must be eliminated, but rather as characteristics of the syndrome which certain people possess. In doing so, we are likely to use greater sensitivity and understanding in our change efforts.

How can we deal with obsessive-compulsive behaviors in a residential environment?

First and foremost, as with the other characteristics related to PWS, be understanding. They did not choose to feel anxious, be "inflexible", or develop rituals and routines that interfere with residence schedules. So here are some things you can do:

- Consider that the residential routine, which was developed for structure and consistency, might be a bit too rigid. We plan our routines to keep things running smoothly, not only for the entire group of residents, but also for the staff. Sometimes we can't even explain why a certain routine or schedule exists or what purpose it serves—it's just "always been that way." Open your mind to changes that might accommodate some of the idiosyncrasies of the individuals living there.
- Identify and honor any rituals or habits that an individual has that are not destructive and do not significantly interfere in the house routine. Make sure that all staff, including weekend part-timers, are aware of these particular rituals or habits and respectfully allow for them in the scheduled activities.
- Given the need for predictability for individuals with obsessive-compulsive behaviors; post schedules, routines, and planned activities in an area that is easily accessible. This type of support reduces the residents' level of stress and anxiety. Written rules and consequences should also be readily available, so there are no surprises. Many individuals benefit from individual contracts addressing specific needs. The idea is to really know the individuals living in the residence and provide the predictability, support and structure they need to feel comfortable and safe. Provide choices whenever possible, but only the number and type that an individual can handle without being overwhelmed. Too many choices can be just as detrimental as too few.
- Provide warnings before a transition. "John, in five minutes we'll be getting ready for dinner, so you might want to finish up what you're doing. I'll tell you when five minutes is up so you can wash your hands."
- Some may benefit from medication when their anxiety is so high that it interferes with their everyday living. No one enjoys being "stressed out". There are a variety of medications that have proven to be very helpful in allowing these individuals to be a bit more relaxed and amenable to learning alternative coping strategies.

- Teach problem solving, planning, and relaxation skills and strategies. These abilities can help an individual in managing daily routines and reduce overall anxiety. If we spent one quarter of the time on these skills as we do on Activities of Daily Living (ADL), we might see happier and less anxious and volatile residents.

In short, relax—don't be so rigid yourself. It's OK to let some things go and not have to be right in every situation.

Does it really matter that much if she insists on going to the bank after the drug store even though it adds 10 more minutes to your trip? Does it really matter if he orders a new book bag through the Internet instead of going to the store where he could save a few bucks? (Keep in mind that a trip to the store necessitates a staff person, which means dependence, whereas ordering on the Internet can be done independently.)

Finally, consider how upset you might be if you had little to no control over your daily rituals and routines; imagine if you had to shower, eat, shop, clean when it was "scheduled" (and not by you!). Then consider how upset you might be if someone was constantly interfering in your rituals and routines. "No, you can't have coffee before breakfast, only with breakfast." "No, you can't go to your room as soon as you get home from work; you must do your chores and exercise first."

E. Self-Injuries Behavior (SIB)

Self-injurious behavior, most notably skin picking, is one of the characteristics that accurately differentiates people with PWS from other groups of people with mental retardation. Studies on skinpicking and PWS have found that 81%-84% of those with PWS engage in skin-picking and other forms of self-injurious behavior, whereas only 20% of individuals with non-specific mental retardation engage in such behaviors.

Self-injurious behaviors can include nose picking, hand biting, head banging, trichotillomania (pulling hair out), and rectal picking.

Why persons with PWS engage in SIB at such a high rate is not yet understood. Medications have been used, especially serotonin reuptake inhibitors such as Prozac, Zoloft, Paxil, and others. These medications have had mixed results, which further highlights the fact that we really don't know what drives persons to hurt themselves. Some conjecture that the picking releases endorphins which gives the person a "high", similar to a "runner's high". Others theorize, given their high pain threshold, that they can engage in this behavior as a self-stimulatory activity without experiencing pain. Still others believe it's all part of the obsessive-compulsive nature of the individual, so that where there is a bump or a piece of loose skin, there is a need to remove it. Again, we simply do not know.

Although not every person with PWS engages in skin picking, it is quite common. Among those that do, there is a great deal of variation. Some pick around their cuticles primarily, with occasional forays to other areas of the body; some pick at various parts of their body, including their rectum. There has been some research specific to PWS that identified preferred parts of the body for picking. The most common area was the leg, followed closely by the head, and then the arms. You are likely to note individual patterns in the residents with whom you work.

For some individuals, picking is an occasional thing. I worked with a man in a group home who rarely picked at all and had no history of serious picking when, seemingly out of the blue, he began picking at his nostril to the point that he literally picked off a good part of it. Then the picking stopped. We surmised he was going through a stressful period, although it didn't appear to be any more or less stressful a time than any other. Unfortunately, as bright as he was, he couldn't articulate what was driving him to pick. I've known other individuals who are constantly covered with sores from picking at their face, legs or wherever there might be a bump or wound. Surgical cuts may pose more complications; there are individuals who have the same wound from a 20-year-old surgery that they can't leave alone long enough to heal.

It can be quite debilitating in several ways: the related health risk of infection; the interference of obsessive picking with attention to other activities; rejection by others; inability to perform certain tasks and jobs because of the unsanitary condition the picking creates. Parents and professionals have tried everything from reward systems

and punishment, to wearing gloves and total body jumpsuits to limit access to most body parts.

There are no established, proven techniques for eliminating skin-picking on a long-term basis; however there are several strategies that show promise, especially when used in combination.

What can be done to help?

First of all, know those individuals who engage in skin picking and where they usually pick on their body. You need this information so you can monitor for any signs of infection. You can accomplish this with a minimum of embarrassment to the individual by doing a visual once over if you are around while the person is showering or dressing. If the person is a fairly serious skin-picker, establish a formal agreement to perform a routine body check, either conducted by your nurse or a designated staff person of the individual's choosing.

It can never hurt to provide incentives to someone for keeping their skin clear although, as with food seeking, it may not be within the person's control to manage the skin picking behavior. However, I have seen people control their picking for a period of time when an especially big reward was involved, such as a trip to Disney World or getting one's hair dyed. Unfortunately, once the reward was obtained, skin picking resumed. It can be tough to keep coming up with effective incentives, although it's always worth a try. Punishment probably works in much the same manner, producing an immediate effect but nothing that lasts long term. (The use of punishment is unethical and illegal in most states without considerable justification; therefore, I do not endorse the use of punishment in this, or any other situation, and so cannot truly attest to its effectiveness.)

In addition to visually monitoring the person or providing incentives to prevent or decrease skin picking behaviors, following are a few more suggestions.

- Medications, as I mentioned before, have produced mixed results. However, it may be worth a try, especially where there are few to no side effects.
- Having the person wear gloves only works if the person is agreeable. Otherwise, off they will come.
- Using a full body jumpsuit is a last resort and should only be used in those instances where the individual's emotional and/or physical health is severely affected—and/or the individual has a desire to stop and is willing to try.
- Prevent dry skin and chapped lips by having the person routinely apply lotion and lip balm of some sort.
- Keep the person's hands and mind occupied. If the person is busy doing something he enjoys, he won't be picking at the same time. If you see that an individual seems to pick during down or quiet times, like watching TV, then make

sure they have something in their hands to fiddle with instead of absent minded picking.

- There is some evidence that vigorously rubbing the person's body with a very rough cloth may reduce the drive to pick. This is something you could teach the individual to do for him/herself. (Discuss this last option with an occupational therapist, as it should be part of a program of sensory integration.)

One agency with which I am very familiar has worked with several adults who have very serious skin-picking behaviors. In one case, a young man in his twenties who engaged in rectal picking as well as generalized skin picking since he was a youngster had been hospitalized on several occasions for a prolapsed rectum and other complications related to picking. A program of medication, activity scheduling, one-to-one support, and massage especially designed for the individual was instituted with almost immediate positive effects. Skin and rectal picking, restraints, ER visits, and days in hospital related to picking decreased steadily and within two months the picking was almost 100% eliminated. The program then began to decrease the medication to none over a period of six months and reduce the intensity of the activity schedule and supervision over a period of several months. I am happy to report that presently (three years later), this young man's picking is virtually non-existent with the support of a program of sensory stimulation only.

Interestingly, at one point he went through a week of refusing the massage and resumed picking. As soon as the massage was reintroduced, the picking stopped. Similar programs were designed for other residents with very serious skin-picking behaviors with similar results. Will this particular treatment work for everyone with the same effect? Probably not; but there is a great deal of anecdotal evidence that similar strategies have been effective in reducing anxiety and agitation which often precedes skin-picking and aggression.

What is important to me about this success story is the perseverance of the agency. They just wouldn't give up on this guy, even though he necessitated constant attention behaviorally and medically. He also made life in his group home rather unpleasant for everyone, staff and residents alike. By not giving up, this young man now can work, have friends and be a welcome member of his community. And the staff has the satisfaction of knowing that they were part of that. They truly changed a life!

Finally, when you are working with someone who skin picks, don't make a big deal out of it, as this increases anxiety and the likelihood of increased picking. For example, if you see a resident across the room start to pick, don't yell, "Hey, John, stop picking!", so that everyone turns and looks at John, causing unnecessary embarrassment and negative attention. Instead, have an agreement with John that when he starts to pick, a staff person will unobtrusively get his attention and give a gestural cue to stop picking, or simply move closer to him and use light touch control if needed.

The point is to be respectful. Skin picking and other forms of SIB is a characteristic

of the syndrome, which is why there is such a high percentage of persons with PWS who engage in it; it is not just some disgusting habit that they picked up somewhere. Remember, understanding and empathy.

F. Underactivity

With some notable exceptions of individuals with hyperactivity, the vast majority of people with PWS are significantly less active as compared to other individuals their age. A characteristic of the syndrome is hypotonia (weak muscle tone) which, combined with obesity, tends to lead to a sedentary lifestyle. Most have delayed motor development as children with some improvement in gross motor and balance over time, but still lag behind individuals of the same age. Coordination is often poor, so participation in sports may be limited.

This is not to say that persons with PWS cannot play and work hard or move with amazing speed when properly motivated. Typically, though, you will find that quiet stationary activities are preferred over more strenuous ones. Yet exercise is precisely what is needed to increase metabolic rate, develop muscle mass, and improve cardiopulmonary functioning.

How can I motivate the residents to engage in physical activity?

This challenge may not be as difficult as you might think. Most “regular” people, except those naturally physical ones, are unlikely to joyfully engage in an exercise program or take up running just because “it’s good for you.” Most of us try out several things before we settle on something we can live with, if not actually enjoy. Even then, we have periods of inactivity mixed in with spurts of exercise madness around the holidays and summer. So don’t expect that the exercise routine that is established in the house is inspiring to each and every one of the residents.

Chances are that exercise is presented and perceived as a chore that must be accomplished in order to earn a point or obtain some reward. It may be written as a goal, month after month and year after year, because the need for exercise is life long. It is also likely that the choices of exercise are limited—in the summer, walking; in the winter, exercycle and a treadmill. Staff may or may not provide supervision, depending on the individual. When it is provided, often the supervision consists of reminders to “keep going” if the resident wants to earn his point, or prompts to “hurry up” and get it done before dinner.

Sometimes residents are threatened with loss of some privilege if they don’t complete their exercise goal in a certain way. Sounds like a lot of fun, doesn’t it?

So, as staff, the first thing to do is to change your attitude. View the need for exercise as

an opportunity to have fun. Create a variety of possible activities that involve different parts of the body. Develop group games as well as individual programs of exercise. Use community resources. Create a healthy sense of competition among the group or between individuals. Assist the residents in setting goals for themselves. Provide incentives. Give choices. Most important, join in.

Be silly, play, and let the residents see that routine exercise is necessary and good for everyone, not a burden placed upon them by virtue of their disability. Doing the same exercises in the same room with the same people (or alone) with the same incentives (if any) day after day for the rest of one's life would certainly dampen anyone's enthusiasm about physical activity. So prevent that from happening. Appreciate the need for incorporating exercise into their daily lives, but in a way that generates energy rather than depletes it.

I have a resident who never ever does exercise no matter what plan we come up with...

There will always be a resident or two who simply refuses to engage in exercise no matter how enticing you have made the activities and the incentives. There's not much you can do about that, except keep trying. If the others are having a really good time and getting some neat rewards or prizes, the resident may come around, but there are no guarantees. I do not support punishing anyone for not wanting to exercise; however, it may be that an incentive is not earned.

Yet you probably feel responsible for ensuring that everyone gets at least a little exercise on a regular basis. You may have to sneak it in the back door. When shopping, park away from the building entrance and at the opposite end of the mall from where you plan to shop. Mall walking is great and provides wonderful and varied distractions from the physical aspect. Never use your handicap sticker (if you have one) unless someone is truly handicapped (which is probably not the case).

Yes, the shopping trip will take longer, especially if you have someone who is still obese and has a hard time walking, but remember that this is a great way to provide exercise without calling it that. Use the parking trick whenever possible; there is a built-in incentive for walking to a favorite store or an event of some kind. Call upon those residents who don't exercise to do you a favor and go upstairs and get something or help you rake the lawn or wash the van—anything that involves physical activity. Your imagination is the only limit.

G. Physical Appearance

The physical characteristics associated with PWS, while not particularly dramatic (with the exception of morbid obesity), do have an effect on the person's self esteem and

self-image and how others react to him/her. Average height for men is just over 5', and average height for women is 4'11". This is assuming no growth hormone was used. In both cases, this is abnormally short, and the world does not cater to short people. Even at home, light switches, cupboards, and closet rods are out of reach, making the individuals who live there more dependent on others than they need to be. These things can be remedied easily and should be; however, other differences are much more difficult to live with.

The men, because of incomplete puberty, usually don't develop facial hair and their voices don't deepen. The combination of these two characteristics along with short stature, small hands and feet, and obesity has caused some of the men to be mistaken for females, which is quite bothersome to them. I know of one fellow who wore a tie at all times to distinguish himself as a male. Another difficulty for the men is having underdeveloped male genitalia. Many of the men I know are troubled by this, especially as more and more of them are increasingly integrated into "regular" school and community activities and share the locker room experience with other nondisabled males.

The women may not have a menstrual cycle, and eventually learn that they, most likely, will never be birth mothers; this is very difficult for us to explain and for them to accept. They are unable to buy the stylish clothing of their same age peers. Their extremely short stature and tiny feet often mean that the clothes available to them are styled for children, resulting in a little girl look on a grown woman, which affects how others interact with her. This is true for the men as well. Both men and women are frequently seen as children and treated as such, which has an impact on how they see themselves and interact with the world.

As a staff member, it is your responsibility to be a role model for the individuals. If you are fairly close in age, it's a great opportunity to informally instruct them in what's cool and what's not for a person in their age group. When you are the same gender, you can use that to develop communication around those unique male or female issues. I encourage a men's night and a women's night at least once a month to explore topics and do those things that are primarily guy stuff (going to a wrestling match) or gal stuff (having a facial and nails done along with a little shopping). Your informal conversation and positive example can teach so much, so don't wait—build in opportunities for "hanging out" time. You can make a big difference in how these men and women handle themselves in the world. Don't miss your chance. Remember, that's why you got into this profession to begin with!

What difference does growth hormone make?

Growth hormone (GH) therapy makes an incredible difference in the individual's appearance. They will be taller and more muscular. The men will not have the soft, feminine look that characterizes those who have not had growth hormone therapy. Growth hormone therapy produces a more normalized appearance in both sexes.

Reportedly, there are also improvements in physical strength and agility, as well as respiratory functioning. The use of GH therapy is increasingly commonplace for infants and children, with the identified side effects being greatly outweighed by the benefits. Introducing GH therapy to adults is the subject of much discussion, both pro and con. Individuals who have had GH therapy as adults report more energy and ability to focus their attention. It is certainly an area to explore with the individuals you support if they express an interest.

H. Impulsivity/Aggression

One of the greatest concerns to staff is how to handle a display of impulsivity and aggressive behaviors. Some may have even heard horror stories about what a 4 1/2 foot tall woman with PWS can do to property and people.

When I first started out; I was warned about how unpredictable and aggressive persons with PWS can be. I soon realized that this was true for some, but not for most.

Only a small percentage of the individuals engage in physical aggression towards other people, with a slightly higher percentage engaging in property damage. Some of those who are unpredictable and aggressive can be helped a great deal by the right medication along with a support plan. Others are helped simply by altering the environment and/or your interaction with them.

I know several individuals with PWS who, while living in non-PWS designated residential programs and usually the only one with PWS, were considered to be major behavioral problems. They became quite unpopular with staff and house mates, and it was everyone's desire that the person no longer live there. Indeed, some of the behaviors were very serious, and there was no doubt that the individual was controlling the environment. In every instance, when that individual had the opportunity to move into a PWS designated residence, there was a dramatic change in behavior and, in some cases, the one no one could stand to work with in the previous residence became the new "favorite."

There may be several reasons for this behavior change; however, I am convinced that the central reason is simply the change in environment from a place where food triggers are all around and where the person with PWS is the "odd man out" to a place that is designed with the needs of the person in mind. Here the same rules apply to all, and the staff is prepared to address the behavioral struggles that may arise. In other words—a place that is safe. Don't underestimate the effect of even simple changes in the environment, both physical and personal. One of the greatest challenges in working with people with PWS is figuring out how to set up the environment and interactions to prevent outbursts and/or minimize their impact when they do occur. Before you recommend a new behavior program or a change in medications, look long and hard at

what you can do right there within the home.

You must also keep in mind that many of the individuals are impulsive. This means that they move into action quickly without taking the time to stop and consider the effect of their words or behavior may have on themselves or others. You'll find that many of the residents snap or yell at someone with seemingly little provocation and engage in verbal arguments over very minor issues or perseverate on small problems that are easily resolved. These verbal encounters may or may not lead to physical aggression, and that has a great deal to do with the person involved and how the verbal interaction is handled by staff.

What triggers an outburst, verbal or physical, and what can we do?

I do not believe that people have outbursts for no reason, even though no reason may be apparent at the time. However, I hear comments like these frequently in my work with PWS programs: "It came out of nowhere... Nobody was doing or saying anything and he just went off... All of a sudden, he started to yell at his house mate who was just walking by..." I contend that, unless an individual is having a psychotic episode and/or hallucinating, there is a reason behind each and every outburst. More often than not, if you take the time, you can trace it back to the cause. Doing this requires thinking like the person with PWS and being aware that the cause may not immediately precede the behavior. Remember that many with PWS are obsessive. That means they may be hanging onto and ruminating about something that happened a couple days prior and suddenly it comes out.

Another thing to keep in mind is to not expect that the cause of the outburst is "reasonable" by your standards. In other words, the individual may be enraged at another resident for saying something like "I have a blue jacket and you don't." This example is not used to trivialize the feelings or minimize the concerns of the person with PWS, but rather to let you see how the process might go. A resident might make such a comment to another to trigger a defensive reaction. Perhaps the offended resident then asks his mom or staff to take him shopping for a new jacket and is told, "No, you already have a good jacket." Now the resentment is building, because another resident has something that he doesn't have. It could come out in stealing the jacket or something else from the other resident, or it could come out as an angry yelling match.

We have found that most outbursts can be traced back to an experience where the person was feeling he was somehow being treated unfairly or a food issue. Here are a couple examples:

You announce excitedly that there's been a change in plans and everyone is going to a dance on Tuesday night instead of visiting the neighboring residence to watch a movie. One of the residents has a rather serious outburst after hearing the news, and you can't figure out why she'd be so upset because she loves the dances. Consider this: she had planned, on that very Tuesday evening, to "obtain" some money from the new

male resident (not PWS) that she recently befriended in that other house. He likes her and wants her to be his girlfriend and is very “generous” with her to win her affections. You can’t possibly know that this was her plan and why your “good news” precipitated a major scene. Yet I’m convinced that such stories lie behind many of those behaviors that seem to “come from nowhere.”

Here’s a real life example of a very serious outburst that, with a little forethought, could have easily been avoided. It was Thursday, October 31, and the residents were having their regular doctor’s appointments. Since the doctor’s office was several miles away, it necessitated the residents missing most, if not all, of their school or workday. Usually, they didn’t mind missing school or work because this particular doctor was very nice to them and always gave them a piece of candy (sugarless, of course) at the end of their appointment. On this particular trip to the doctor, one of the residents began to bang on the windows of the van and hit the person next to him while trying to get to the driver. It was very disturbing as this resident was one who especially loved going on doctor visits. No one could get him to articulate why he was so upset. The behavior continued at the doctor’s office in spite of the best efforts of the doctor and his offers of candy for good behavior.

You may have already guessed what precipitated this young man’s unexpected outburst. Yes, it was Halloween and his school was having a party at which many treats were available. It is unlikely that a person with PWS will discuss this matter with staff either because of a limited understanding of time concepts and poor planning skills, or they do not want the staff to know that they hope to eat lots of food not on their menu. The situation, however, could have been predicted. That’s a large part of your work. Anticipating, predicting, and planning. I guarantee you that a significant percentage of the potential outbursts can (and should) be avoided with forethought.

Here is another example. In spite of your best efforts, an individual starts getting into a verbal tug of war with you about going to visit his family over the weekend after you told him that his mom just called and cancelled because she has to work. He insists he’s going home and you can’t stop him and his mother said he could, going on and on with his voice getting higher and higher. You continue to say that his mom just called and that she is going to call back to reschedule. He just keeps yelling about going home.

The biggest mistake that you can make is to continue trying to convince him that what you are saying is right. The more you talk, the more he’s going to resist and the more upset he’s going to get. Stop talking about it! Calmly say that he can call his mom at 5:30, when she gets home from work, and he can ask her directly. If it helps, set a timer to go off at 5:30. Write it down, especially if you are going off duty before 5:30, or tell a staff person in front of him about the phone call to be made. Then don’t discuss it any more. He may continue to rant and rave, but at least you’re not fueling it further. If it helps, provide periodic reminders of the 5:30 phone call.

In other words, let it go. Your logical explanations mean nothing. All the person hears

is no; it's bad news and he's upset about it. Some individuals can get wound up pretty quickly and move into aggressive behavior if you don't back off right away. You have to know the person and be prepared to handle his or her frustrations. In this situation, as a staff person, I might have asked the mom during her initial call to call back after her son arrives home from work and speak directly to him about the change in plans as well as rescheduling the visit so he has another date right away. After they talk, I would ask to speak to his mom to double check what mom has told her son and then write down the new information on the activities calendar. In doing this, I have just saved myself, and everyone else in the house, a couple hours of grief by not being the "go-between" (which usually becomes the "bad guy" role).

There will be times when a person does become aggressive and hurts himself or others. In these instances, the use of physical intervention on your part may be warranted as a last resort. There are numerous crisis intervention programs which teach you about all the verbal de-escalation steps you should take prior to using any form of restraint. But keep in mind the negative effect too much conversation may have during an outburst. For people with PWS, talk just isn't calming and often increases the anxiety and agitation.

Physical intervention of any sort should be used judiciously and only by trained staff. It is quite easy to get hurt or hurt the resident if restraint techniques are administered improperly. Given the medical considerations of many persons with PWS (obesity and enlarged heart), we recommend avoiding take-downs resulting in a prone restraint (especially face down) and using two-person escorts when necessary. There is one recorded case of an individual with PWS who died as a result of a prone restraint, so special considerations need to be made for physically managing an individual who is in danger of harming himself or others. Otherwise, follow the mandates of the training you received, keeping in mind my caveat about too much talk.

It is physically and emotionally draining to engage in physical intervention with a resident. Remember, though, that the individual does not want to be out of control and is relying on you to keep them safe. So do what you are trained to do with empathy and compassion, or don't involve yourself at all. There are some rare instances where individuals may act out for the sole purpose of being restrained; they enjoy the closeness and being held. Watch for the possibility of that pattern. And then do something about meeting the person's need to have closeness and physical contact.

In the final analysis, the best advice is to be prepared for, but don't assume, the worst.

III. Life In The Residence

A. Type and Size

There are many, many residential options for adults with PWS throughout the United States, although not all are available within each state. In fact, there are many states where no PWS specific residences exist at all. How various residential programs are referred to varies by state, but there are essentially four categories.

- *Intermediate Care Facility (ICF/MR)*: Basically, this is a group home for individuals with mental retardation—usually 8-12 or more residents — designed to serve persons with severe behavioral, medical, intellectual impairments. Twenty-four-hour supervision is provided as well as lots of clinical services—nursing, nutrition, psychology—plus a high staff to resident ratio. Intermediate Care Facilities are on the way out in most states as they are a very expensive mix of federal and state dollars. They are considered more restrictive than a group home/community residence.
- *Group Home/Community Residence (CR)/Individualized Residential Alternative (IRA)*: These homes, serving 3-12 residents, offer 24-hr supervision but not a lot of clinical/support services. They have a lower staff to resident ratio. Most adults with PWS live in these settings although many more are needed. Weight and behavior are best managed here.
- *Semi-Supervised Homes/Apartments*: These vary but generally are houses or apartments serving 2-4 people where staff may be available but not on-site at all times. Staffing can range from a couple hours a day with or without someone on-site overnight to staff supervision for most of the at-home hours with an overnight staff. In some cases, the individual may have an apartment by himself or with a roommate in an apartment building with other disabled and non-disabled people where a staff person also resides and is available. One fairly successful model is in Michigan where there are three houses side by side, two housing three residents each and one housing one resident with part of the house being an apartment for the staff person. Weight remains an issue, so many controls need to be in place.
- *Individualized Supported Living*: This is a living situation where an individual with PWS shares a house or apartment with a non-disabled person (e.g., paid roommate or college student in need of housing) who is cognizant of the characteristics of PWS. Weight is an issue though may be managed adequately to prevent morbid obesity. Family support is usually needed as well.

Any of these settings may be designated specifically for individuals with PWS or may include individuals with and without PWS. Generally, the person with PWS in a mixed home does not fare as well with regard to behavior and weight and is often seen as a major problem. The exception is when integrated group homes are designed with the special needs of the person with PWS in mind and staff and other residents are geared

up for the situation. Still, PWS specific safeguards are necessary to manage weight and behaviors.

Finally, I know of no successful totally independent living situations.

B. Physical Set-Up

1. Kitchen/Food Storage Areas

It's been very well established that certain environmental controls are necessary in a home where individuals with PWS reside. Food should be made inaccessible either by having a locked kitchen or by locking the refrigerator and food storage areas in an open kitchen. Some programs like to have their kitchen accessible and store there only those foods that are to be used during that day or are considered "free foods". It is argued that this provides a more normalized setting and residents can more easily participate in food preparation, if appropriate. Other programs find that some of their residents just can't handle that degree of exposure to food. They stand in the kitchen and watch each meal being prepared and are unable to engage in anything else. In that case, a locked kitchen provides a more relaxed home environment.

However, having a locked kitchen and food storage areas does not mean that there can be absolutely no contact with food or routine kitchen activities, although this is often the subject of much debate. You will hear parents, experts, and experienced staffers argue that any access to food is too much and only creates unnecessary anxiety for the resident. Some providers do all the meal preparation and cooking during the overnight shift to avoid distracting the residents during the day. The degree to which this is effective may have a great deal to do with how easily smells travel within a particular house. You don't want the residents up all night imagining the foods that go with the smells wafting into their rooms! There is another benefit, however; if food is being prepared during sleep hours, then day staff is available to interact with the residents rather than locked up in a kitchen for a few hours each day.

In any case, I (and most other providers I know) feel that each person should be individually assessed with regard to their comfort level around food. Some residents will be able to mix the drink for dinner or cut up vegetables for the salad and perhaps more, albeit with supervision. Others will not be able to withstand the temptation to eat the food being prepared and should not have to deal with that stress. This is not to suggest that there should be a formal goal for meal preparation as would be typical for most residents with developmental disabilities. On the contrary, this is where serious programmatic differences lie.

The individuals in your program represent a range of interest and ability with regard to food. So you need to be creative to enable each person to have access to the

kitchen and food to the extent that they can and desire. And remember that people change—and so should your program.

2. Bedrooms

Ideally, everyone has his or her own bedroom with a lock (a lock that only the resident and staff have the combination or a key to enter). Where bedrooms are shared, there should be individual closets with locks so that there is a secure space for whatever items the resident wants to protect. (DVDs, CDs, and video games seem to be popular items that frequently go missing.)

What if a resident doesn't know how to use a key?

Provide whatever instruction is needed. If the individual is unable for cognitive or physical reasons to learn the task, consider a different type of locking mechanism, such as a combination lock for that person or an alternative monitoring system, such as an alarm. Keeping the room locked and having staff provide access may be acceptable to the individual.

What if a resident is always losing his key?

Experiment with different key chains and strategies for remembering. A way to avoid common problems with keys is to provide combination door locks. They have proven to be very effective and require far less maintenance. Of course, there is the risk of the combination becoming known. All it takes is the watchful eye of a resident standing by while another enters his room!

What if a resident forgets to lock his room?

Help him to remember with verbal reminders or by putting a visual reminder by his door. Perhaps if there is a natural consequence such as another resident entering the room and taking something special, the person will begin to remember the importance of locking the door.

Whatever locking mechanism you choose must allow the resident to open the door from the inside with one hand in case of an emergency.

3. Office/Staff Space

A safe space should be provided for staff to keep their belongings—purses, knapsacks, coats, and such. It is then the responsibility of the staff to use that space to prevent their personal items from being stolen. It's a sure bet if you leave your purse on the dining room table while you run to answer the phone, your money and candy bar will be gone when you return. By using the space provided, you are ensuring the emotional safety and security of the residents, which is at the core of your job. Staff should also have a space where they can eat separately from the residents if they are eating different food or are on a different meal schedule than the residents.

Records, paperwork, data, and memos all should be maintained in a safe area such

as a locked file cabinet in a locked room. It's all too easy to forget to lock up a desk drawer, and the next thing you know, a resident's file is missing along with some confidential information about others. Make no mistake, they are interested!

Some individuals may alter or tear up their records when angry, and there goes six months worth of data! Others may simply find confidential information about housemates or agency news just too good to resist. Then you spend all kinds of time and energy to find out where the leak is!

4. Medications, Medical and Personal Hygiene Supplies

Medications and treatments of all sorts (prescription and non-prescription) should be safely locked away. For many individuals, medicine is food. Cough syrup, laxatives, antacids, aspirin, toothpaste and mouthwash are considered to be desirable food items by some. You'll know for whom this is true when you find that a resident is running out of these supplies in an unusually short period of time. This isn't true for everyone, so don't assume, but do pay attention.

5. Money

Money should also be made inaccessible. Money equals food and should be kept in a locked container or safe. Residents should not be around when the staff is opening the safe as they may figure out the combination and try to use it later. It's usually not a good idea to have residents keep money in their rooms, even though they might have their own rooms or locked storage area. On that one occasion they forget to lock up, the money will turn up missing. It's just not worth what will follow. The exception is when the cash is part of a budgeting program; for example, an individual has his daily train/bus and coffee money for work. Encourage the residents to keep their cash in the safe until needed, assuring them that they can check on it regularly and, of course, involve them in a weekly budgeting program.

6. Privacy

Another important type of space within a home is an area that provides a little bit of privacy— perhaps a den where two people can watch a movie together, or a phone call can be made away from the crowd, or a staff person can have a private conversation with a resident. This is especially important where residents share bedrooms or there are restrictions on how bedrooms may be utilized (e.g., no visitors allowed).

7. Exercise

Of course, the ideal house has an area for exercise. This can be tough in many homes, so one has to be creative. If you are short on space for treadmills and exercycles and floor mats and such, consider the stairs as exercise equipment (if you have any), do aerobic exercises, and use your yard if you have one. Use community facilities and generic resources such as YMCAs, gyms, health clubs, public pools, skating rinks, and community running tracks whenever possible. These places help the residents to feel like "regular" people and facilitate socialization and

integration. (Just don't take the residents there in large groups, which only serves to draw negative attention to them.) If the cost of individual memberships is prohibitive, request a family membership. It may take some time and a bit of advocacy, but it's worth the fight for those individuals and programs that lack adequate funds.

8. Alarms

You may need to have all means of egress alarmed, and in certain cases, bars on windows. I worked with a woman who was prevented just in the nick of time from jumping from the roof outside her second floor bedroom window to the ground. No, she wasn't suicidal... she just wanted to leave. In some residences, there is absolutely no problem with people running away and alarms aren't necessary, but you may not know that right away. One difficulty with alarms is ensuring that any codes that are used to activate and deactivate are kept secret from the residents. I recall showing some parents around a group home I managed, and when I arrived at the back door leading to the deck, I realized that I had forgotten the code to deactivate the alarm. My fellow tour guide, a resident, chimed in with the numbers! Needless to say, I was a bit embarrassed and, as always, humbled. (This same resident showed me how to use a library card to get into another resident's room when it was locked.) If none of your residents leave the house without notice, then don't run out and put alarms on the doors. Use the money for something more useful. However, people do change and new residents may move in, so keep your options open.

9. Outside trash areas

It is usually a good idea to build or purchase a trash bin which holds your trashcans and is lockable. Some individuals may go into the household trash (and the neighbors' trash, too) in search of food, so it is wise to take preventative measures. In this way, you only have to keep a careful eye on the trashcans on trash day when they are brought to the curb. You may feel this is unnecessary because the residents do not leave the house without supervision, but that may not always be the case, and/or a person may leave the residence unbeknownst to you and head for the trash cans. I always figure it makes things easier for certain residents when temptation is not so close at hand.

C. Routine/Structure

We often hear how persons with PWS are so inflexible and can't handle transitions and change very well. There may be a number of reasons for that, but there is one that may be the most significant. Imagine that you have PWS and your world revolved around your next meal or snack. As a child, you are dependent on your parents to ensure that food is forthcoming, and over time you come to trust that they will always give you what you need and are promised. Then you move into a residence with a different schedule than you had at home and lots of different staff people coming and going at all different

times and doing things differently. Whom can you trust to meet this very basic, yet overwhelming need of yours?

While we can't control the many staff people involved in supervising a program, we can control the scheduling of activities to a great degree. Meal times need to be on a fixed schedule, and staff should work diligently to adhere to that schedule. Over time, you'll find that many of the residents are able to be a bit more flexible when dinner is a few minutes late.

But that will only occur because you've built trust. The residents know through experience that a meal being late doesn't mean it won't happen at all. I believe that flexibility is developed through first establishing a sense of security from which the individuals can move beyond the issue which is causing them anxiety; most often, food. In a way, their flexibility starts with your rigidity!

It's not only about mealtime. Most activities that occur throughout the day have to be scheduled. Predictability and consistency are key to building a safe and peaceful environment. Having schedules in writing is extremely helpful in facilitating the routine. Have a house calendar identifying social and recreational activities. Have a chore chart that the residents refer to on a daily basis. You might also have individual schedules, including the use of appointment books for some or picture charts for others.

One of the benefits of written schedules is that it allows you, as the staff person, to avoid getting into verbal explanations of things, which can lead to an outburst if the individual doesn't want to do something you are asking of him. Instead, you simply refer to the chart and move on. Of course, this doesn't guarantee that the individual will be cooperative, but at least you haven't escalated the situation. Involve the residents in developing routines and schedules. Change responsibilities and activities periodically, so that residents have different shower times and chores and opportunities to ride in the front seat of the house vehicle. Above all else, be fair!

You can also use an individual's routine as the basis for a reward program. Common complaints about residents with PWS include a lack of motivation to do daily chores, refusal to exercise, and inconsistent performance of daily personal hygiene activities. For example, the person who is slow in the morning and misses their ride to work or program may need an extra incentive. Completing the list of morning activities, like showering, brushing teeth and hair, applying deodorant, putting on clean clothes, and arriving to breakfast on time, could result in a second cup of coffee. If these activities aren't complete, then there is no time for that second cup.

Showering could be a required activity prior to the evening snack or an outing. If Saturday is the big chore day, then planned activities are scheduled to follow the completion of those chores. Just like real life!

At the same time that you want to provide structure and routine, you have to be aware

of and flexible enough to meet individual needs. If a resident is taking a semester long class on Wednesday night, then you may need to change his laundry day or whatever else was scheduled for that day so he doesn't feel rushed, pressured and resentful. Consider your own rhythms and routines and what you would hope for from someone who has a great deal of control over your daily life. I have seen programs go from very structured at the outset to a gradual loosening over time as everyone learned to trust that their needs would be met no matter what. This is what you want to achieve. Other programs are so rigid that nothing ever changes for fear that a single alteration in routine or structure would throw the whole program into turmoil. I would predict an increase in behavior problems in such a program.

It has been my observation that people need to experience some change to accommodate their personal growth and when that does not occur, there is resentment and subsequent acting out. Thoughtful and carefully implemented changes which incorporate resident input will increase the likelihood that the program—the home—will be a place where people want to live, a place they value and enjoy.

On the opposite end of the spectrum, there are the programs that have little to no structure, believing that adults can and should have the freedom to make their own decisions and establish their own routines. My experience with those programs is that it is “too much too soon” and the residents can't handle the lack of continuity and consistency. Typically, there are lots of behavior problems in such settings. As a result, what invariably happens is that the program then tries to institute structure and rules where none existed before and the residents naturally react against them.

It is my firm belief that it is much easier (and wiser) to loosen up than to tighten up and that structure and consistency allows for trust to develop. The residents learn that their environment will provide what they need, and the staff learns what to expect from each of the residents under different circumstances. From there, change is possible.

With all this focus on structure and routine, what do I do when plans are suddenly changed for reasons I can't control?

If there is no opportunity to provide the resident with prior notice about an upcoming change in routine or scheduled activities, then you do the best you can to make the change as minimally disruptive as possible. My advice is always to present the change (which is usually perceived by the resident as losing something) along with a replacement (so the residents immediately perceive they are getting something).

For example, “We can't go out on a picnic today because the van won't start, but we can still have a picnic in the back yard at lunch time and invite some of your friends over.” Or, “We can't go to the park for a picnic because it's raining, but we can go to the movies and have a picnic next week.” The point is that the residents were most likely looking forward to some event or activity and they are feeling disappointed. It is your job to come up with something else that they can look forward to and enjoy. It distracts them

from the “loss” and can prevent potential problems. Of course, there are no guarantees that everyone will be satisfied with your alternatives. But if you know what the residents like and are creative enough, it usually works.

It is essential that you recognize the role of food in any of the changes. While it may seem obvious to you that you are still going to have lunch around noon time even if the field trip is cancelled, that is not the case with a person with PWS. You need to deal with the food aspect of the activity immediately and specifically, as in my first example. Don't ever forget that food is foremost on their minds and there is tremendous anxiety attached to any doubt about the when's, where's, and how's related to it. Respect their need to have closure on any food matters before they can let go, accept a change, and move on.

D. Nutrition

There are many types of weight management programs available to you, and undoubtedly your program has settled on one or a combination of a couple that works well for your residents. Probably the most common is the American Dietetic Association's Exchange System. This is the system most commonly used by dietitians and has many advantages. It allows for a wide selection of foods offering variety and versatility to the person with PWS within the person's specific calorie allotment. By categorizing foods, food choices from each of the different lists assures a variety of healthful foods. What I like about it is how the residents and staff are able to understand the different food categories and the equivalent exchanges within each. This allows for greater flexibility in menu planning and greater ease in making substitutions when necessary. It is also a system that allows individuals to be knowledgeable and accountable for what they eat. When given a choice to eat a special treat or their regular menu, they can understand what exchanges need to be made and make an informed decision. Staff seems to like it as well. They learn that if (heaven forbid) you run out of Corn Flakes, you know you can substitute an equal amount of Total. Be sure the residents have this knowledge as well or they might challenge you (and, in my experience, they are more often right than not when it comes to food exchanges).

Another popular program is the Red-Yellow-Green Weight Control System. This system categorizes foods into three calorie groups: low (Green-Go foods), moderate (Yellow-Caution foods), and high (Red-Stop foods). The specifics of how much of each category of food is allowed for a particular individual are determined, and the menu is designed accordingly. It is an easy system for the residents and their families and is often used at home. It is, by the way, the system used by The Children's Institute (which provides an in-patient program for people with PWS in crisis) in Pittsburgh, PA.

Some programs have adopted a modified Weight Watchers point system, where every food item has a point value and each individual is allotted a certain number of food

points for the day. In this way, menus can be quite versatile and individualized, which is a terrific advantage. A disadvantage in a group setting could be the difficulty of providing that degree of individualization. Anything is possible, however, and innovation is a good thing. Again, it must be thoughtful, carefully implemented innovation if you want your system to be accepted and successful.

Regardless of the system you choose, being on a restrictive diet means that menus must be designed carefully to ensure that individual nutritional needs are met. This requires the oversight of a nutritionist or dietician, who should be accessible to the residents periodically to discuss their dietary plans and to provide training and counseling regarding nutrition.

You should be able to call the dietician with “emergency” questions, like you just found out that there is going to be a Halloween party at the workshop and you do not know how to adapt the residents’ menu for that day to allow for some treats. A really good idea for non-emergency situations is to keep a notebook with food/nutrition questions that you and the residents may have. Then, when you are in contact with the nutritionist, she can address them, preferably in writing so there is no doubt.

Keep in mind that people with PWS have food preferences and food dislikes. Make sure that the dietician or nutritionist is aware of this and designs menus accordingly. Variety is very important. Fall/Winter/Spring/Summer (four week cycles) menus should be rotated to utilize seasonal fruits and vegetables. Using recipes that include plenty of spices and a pleasing appearance is important. Being on a weight loss dietary plan doesn’t mean one has to eat bland and boring food. I believe that the menu for the day (if not week) should be available to the residents. Meals shouldn’t be a mystery, and knowing what’s on the menu allows for exchanges to be discussed and planned for ahead of time.

Some providers have reported that a few of their residents become obsessed with the menu and perseverate on it, so they do not make it available to them. It may be that these individuals are simply seeking reassurance, which can be managed in a number of ways. I would first question if the residents are obsessing because the menu is frequently altered and deal with that problem up front.

The residents do have different caloric requirements. In spite of what you may have heard, it is not true that they must all have exactly the same amount of food or there will be a major problem. I have never witnessed a problem around variations in portions, except where it is perceived that the actual portion is different from the prescribed amount. “Hey, she got too much, she’s on 1200 calories and so am I and she’s got more than I did!” Or, “You didn’t give me the right amount of juice—this isn’t four ounces and I’m supposed to get four ounces!” It is unlikely that you will ever hear someone claiming that they received more than their allotted amount of food.

The residents understand that weight loss equals more calories and weight gain equals fewer. They can accept when someone has larger portions because they know that the

person has lost weight by sticking to the menu plan and participating in exercise. Seeing those larger portions can be an incentive. Differences are important to acknowledge and respect. You must make absolutely certain, however, that you weigh and measure everything or that the residents are supervised in their weighing and measuring and have the proper equipment, training, and supervision to do so. Even if you are a long term veteran and have weighed and measured for years, you are not able to weigh and measure precisely by eye. And it's just not worth the upset if you make a mistake. If you don't believe me, try it and see who among you can prepare a dinner plate according to the menu by eye alone! You'll be surprised!

Using prepackaged condiments and dressings can serve to ensure appropriate quantities and also allow for greater independence at mealtime for the residents. Do keep in mind that a condiment alone can be a desirable food, so don't leave them accessible.

Just because someone is on a restricted diet doesn't mean they can't have treats and enjoy a variety of party or fun food. It's all about planning and involving the residents in making choices. For example, "Today is your roommate's birthday and we're having a frozen yogurt cake. Would you like to trade your lunch fruit and dinner bread for a piece of the cake or stick to the menu as planned?" This teaches healthy choices and allows them to have some control over this very controlled aspect of their lives.

Finally, as I discussed earlier, you may hear many different ideas about how to control and manage food in a residence. Some programs are very rigid. No one ever has access to food. No one is involved in shopping or meal preparation. No one is allowed anywhere near the kitchen. Everyone is on the same number of calories. Smaller plates are used to make food portions look larger. Salads are unlimited (not so with salad dressing). Residents are not involved in menu planning. I don't support any of these particular policies across the board, as they are more controlling than necessary for many people and treat everyone alike.

Some of the residents can be involved in food shopping and meal preparation, and all should have an opportunity to discuss meal plans on a regular basis—after all, it's their meal plan. I'm not convinced that tricks like smaller plates serve any real purpose or fool anyone (except young children). I also don't think unlimited salad makes a whole lot of sense. Seconds, yes; unlimited, to what end? We know that the person will not necessarily get "full" and be less likely to want other types of food or reduce food seeking.

My goal has always been to have the individuals behave in a manner around food as consistent with the general population as is possible. To me, that means treating them as you would anyone else in the general population whenever feasible. You should expect appropriate manners and behavior around food at home and in public; being too loose or too rigid will not help the individuals become integrated and accepted into their community.

After years of hearing about the many ways different programs manage food, I have come to believe that there is no one right way. As long as the residents are losing weight, are provided with an individualized and nutritious menu, are given a reasonable amount of control over the food in their lives and enjoy the food they get, then chances are you're on the right track. But there is always room for change, so listen to what others are doing. Try some things out. Just remember—baby steps.

What do I do when a resident eats food not on his menu plan?

When someone is discovered eating a coworker's lunch in addition to his or her own, a reasonable response is to say, "You have a choice. You can continue eating your lunch and have equivalent calories deducted from your evening meal, or you can stop now and have most of the meal that is planned for you at dinner time." There will be occasions when an individual decides to continue eating non-menu food and will end up at the dinner table with a salad and broth while the others enjoy their full meal. They won't like it, but if they knew this was the procedure ahead of time and they were given a choice in the moment, they will be less likely to get upset. I've never experienced someone having an outburst as a result of this practice. And most make a different choice the next time. Just don't make a big deal out of it. The point isn't punishment; it's about keeping healthy.

E. Weight

What's the correct weight for an individual? How often should they be weighed? What to do when there is a weight gain? What if someone keeps losing when they are at their ideal body weight?

These are all good questions—with no single or easy answers.

A medical professional can help determine the ideal body weight range for each resident. You will also hear professionals talk about the individual's Body Mass Index (BMI), which is a formula that provides a measure of total body fat. With regard to the body weight range, note the word "range". That's important. No human being can stay at exactly the same weight every day. Don't hold them to a tougher (if not impossible) standard. Often, you or the person's family may feel that the "ideal" weight is too low—that the individual is just too thin. Talk to your physician, nurse, or dietician and come to an acceptable weight range that all can support. If you don't do this, then mom is going to fatten him up on home visits while you reduce his calories to take it off when he's at the residence. It's a silly, unhealthy and unnecessary cycle that only hurts the individual you are trying to help. Be flexible!

I recommend daily weighing when a resident first comes into a program and until they are within their ideal body weight range. Weighing should occur in private and be free of judgment. It's not necessary to comment on every pound gained. It's going to happen.

Certainly, praise for sticking to the menu plan and losing or maintaining is always a good thing to do. But unless you find that someone has gained an inordinate amount of weight overnight, there is no need to question or challenge the resident. Daily weighing allows you to catch any weight gain when it happens, which allows you to figure out the food source more easily.

After a person has stabilized for a few months, you could decrease the frequency of weigh-ins to one time per week, but always just before and after home visits or other special trips/outings. When an individual has had little to no weight change for a year, reduce weigh-ins to monthly if that change isn't upsetting to the individual. I suggest reinstating daily weigh-ins when there are changes in the person's life such as a new day program or recreational activities, increased out-of-residence visits, a new boyfriend or girlfriend—basically any change that creates the possibility of a new food source. It would be a shame to allow the person to gain significant amounts of weight during what could be a stressful (even if positive) period anyway.

Where there is a substantial weight gain, most programs institute a calorie cutback until the person is back on track. It usually doesn't have to be a terribly large reduction in calories, as long as any food sources have been eliminated. The person should know that he will return to his previous level of calories as soon as his weight reaches a certain point. In general, however, if the individual is already on a weight loss diet (rather than maintenance), simply resuming the diet plan will result in weight loss so there is no real need for a cutback of calories. I suggest avoiding cutbacks unless the weight gain necessitates it. It must feel like punishment to the individual. Similarly, having the person engage in a more strenuous exercise program until the requisite amount of weight is lost sends the message that exercise is a burdensome task that must be endured, rather than a pleasurable although essential activity. Remember, this is a life long struggle and the person has little to no control over weight, so keep the focus on health, not pounds.

Some individuals will choose to reduce calories or increase exercise to get back to their original weight. If either strategy reduces anxiety and promotes a feeling of well-being, provide whatever support the individual needs or wants. Taking control of one's health is certainly a terrific goal for a person with PWS, and every step along the way should be applauded.

Also keep in mind that these individuals have a depressed metabolic rate, so a great deal of weight can be gained in a very short period of time. One example is a fellow who gained 24 pounds in just 36 hours on a home visit. Impossible, you say! No, I'm afraid it is not. This isn't typical but can occur when a person is left to his own devices. Of course, that kind of rapid weight gain is a health risk in and of itself.

In the last several years, there have been an increasing number of cases of severe gastric illness or acute idiopathic gastric dilation. In laypersons' terms, this is where part of the stomach tissue dies after a binging episode and can cause severe medical problems, even death. If a resident complains of stomach pain, along with abdominal

bloating and vomiting, you should call an ambulance immediately as these are indicators of severe gastric illness. Frequently, this condition develops during a home visit where the supervision around food may not be as tight as it is in the residence. Thinner individuals may be more at risk than heavier ones—another reminder that PWS never goes away and vigilance must be maintained throughout their lives.

In addition to rapid weight gains, you may find that one of the residents has been steadily gaining weight over time and absolutely nothing in his routine has changed. Here's the fun part. You have to do a little detective work and discover his food source. It may not be easy, but it's sure to be interesting

One of my favorite stories about trying to discover how someone was managing to gain weight when nothing at all had changed in his life took place in Cape Cod in Massachusetts. Cape Cod is a beautiful coastal region consisting of small quaint communities. There is no crime to speak of, and people don't feel compelled to lock their cars while food shopping or their houses when they retire for the evening. In one of several residences for adults with PWS on the Cape, there was a resident who began to gain weight, and no one could figure out where he was getting the food. They checked his workplace. They kept a close eye on him in the community. They monitored his menu and exercise program. Nothing. Yet he kept putting on weight. Then one of the staff, as a last resort, volunteered to stay up through the night (the staff were not required to do so in this particular home) just to see if the fellow had a food source he got to at night. Well, lo and behold, the resident did get up during the night, walked out the back door across his back yard and into the house of the back yard neighbor, an elderly gentleman who lived alone. He went to the neighbor's pantry, helped himself to a loaf of bread and a jar of peanut butter which he finished off, disposed of the evidence and returned home.

Apparently this had been his habit for quite some time and was the cause of his weight gain. Of course, the staff had to let the neighbor know what had been going on in his house, so they sheepishly broke the news to him. Much to their surprise, this grandfatherly man gave a huge sigh and said, "Thank God. Every morning I would come downstairs to fix myself some toast with peanut butter and there wouldn't be any. So, I'd go to the supermarket and buy another loaf of bread and jar of peanut butter, put it in my pantry, come down the next morning, and it would be gone. This kept happening, and I didn't dare tell my daughter for fear she'd put me in a home..."

This story had a happy ending. Others are fraught with more danger, like persons who panhandle for money; steal it from family, friends, or staff; steal food from stores; or even trade sexual favors for food or money. So it's not only important to uncover food sources to prevent weight gain, but also to prevent a potentially dangerous and life threatening situation from occurring.

At the other extreme are those few individuals who become underweight. As is the case with people with eating disorders, losing too much weight is extremely unhealthy. It can

be particularly dangerous if the loss includes bingeing-purging behavior where the person eats an excessive amount of food all at once and then purges, as in vomiting, using diuretics and laxatives, and over-exercising. This is known to happen with people with PWS. Often it is around family visits when they know they will have greater access to food. They take advantage of the opportunity to gorge, but don't want to be penalized at the residence by having calories reduced or losing some other privilege, or being made to increase daily exercise. So they develop their own strategy to deal with the weight gain, and it usually is not a very healthy one.

When the individuals do reach their ideal body weight range, they will need to have their calories continually adjusted until a maintenance level has been achieved. Once achieved, staff must continue to monitor the person's weight to ensure that the dietician or other health professional can make the appropriate adjustments as needed in a timely manner.

Managing weight is a lifelong activity for people with PWS, so do all that you can to make it easier for the individual. Make food inaccessible, yet allow meals to be a source of pleasure as they should be for anyone; maximize opportunities to exercise, though you don't have to call it that; encourage participation in activities that don't involve food; find work or something else that is meaningful enough to the individual that it provides an incentive to maintain a healthy weight.

F. Motivation

You'll hear about and perhaps experience problems in this area quite frequently. Motivation is a complicated phenomenon and no less so for individuals with PWS. Most of us are not particularly motivated to do daily chores, exercise on a regular basis, or even to go to work every day. What gets us to perform these tasks?

We draw on both internal and external motivation... "When I clean my room it looks good and I feel better when things are in order." (internal) Or "I clean my room because if I don't my mother gives me a really hard time and I can't stand it when she does that." (external) With exercise, we remind ourselves of how much better we look and feel when we exercise regularly. In addition, we often reward ourselves after a good workout with some kind of treat. As far as work goes, sometimes we go to work because we really enjoy the job and the people with whom we work. We feel valuable and valued. Of course, the external motivator is the paycheck. At times that is the only motivation!

Now, consider that people with PWS seem to lack the ability to draw on internal motivation. That leaves us with having to discover what external motivators or rewards would be effective in helping the person complete these necessary, everyday, life sustaining tasks.

1. Household Responsibilities

With household chores, make sure there's a time in the day or week that is set aside for specific chores and that it doesn't conflict with a favorite TV show or is scheduled when the person is at his lowest level of energy. And help. Get in there with the resident. Lend a hand. Chances are they need some instruction anyway. It can also provide an opportunity to be alone with the individual and talk privately. You can add external motivation by setting up a system of surprise spot checks. Each person would have certain criteria to meet for their room to be considered clean. For some, it might be getting rid of old magazines and coupons; for others, it could be clearing off the tops of dressers and hanging clothes in the closet rather than piling them in a heap on the floor. Every so often (at least once a month) do a surprise spot check and whoever meets their individualized criteria goes out for frozen yogurt or coffee or whatever works.

2. Exercise

I had the good fortune to work with a physical therapist in developing an exercise program for five individuals living in a PWS designated group home. Each resident had a personal goal with regard to daily (except for Sunday) physical activity, both in terms of type and amount. Meeting the goal resulted in a sticker which, when tallied at the end of the month, determined who would be the Athlete of the Month and be awarded various and sundry prizes. All five residents were very active participants in the program; they consistently exceeded their goals with regard to time with 50 minutes per day being the overall goal, weight was lost, and muscle mass greatly increased. What kept the residents motivated?

We determined that several factors led to the success of our program: variety and choice of exercise, individualized goals, music, water breaks, and, most important, staff participation. It became clear that the main ingredient in getting folks to engage in exercise was to join in. Most people like to see someone else sweat as much as they do, especially when it's a staff person! It feels a lot better than having you stand alongside them, telling them to "keep going—you only have 15 minutes left." What kind of motivation is that? Make exercising a fun and playful activity. Be their cheerleader while you also participate. And consider a reward system for completion of exercise.

3. Work

Motivation to go to work is a tough one because so many of the residents aren't actually working. They may be in day habilitation programs where they do not get paid. Or they may be in workshops where they do make a nominal sum—when work is available. And typically the work itself is pretty mundane. I find it very difficult to convince someone in a day treatment or day habilitation that going to the program is a meaningful and worthwhile thing to do. If you're having the same difficulty, you might want to consider offering an external reward for regular attendance. Of course, even more important is putting your effort into getting the person into a more appropriate work situation.

We often tell the residents that they can move on once they learn A, B and C or when their behavior improves. Unfortunately in some cases, even when they learn A, B, and C, we then tell them they need to learn D, E, and F and so forth because there are no appropriate alternatives. People with disabilities spend a lifetime waiting. Sometimes behavior difficulties can be tied to the environment itself. Someone is sleeping all day at work because he's bored to tears and he doesn't make any money anyway (or very little). Perhaps instead of saying, "When you stop sleeping at program/work, we'll consider looking for a job for you," we should look for the job and see if the individual stops sleeping.

Finally, there is no magic about motivating people. First, look at what it is you are trying to get them to do and decide how important it is; second, remember their lack of internal motivation and look for external motivators; and third, joining in has proven to be the best motivator of all, whether it's exercise or housecleaning. Don't just stand there telling the residents what to do—jump in and encourage them to get the task done so you can move on to something else—something they really enjoy.

But what do I do when a resident absolutely refuses to exercise, or complete chores, or go to day program?

I don't have an easy answer for that one. I would try to discover if there is a particular reason for the refusal(s). There may be a problem at the day program, such as a strong dislike for a certain staff person or it could be just too boring and the person gets little gratification from attending. Refusing to do chores could be due to never having been expected to do that kind of work in the past (not uncommon) and never having learned that it is truly an adult expectation. Perhaps the individual doesn't value chores as an aspect of being independent. Refusing exercise could relate to disliking the exercises one is expected to do, feeling uncomfortable doing them due to poor coordination and balance, or simply not liking the whole experience of exercising. Assess the person for depression. In some cases, refusals in any of these areas could simply be a way for the individual to assert him or herself.

Once you have identified a reason, you can work with the person to come up with a solution. Sometimes simple incentives help, but depending on the strength and reason for the resistance, the incentive may have to be more powerful than an extra cup of coffee. Ultimately, there is no point in forcing anyone to do something they really don't want to do because the end result is most likely to be a daily struggle at best and behavior problems at worst. (Of course, this does not apply to health and safety issues.) Sometimes the best strategy is to do nothing. In time the person may feel that he is missing out on something as he sees others being active and earning privileges or being praised. That doesn't mean you should completely ignore refusals or the disinterested behavior. Instead, keep a watchful eye and look for opportunities to engage the person. Once again, know the individuals, use your creativity, and don't give up.

G. Communication

1. Staff

Most residential staff establish a network of informal communication that can be fairly effective if everyone is kept in the loop. Examples of informal communication could be when you stay a little longer after your shift to let the next shift know that one of the residents is having a particularly rough day. Or you call a weekend staff person at home to let them know that the residents have decided to go to the amusement park next Saturday so there will be extra staff on duty and money put aside in the safe. I think informal communication is essential to smooth operations and to keeping staff close. However, it is not sufficient in maintaining effective communication across all shifts at all times.

When there are breakdowns in communication, the whole program suffers. People with PWS are masters at “splitting.” They will tell you that the previous shift said they could do a certain thing, and you have no way of verifying it because the person on the previous shift is unreachable. This is an all too common occurrence when only informal communication is utilized.

The wise thing to do is to have an established formal communication system. Have a staff log that specifies any decision making that went on and should be known to all. This is very important even though the issue may seem small to you. Perhaps you agreed that a resident could stay up a half hour later that night. The resident tells the next shift that you said one hour; if it isn't written down, they have no way of knowing. Or perhaps you told a resident that if he completes all his chores without complaint, he could have an extra 10 minutes for his phone call that evening. When the time comes that he is ready to make his call, he is told no to the extra time because you failed to inform the next staff, causing the resident to become very upset. A simple note in the communication log would have prevented that. I must admit, however, that even with the log, people forget and mistakes are made. If you aren't sure of something and have to make a decision, do so and let the person know that if it turns out you were wrong you'll make it up to him or her later.

As mentioned previously, there should also be a communication log for the dietician. You might also want one for the nurse and the psychologist or behavior specialist, especially if you don't see them very often. Perhaps the nurse has recommended a change in the type of sunscreen to be used, but has not discussed it with the residents. You may get resistance to such a change unless it is heard directly from the source. Get the nurse to write it in the log so you can show it to the residents. Perhaps the residents want to change their behavior contracts, but the psychologist typically comes during the day when they aren't home. Assisting the residents in writing down any concerns in a log will help them feel that they have a voice and that

you care about them. Just be sure that the clinicians review the log and respond.

In some cases you may need a communication log with the day program, although this could be experienced by some as “being treated like a baby”. Others may not mind at all, especially if the purpose of the communication is to support the person and can lead to rewards later.

2. Work/Vocational Program

If all parties are agreeable, you may want the vocational or work program to provide the following information: behaviors with regard to accomplishing work tasks; a record of any food the individual may have eaten and which is not on his menu (so you can adjust the evening meal); or if he has taken any items from others so you can assist him in making restitution. It is always wise to have one contact person at the job or program who gives you the information you need, especially if you have more than one resident attending. The downside of a log going back and forth is the enhanced likelihood of it being lost or pages being torn out. After all, if you had a bad day at work, would you want the people you live with to know about it? A phone call is often a more effective mode of communication with an employer or day program.

Indeed, a log does not necessarily take the place of a more immediate phone call or email, but it can serve to relieve the anxiety related to a specific issue the resident is carrying around. Since it is in writing and in tangible form, it can be checked on easily.

3. Residents

I've always felt that any group of individuals living together needs a forum in which to vent, plan, problem solve, and make decisions. It's a way to empower the individuals while teaching social and communication skills. The ideal is a structured group with a facilitator, preferably not a direct service staff person or the house manager (the psychologist, social worker, or behavior specialist are all good choices). The meetings should have a regular format and a specific agenda along with some open-ended time for discussion. Other than mealtime, this is the one opportunity you're likely to have to gather the group together for a single purpose. Since persons with PWS typically have poor social skills, especially in a group setting, it is a terrific opportunity for teaching behaviors such as listening, turn taking, problem solving and promoting sharing and empathy. It also provides a forum for presenting training programs, such as health or dietary training, sex education, and living with Prader-Willi syndrome. I've used these weekly meetings for all of the above, including deciding on house rules regarding pets, appropriate consequences, visitation and phone call policies and more. Remember, your job is to teach people to be more competent in self-management, not to instill acquiescence to your rule.

4. Families

Be proactive in your communication with family members. Call when something positive has happened; otherwise, when the parents hear your voice, they prepare

to be defensive because a call from their child's school or program has always meant bad news. Hold events that involve families, such as summer picnics, holiday dinners, and agency-sponsored events. Integrate the resident's two homes. Assume good faith and make it a priority to establish a positive working relationship with the family. Take the initiative. Listen. Compromise.

See Chapter VI, Sections F & G: Providers: Some Do's and Don'ts for Improving Parent/Provider Relationships for more specific ideas on communication and relationship building with families. PWSA(USA) gives permission to make copies of the "Do's and Don'ts for Improving Parent /Provider Relationships." This may be a useful handout to give to the parent when they first make contact with the provider.

H. Community Utilization

I strongly recommend getting out into your community as much as possible. I know it's not always easy. There are always one or two individuals that have the potential to cause problems in the community, from stealing food to having an outburst over some unanticipated problem. You have to do much more planning than you might do for those without PWS. You will need to know what sort of access to food there is in a particular environment so you can plan for that. You will also want to make sure you have enough staff on hand to handle any problematic behaviors that may arise. It's very important that you are able to manage an out-of-control individual and attend to the rest of the group as well. A common complaint among group home residents is that someone they live with ruins it for the rest of them. They can't go out because of a particular individual or their activities are limited in certain ways. Parents share this complaint. Select and prepare for your outings carefully so that everyone, staff included, has a good time.

I make it a policy not to take a new resident out in the community with only one staff person until we know that person well and know how they handle themselves in a variety of settings, particularly where there is food. Do they pick up popcorn from the theatre floor or go through trash cans at the park or take food from supermarket displays? And not only food—some individuals are quite adept at stealing a variety of other items as well. For most residents, none of these situations are problematic and extra supervision is not needed. For others, one-to-one supervision is a necessary safeguard to prevent food seeking or stealing.

A staff person told me the story of how she went into a drug store with a resident and since she wasn't that familiar with him in the community, she walked arm and arm with him. They went down a couple of aisles, collecting items for purchase and paid for them. As they were going out the door, the alarm went off. The staff person assumed it was a mistake until a quick search revealed that her companion somehow had used his free hand to grab items and stash them up the sleeve of his jacket. She has yet to figure out how he managed that while being so intimately attached to him.

Have a plan for any problems that may occur: who stays with the other individuals while you go to the van with the one who's having trouble; how to handle the person who decides to have a sit-down strike in the middle of the street; what to do if you discover that a resident stole something. Develop strategies with your team. Recognize that these strategies may be different for different people. You'll be a much happier staff person if you know before they occur how to handle potentially embarrassing, if not volatile, situations. Even if your efforts aren't 100% effective, at least you have a plan to follow that had been agreed upon. It protects you, the resident, the agency and perhaps even community members.

Sometimes it is wise to take the initiative in getting to know your immediate neighbors and shopkeepers. Let them know enough about PWS so that they can be helpful, but not scared or resentful of your presence.

For example, if the residence is near a deli or other store, let the shopkeeper know that if anyone from the residence comes in and makes a purchase without a written and signed note (until you notify them otherwise), then it is probably an illegitimate purchase and would they please call you immediately. Of course, the residents must agree to this plan. It's an issue of confidentiality, and you don't want them to be surprised and outraged when the shopkeeper makes the call. Even so, you may have residents faking notes or simply stealing, and you'll have to deal with that accordingly. However, keeping the shopkeepers informed can make the whole process go much more smoothly.

Your neighbors should know that if one of the residents knocks on their door with claims of needing to borrow a cup of sugar for the evening's baking, they should give the house a call just to be sure. You want to be good neighbors, so work with your team to come up with ways to be involved and supported within the local community.

Even with all the potential problems in utilizing the community, it's important that the residents do so in the same way that any community member would. This may include banking, church/synagogue, shopping, haircut, post office, drug store, food store (if appropriate), gym, movies, bowling and any other social and recreational resources available. This is what it means to live in a community residence—otherwise it's just a house located within the community.

I. Families

I have found that the families are typically quite involved in their child's care, even into adulthood. You can make this work for you or against you. Developing a relationship with the families takes time and effort so that trust is developed, as is true in any relationship. Take the initiative and involve the families in as many appropriate ways as possible. You need all the help you can get.

But sometimes the parents tell the staff what to do, which undermines the program supervisor and confuses the staff.

This issue of “Who’s in charge?” seems to be the one that causes the most consternation and, occasionally, outright destruction of programs. I’ve heard parents say that they should control the program because they are the experts. Providers say that they must control the program because, ultimately, they are responsible for the person’s care and are subject to a variety of regulations from multiple sources. They believe that they are the experts in group living.

The truth of the matter is this: the parents are the experts on their child, and you, the provider, are the expert in group home living, so you really are dependent on one another. The problem with engaging in this battle is that nobody wins. A great deal of time and emotion is put into the power struggle, depleting energy that should go into the program and the people you support. Sometimes a parent’s interest is so focused on their own child that it conflicts with the needs of others. On the other hand, sometimes the residential program makes decisions (albeit unwittingly) based on convenience or group need without adequately considering individual needs.

In my work with families here and abroad, I have found that they all share the same concerns: adequate staff training and supervision; staff turnover; adequate recreation and leisure activities; communication, both with the families and among staff about their son or daughter. These are perfectly reasonable concerns and need to be addressed upfront. You may not be able to control some of the management-related issues, but you certainly can work as a staff to address activity planning and communication. As a direct service support person, it is your job to ensure that information gets to the right people. If you speak with mom and she says she’s picking up her son the next day at 3 pm and he needs to have a bag packed, then you are responsible for making sure whoever needs to know gets that message. If mom arrives and her son is not ready to leave or is dressed inappropriately for the occasion, parents lose faith and trust in the program to care for their child properly and as the special individual he is. That’s a kind of damage that is difficult to undo.

Another type of problem that some direct support staff experience with families is becoming overly involved. Perhaps you have developed a special fondness for one of the residents and her family, and they feel similarly. There is nothing inherently wrong with that. However, you may find yourself in conversations where you are providing more information about a situation than you are supposed to or even sharing your personal views about how things operate in the house, other staff members, and agency business. You are there to support the residents and that means being supportive to both the families and the program—not taking sides during difficult times, no matter what your personal views may be. It takes us all to make the residence fulfill governing mandates and be a comfortable home at the same time. Be a collaborator, a bridge

builder, a professional.

J. Health Issues

Individuals with Prader-Willi syndrome have many, many health and medical concerns. Undoubtedly you have, or will, receive training in the specific health issues affecting the individuals you support, so I will not go into detail here. Suffice it to say that your major concern will be managing weight so that the many medical problems associated with obesity can be prevented, including gastroparesis (see Chapter VI Section C: A Medical Reference Guide for Parents and Caregivers). You must also be concerned with musculoskeletal disorders, such as hypotonia (low muscle tone), scoliosis (curvature of the spine), and osteoporosis (compromised bone strength). Each of these concerns can affect mobility, exercise, and activities of daily living. There may be a range of severity in each of these conditions among your residents, with treatment and intervention varying accordingly.

Some of your residents may have respiratory and circulatory disorders. In fact, respiratory disorders such as hypoventilation, sleep apnea and other sleep related disorders are major causes of death for individuals with PWS. It is recommended that all individuals with PWS be evaluated with a sleep study with appropriate treatment based on the results. It is not unusual for an obese individual with PWS to be prescribed a program of weight loss and continuous positive airway pressure (CPAP) during sleep hours. You will need to be familiar with how the CPAP machine works and ensure that the resident uses it.

Other health and medical related concerns include constipation, dental and vision problems, body temperature abnormalities, high pain threshold, lack of vomiting, and adverse reactions to some medications. Understanding and managing these health issues have enabled persons with PWS to live a normal lifespan, something that is only now becoming the norm, thanks to residential programs like the one in which you are working. Become as expert as you can in all of these areas and remember that there is an interactive effect. Lack of sleep due to apnea may lead to behavior problems or sleeping on the job during the day. Osteoporosis causes the individual to be much more fracture prone, so exercise and physical activity needs to be carefully designed and monitored. In short, you need to be informed and vigilant.

K. Medications

To date, there has been no medication that effectively controls appetite in persons with PWS. I hear about individuals using diet pills and such, but they are ineffective and ultimately a disservice to the individual. Perhaps this will change in the near future.

For now, medications are primarily used to help to manage challenging behaviors, like aggression, depression, and obsessive-compulsive behaviors, and can be effective in the same way that they are in the general population.

If a resident is in distress, seek out a psychiatrist who has knowledge about PWS, or at least a sincere willingness to learn. We have found that people with PWS are at increased risk of psychiatric disorders, particularly psychosis, obsessive-compulsive disorders, and mood disorders, as compared to the general population of individuals with mental retardation. Specific symptoms may vary from those without PWS, so medication protocols may also be somewhat different.

Dosing must consider weight and depressed metabolism, so physicians and psychiatrists need to familiarize themselves with Prader-Willi syndrome and the literature on medication types and amounts. While certain medications have been more or less effective for specific conditions than others, each resident is an individual and needs to be medicated accordingly. There is no PWS medication formula, and no medication known to date has eradicated any of the behavioral conditions associated with PWS.

However, some medications have enabled caretakers to more effectively redirect or channel the person away from the problem behavior. This is an area that changes rapidly and one that you need to pursue with knowledgeable medical professionals.

L. Sexuality

In general, people with PWS do not proceed through typical stages of physiological sexual development. While hormone replacement therapy (testosterone for males and estrogen for females) is available and has many positive effects, it is not yet a commonplace practice.

Sexual development in males with Prader-Willi syndrome presents a range. The testicles are present but may be underdeveloped. The penis is typically normally formed and may be normal or small in size. Pubic and axillary hair may develop early or normally, but the remainder of pubertal development is abnormal (i.e., delayed and usually incomplete). Rarely do adult males experience voice change, typical male body development and constitution, or substantial facial or body hair.

Females with PWS typically have primary amenorrhea (failure to have menstrual periods) and immature breast development. There are exceptions where girls have developed normally or even experienced early development.

Until 1999, the prevailing belief was that individuals with PWS were not capable of reproduction. Now, with three documented cases of women with PWS giving birth, we

know that assumption to be false. (No cases of males with PWS fathering a child have been documented, but according to medical experts, it is not out of the question.)

Little is known about their sexual drive and what sexual behaviors they would engage in if given the opportunity. This is true in part because there has been a long-standing assumption that because of their incomplete puberty they have neither interest nor capacity for sexual behavior. They have been viewed as children in this regard so efforts have mainly been focused on protecting them from exploitation.

It has only been in more recent years, with the development of residential programs, that we are seeing adults with PWS become overtly interested and engaged in sexual activity. In these settings, away from parental protectiveness, adults have greater opportunity to meet potential romantic/sexual partners and are not necessarily discouraged from developing emotionally and physically intimate relationships. If such a relationship does develop, the care providers are responsible for assessing whether or not the parties involved are capable of giving informed consent to engage in sexual activity with one another. They are also responsible for providing a program of sex education appropriate to the individuals' needs and level of understanding.

To my knowledge there have been no studies; however, we do know now, through direct experience, that some individuals with PWS masturbate and are sexual with others (of both genders), up to and including intercourse. Simply put, individuals with PWS, though as a group having lowered sexual drive as a result of diminished levels of sex hormones, are not asexual. There is a range of interest, drive, behavior and capacity for reproduction.

Sexual activity aside, they are socialized in much the same manner as typically developing teens and young adults and are subject to the same societal standards and messages regarding social-sexual behavior. They are exposed to media depictions of relationships, both sexual and romantic. They share the same dreams and aspirations as other young adults—to be romantic, marry, and have children

Moreover, they are equally seduced by sexually suggestive media and, because of some cognitive limitations, may not always effectively separate fantasy from reality where sexual behavior is concerned. This may account, in part, for the higher rate of sex offenses by people with mental retardation than found in the general population. It is important that you provide some guidance to them as they explore this area of their development. Make sure you are given training in sexuality and the role you can play in teaching and supporting the residents, including the policies of your specific agency.

This has been a long-standing issue in the field of developmental disabilities. Rather than assuming childlike ignorance and innocence, one response has been to provide appropriate sex education. Because of the many misconceptions and stereotypes just discussed, this approach has been less prevalent in services for people with PWS until recently.

Generally, provider agencies have a set of policies and procedures regarding the management of sexual behavior among persons in their care. This information should be made known to staff, parents and residents as deemed appropriate. Training by experts in developmental disabilities and sexuality should be provided to staff so that their comfort level in addressing issues of sexuality and sexual expression is enhanced. Families may be adamantly opposed to the possibility of any opportunity for their child to be sexually expressive and expect the agency to prevent such possibilities. This position may conflict with the established rights for people with disabilities living in residential settings.

In spite of all the likely problems that will arise in coming to grips with the sexuality of people with PWS, it must not be avoided. If it is, we will see an increase in pregnancies, sexually transmitted disease, and abuse. Start talking about this within your program. There are many terrific teaching/training resources available for staff, parents, and residents.

M. Vocational Services/Work

There are many vocational training and job options available to individuals with mental retardation and other developmental disabilities; however, few provide the degree of supervision required for the success of individuals with PWS. For me, this is one of the most difficult areas in supporting people with PWS who want and deserve to work. Following are brief descriptions of the most typical vocational placements for individuals with disabilities. They are listed in order of most to least restrictive.

Day Treatment: This is the day program equivalent of the ICF. It is funded with federal and state money and serves people with severe behavioral, medical, intellectual impairments. No job training is provided. The focus is on ADL and social skills, along with some academics and community utilization. It does provide a comprehensive clinical team to develop treatment plans as is consistent with the target population. I know many individuals with PWS in Day Treatment for the sole reason of not being accepted into other programs for behavioral reasons. Unfortunately, it offers little challenge or growth for them.

Day Activity: This is a generic title representing programs which offer a variety of daily living and social skill training programs along with some vocational training and community utilization. Such programs may have some clinical staff.

Day Habilitation: This is a Medicaid program. With the reduction in sheltered workshops, many individuals were moved into Day Habilitation, which does not provide paid work. Purportedly, it is designed to prepare people for paid work through volunteering at various community sites, such as nursing homes and recycling centers. Community utilization, such as shopping at a mall is also part of the program. Typically, there are minimal clinical staff with a low staff:client ratio.

Sheltered workshops: People with disabilities do piece work for pay under staff supervision. Typical jobs include packaging and product assembly. Training may be offered in other areas, such as maintenance and clerical work. Some workshops have a job placement component where individuals are supervised in community jobs for a part of the day. There may be some clinical staff. In addition to the reduction of these programs, they are not always open to folks with PWS because of the level of supervision required around food-seeking and other behaviors.

Enclaves: This entails a work crew with a crew chief (staff) who go into a competitive employment site, such as a factory. They usually work in close proximity to one another with supervision provided by the staff person, although some become increasingly integrated in the general worksite.

Supported employment: The individual receives assistance in locating work, using public transportation, and developing the social and technical skills needed for a community-based job. Initially, a “job coach” is provided who “fades out” as the individual becomes more independent at a particular job. The goal is for the worker to successfully maintain employment on his own.

Competitive employment: The individual is employed in the community without any particular program based services, although the individual may have had a job coach initially to help with learning the job tasks, developing work behaviors, and building supports within the workplace.

Most adults with PWS are participants in either workshops or enclaves even though they may have excellent skills in performing certain job tasks such as office work or animal care. The difficulty is removing the temptation of food from typical work environments. Reasons for job loss for individuals with PWS are related to food stealing, returning late from breaks or meal times, and argumentativeness. None of this is surprising to those of us who are familiar with PWS. The solutions involve intense training, supervision, environmental modifications, and getting the employer and co-workers to become invested in the person’s success. We need to deviate a bit from our typical expectations of individuals with disabilities and be content with part-time employment for many. It must be difficult to fight off the desire to take unauthorized food for eight or nine hours at a clip.

We need to allow the individual to ease into the workplace and develop supportive relationships before adding the stress of full employment (if ever). Most jobs involve substantial stress from getting there on time, to accepting criticism, to changing from task to task and working with different people. These are not areas of strength for people with PWS, so look for places of employment where these stressors, in addition to easy food access, can be minimized. Keep in mind that some individuals will become immediately bored with tedious, repetitive tasks; while others will be relieved and pleased to be engaged in a predictable, unchanging activity that they have mastered. All

too often, we project our needs and desires on the individuals with whom we work.

This is an area of service that lags far behind all others for individuals with PWS. It requires creativity and commitment, planning and patience, flexibility and fit. There is definitely no “one size fits all” when it comes to vocational services, and you will need to work very closely with any employer whether it’s another agency or a competitive business. Without your support, no placement will be successful.

N. Individual Challenge and Growth

Working in a residence for persons with PWS isn’t just about helping them lose weight and encouraging them to exercise. Weight loss is the easy part in a controlled environment. Helping them to maximize their skills and minimize their problem behaviors is the real challenge. The goal is to help people achieve their dreams. This can only happen in an environment that is knowledgeable and respectful of the disability, utilizes a positive approach in managing behaviors, focuses on strengthening skills and developing interests, and believes that people, even those with Prader-Willi syndrome, can grow and change.

Over the past several years, many stereotypes about the limitations of people with PWS have been challenged, and many creative ways to support them have been developed. Your primary function is to ensure their good health, but even that can be accomplished with the participation of the individuals themselves. In fact, maximum involvement in designing their own programs and services should be encouraged. In some cases, I’ve seen too much push for change and growth where the individuals are presented with opportunities, freedom, and decisions for which they are not ready. Remember, they cannot follow the same path as others with equivalent IQs but without a diagnosis of PWS. You will hear terms like person-centered planning being discussed and perhaps implemented in your state or program. Certainly, maintaining a focus on a person rather than what services may or may not be available is very important. Unfortunately, some policy makers and even practitioners are not well-versed in both Person Centered Planning and Prader-Willi syndrome and have created unfortunate situations where the residents have more power and control than they can handle and have suffered medically and behaviorally.

The pace is much slower and the limitations imposed by the syndrome may be too severe to accomplish all that we would hope. For example, we know of no one with PWS, regardless of IQ, who has lived independently and remained healthy. Our experience is that they suffer medically and, without intervention, die from complications related to obesity. Total independence need not be a goal for individuals with PWS, or anyone for that matter. Until there is a way to control the food seeking drive, we must focus instead on increased independence in day-to-day life. I guarantee you will be quite surprised with how much some individuals can handle with the proper supports. You are that support!

IV. Behavior Management Strategies

A. Environment Management

Be a detective before the crime. And chances are there will be a “crime”—in that each new situation presents the possibility of a food source for the person with PWS. This manual identifies many food sources and what you can do to avoid or eliminate them. But since no manual can provide you with an exhaustive list, I highly recommend that you put yourself in the shoes of a person with Prader-Willi syndrome.

If you start to think like they do and go through the possibilities of food sources in your head and literally walk through a new environment with that in mind—you can, through appropriate planning and safeguards, greatly reduce the probability of the individual obtaining food. Try it for a day. Imagine that you are a person with PWS from the moment you awaken to the moment you fall asleep. Keep a log of what challenges you faced in each new place you went and each person you encountered. Where, if anywhere, did you feel free from the temptation of food? When and where were you able to relax and just be? How about how people interacted with you? Was your boss bossy? Was the sales clerk helpful and friendly? Was your housemate in a grouchy mood? Did she borrow something without asking? An exercise like this will make it easier for you to recognize and appreciate the triggers to many behavior problems you will encounter. Once you can experience the world as a person with PWS, you can develop strategies for making life just a bit easier for the residents.

Environmental Management incorporates more than the physical environment. It also includes the psychological and emotional environment. Ideally, you have, or will be, provided with training on how to interact with the residents in your role as staff. Are you there as a friend, a parent, a teacher, a boss? Should you be more or less controlling in your interaction with the residents? How do they need to view you to feel safe and secure? The interpersonal dynamics involved in your job are often quite complicated, so the need for support and supervision will never end. Let me provide a few simple guidelines here.

- Be knowledgeable
- Be empathetic
- Be respectful
- Be realistic
- Be reasonable
- Be humble
- Be human

You have been hired to support a group of individuals with unique and very challenging

needs. They know it and you know it. Learn about the syndrome and how it is expressed in the individuals with whom you work.

Appreciate how difficult it must be to have PWS. Respect and acknowledge the effort that must be made to get through each day without some kind of problem.

Given the many challenges that the person with PWS faces, hold realistic expectations. No one achieves and maintains 100% of anything, yet we often hold residents of our programs to just such an impossible standard.

Focus on being reasonable, not right. You can change your position on something if the resident has presented a good argument. Why not? You will earn the respect of the residents and coworkers alike, and it makes for a more interesting working environment. No matter how long you've worked with individuals with PWS or how good you are, you will make a mistake; they will do something you didn't predict. Then you just need to take a deep breath and admit that being really good means keeping your eyes and mind open and always asking questions.

Finally, it's ok for the residents to see you as a regular human being who is good at some things and not others. You may be the one they turn to for clever craft ideas but wince when they know it's your turn to cook dinner. You can also be happy and sad and share those feelings. I've come into my program announcing that it would behoove everyone to keep the peace on a particular day because I was up all night or just spent two hours in traffic or simply woke up grouchy. (Your coworkers will appreciate it as well.) Above all else—be fair and have fun. If you play by the rules and you're having a good time, the residents are having a good time, too, and fewer problems will arise.

1. Residence

A well-designed and structured home environment makes for a peaceful environment! When food is simply not available, behavior problems associated with food (and there's a whole lot of them) are drastically reduced. Remember not to let things slip just because everyone is at their ideal weight. Prader-Willi syndrome is life-long and so is the drive for food.

A new resident moving in, a rearrangement of bedrooms or roommates, staff turnover, change in management—all of these factors create new food opportunities. State and agency policies regarding resident rights, especially those relating to access to food and money, have created huge changes in how providers design and manage the residential environment. Sadly, when policy makers and managers do not adequately understand the ramifications of PWS, policies quite appropriate for individuals with other kinds of developmental disabilities are applied with disastrous health and behavioral outcomes for the individuals with PWS.

Changes will occur in your residence, and change is not necessarily a bad thing. Just be on the lookout for how those changes can affect the safety and stability of

the individuals you support.

2. Work/Vocational

The workplace environment has an overabundance of food sources (including money and other items that can be used for trading). Here is a partial list. Share it with the vocational staff. Take a tour together of the workplace or day program. Add to the list and then see what you can do to reduce or eliminate some of the food sources you've identified.

- Lockers
 - Trash cans (especially those without lids)
 - Staff desks
 - Coat pockets
 - Purses/knapsacks
 - Staff lounge
 - Meeting rooms
 - Staff offices
 - Employee refrigerator/cupboards
 - Cafeteria
 - Drink/snack machines
 - Coffee/lunch truck
 - Leftovers on lunch tables
 - Condiment packets
 - Holiday and special occasion celebrations
 - Co-workers
 - Uninformed staff
 - Add your own
-
-
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One of the biggest concerns of vocational staff is that there are not enough staff people to monitor any one individual all day. It's true. Many workshops are quite large and provide a 1:20 ratio of staff to workers. The best solution is to have the person with PWS located in specified areas at specific times with one staff person identified as the primary supervisor. This person would also be the contact person for the residence and the other vocational program staff.

Ideally, PWS specific training would be provided at the vocational program site

with all personnel in attendance: direct service workers, supervisors, clinicians, administrators, job coaches, food staff, administrators, and anyone else who is likely to come in contact with the individual with PWS. The purpose of having everyone possible attend is so that no one person is responsible for providing supervision. In this way, if the worker with PWS strays from the area to which he is assigned, everyone notices and can notify the primary supervisor. Or if any of the staff notice that the worker has a candy bar and they've been trained to know that candy bars are not on the menu, they will know how to handle it and notify the primary supervisor.

In short, there are 20 sets of eyes on the lookout, not just one. It's the only way it can really work in a large vocational setting. And it really can work!

The primary supervisor is key in supporting the individual across settings. This is the staff person who would be most familiar with any residential issues, policies and such and would be sure to keep the residence informed of any relevant vocational concerns. Having an identified vocational person allows for communication and coordination. The person with PWS knows that there is a positive connection between work and home.

Often what is more challenging is providing oversight for the individual who works in competitive employment without a job coach. Unless there are informed and understanding supervisors and coworkers, there can be many food temptations and behavioral triggers that make it quite difficult for the worker with PWS to control the drive for food and, for many, temper outbursts. In any case, there must be close and regular communication between the workplace and the residence to ensure that any problems are identified and resolved early on. Competitive employment is an appropriate goal for many individuals with PWS, but there is still the need for a specifically designed supportive work environment.

3. Social Events

Numerous questions should be considered when you and your residents are going to participate in an outing where food is involved. Will there be enough supervision? Did you review, and perhaps write down, the food options available to the residents prior to going out, including decisions about food substitutions? Are you prepared to leave the situation if a resident becomes overwhelmed with the availability of food and can't stick to her plan? How will you handle the individual who is discovered eating something other than what was decided upon? What about the resident who goes up to a stranger and asks for food or money? How will you manage the individual who physically plops himself down in the middle of the event and refuses to budge until he gets what he wants? I know how embarrassing it is to be with an adult who is having an outburst in public, so it's important to be prepared because the residents really like to go out and don't want to "blow it", but may need your help.

Of course, not everyone enjoys the same activities, so be prepared if someone is

B. Prevention Planning

1. Plan A and Plan B

The house has planned an outing to the park next Saturday, weather permitting. It's written on the calendar, and everyone is looking forward to it. Saturday arrives with fine weather, but a staff person calls in sick and you can't find a replacement. You can't safely go out in the community with just one staff person and 8-10 people. The trip is cancelled for the day and rescheduled for the following Saturday. A resident or two become upset and start yelling, "But you said we were going if the weather was good. Everyone decided and it's written on the calendar!"

All the rational explanations in the world just will not matter, and it's not that they aren't smart enough to understand. That's not it. All they know is that you took something away that was promised, and they feel that you violated their rights. You hear cries of "That's not fair!" or "I'm going to call my mother."

It is very helpful to anticipate these reactions and to always have Plan A and Plan B set up ahead of time, preferably in writing. Explain that Plan B will be followed when Plan A cannot be. This could happen for any number of reasons, such as vehicle failure, staff shortage, weather, no money, a resident having trouble and not in shape to go out into the community, or the boss having other plans. (Never assume that your list of exceptions will cover all the bases; in fact, make it very clear that the list is for examples only.)

Specify that the staff person on duty (or manager, if available) will make the final decision about whether or not the trip will occur or if the house will do Plan B instead. Having the alternate plan and a person in authority to be the final decision-maker is really helpful to people with PWS. It keeps things clean and simple and under control. If a planned event is cancelled, immediately shift the focus to Plan B with special attention to any changes in meal or snack time. Refer to the calendar where Plan A and B are written to avoid needless discussion. If possible, write in the new date for the cancelled event.

2. Put things in writing

I don't fully understand why this works so well, but it seems to make a big difference. First, it makes whatever the information is more official. Second, it prevents a verbal argument from occurring, which only serves to make the person more upset. Third, it depersonalizes the situation. You aren't doing something hurtful to the individual; you are just abiding by the rules as they have been written. People with the syndrome tend to take most things personally. Abstract reasoning is not one of their strengths, and having information written down in understandable language keeps things concrete.

People with PWS are also quite astute at identifying the power hierarchy, so

having the decisions, rules, schedules, plans and policies signed by someone in authority gives them additional weight. Often it's wise to include mom, dad, or other caretaker's signature as well.

3. Scheduling of Activities

Sometimes the simple and obvious solutions are the best. How activities are scheduled can make a big difference in whether or not they are accomplished. The rule here is to have more preferred activities follow less preferred activities. For example, inform a resident that as soon as he's finished doing the dishes, he can watch TV. Or remind a resident that when he has finished his shower, it will be time for snack. In this way, you have created external motivation by simply changing the schedule. In fact, isn't this how most of us were raised and how we help ourselves get through the drudgery of daily life? Think about it. As a student, we tell ourselves that as soon as we get our paper written we can go out with our friends.

Or, as adults, we tell ourselves that as soon as we clean the house we can start on that art project we want to do. Ideally, we create a balance between the mundane and the interesting activities that fill our day; what has to be done gets done, and it's made less tiresome because of the pleasurable activity that follows.

C. Formal Behavior Management Programs

Before describing specific models, it is important to discuss the difference between Behavior Management and Behavior Modification. Behavior modification is based on the principle that (almost) all behavior is learned and, therefore, can be unlearned and replaced with other behaviors as a result of a systematic application of rewards or punishments. Behavior management utilizes proactive, preventive management strategies to address specific behavior concerns, particularly those which are genetically based or neurologically driven, as in the case of Prader-Willi syndrome. Most programs use a combination of both approaches, but with primary reliance on behavior management.

With very little access to internal controls, people with PWS require external supports to safely manage their health and behaviors. This is another essential difference between them and others at similar intellectual levels. They do not progress nicely through training and behavior modification programs, or integrate skills through practice and consequences. They are unable to reach the same levels of independence as their peers.

They do not "grow out" of these behaviors and drives—and cannot because they are genetically based. They can, however, as they mature and their world gets larger, recognize that there are other things that they want in their lives and, with help, learn to control some of the behaviors that get in the way.

For example, a young woman in an upstate New York PWS group home got a volunteer position in an animal shelter. She loved animals and really wanted this job. There was a staff refrigerator, and she found herself unable to resist taking other people's food from it. She wanted the position so much that she asked her boss if they could lock the fridge. Unfortunately, the boss said no, and the young woman had to leave her position.

But how terrific it was that she was able to find something so important to her that she asked for help to manage her drive for food.

Another example is a man living in a group home who's been working at a supermarket for many years without a problem. He begged and begged for the job, and finally the staff decided to give him a chance. He proved that there was something so important that he could hold it together, at least for that purpose.

He knows he will lose the job if he is found stealing and/or gains weight as a result of getting food from the store. However, his ability to manage on the job doesn't mean that if he went to a picnic he wouldn't gorge. But that's ok. Look what he is able to do with the external support.

What is important about these two stories is recognizing how the right kind of external supports enabled (or could have enabled) these individuals to maximize their internal control. Rather than spend a great deal of time and energy trying to make people develop internal control through behavior modification programs, why not provide them with adequate external support to experience some successes in their lives, which, in turn, might build some self-management skills as well.

I hear more and more "success" stories as time goes by and as we, the caretakers, better understand the needs of the individuals we work with. Each and every one of these successes is within a context of support and external controls and was arrived at over time with many baby steps along the way. I believe that if we change our focus and expectations from having the individual stop particular behaviors and become independent in the traditional sense of the word (alone, by self, without support) to developing ways of assisting them in managing their behaviors, they will have success and independence. Think of independence for persons with PWS in the same way as an individual who can't walk has independence with his wheelchair, or a person with quadriplegia has independence with the support of his personal aide.

The "failures" for people with PWS occur when there is no regard for the disability itself and unreasonable expectations are placed on the person to learn what to do and what not to do in an environment that is fraught with peril—meaning temptation is all around with no controls. We can do much better than that and, for the most part, as a growing group of professionals, we are.

The following is a review some of the most commonly adopted behavior management

strategies. It is likely that your program uses some version of one of the following, although it probably does not operate in precisely the same manner as I describe. Don't worry. There is no one universally accepted behavior management system for working with individuals with PWS.

1. Level System

There are many variations of this type of behavior management strategy, but most follow the same basic principles.

- *Individualized Expectations:* Each person has their own list of routine responsibilities and expectations. They generally encompass four areas: activities of daily living, emotional/ behavioral, work/recreation/leisure (or community), and peer/interpersonal.
- The list need not be exhaustive. In fact, if you try and address every area of need, you and the resident will be overwhelmed and the plan will be doomed to failure.
- *Points:* As the person accomplishes his/her responsibilities, a point is earned. They are totaled at the end of the day, usually just before bedtime. The sum of the points will fall into one of three levels, each having associated privileges and reinforcers/rewards. The person reviews his points and then knows what "level" he's on for the next day.
- *Levels/Rewards:* The privileges and reinforcers associated with each level provide a range in number and desirability. For example, Level 1 would carry the fewest rewards, and Level 3 would carry the most (and "best"). Ideally, the various rewards and privileges are individualized.
- *Positive:* There is no punishment inherent in the level system. Even at Level 1, routine activities are not curtailed; only privileges are withheld. Many programs do include an "automatic drop" to Level 1 if an individual is aggressive toward self or others or has attempted to elope (run away). While this is experienced as punishment by the individual, it's more of a safeguard to the program. You certainly don't want to be involving an agitated resident in community activities simply because he earned a Level 2 or 3 the day before.
- *Short-Term:* The Level system treats each 24-hour cycle as a fresh start, which is important in working with persons who are impulsive and lack internal control.

The Level system should focus on what has been accomplished rather than on what has not. Ideally, it emphasizes appropriate choices, positive consequences, and individual responsibility. Since the daily expectations are usually written (or use pictures for those who cannot read), the residents can perform their responsibilities without constant staff intervention. They may need only to be reminded of their individualized program.

Again, there are many variations to this model, and each program should investigate systems that are currently being used before deciding on one. As always, involve the

residents in the design of their program. Present it as a way to provide the person with external support to accomplish goals, not as a list of rigid rules to follow. I have seen where the latter has become the case. The Level system was used to threaten and coerce rather than support.

I have also known programs that established a set of expectations and rewards for each individual and left it unchanged year after year. It then becomes mundane and meaningless. One program I visited had been utilizing a Level system for many, many years and had not taken a good hard look at its effectiveness for quite some time. As it turned out, the residents were hoarding their points as they were earned. They just kept saving them for no particular purpose except to have them. To me, that was clear evidence that the value of whatever could be purchased with the points was not very great, and any changes in behaviors, whether good or bad, were probably not connected at all to the Level system in place. Of course, once this problem was identified, the program was faced with introducing change to a system that was well entrenched and simply part of the fabric of life in the residence. It took a while, but over time, the level system was revised with the residents' input.

I have also seen Level systems that have a negative slant where points are earned for simply not engaging in a problem behavior rather than earning points for engaging in desirable behaviors. I believe that our best chance at teaching self-management is in supporting positive behaviors rather than punishing those we find problematic.

Many behavior plans also have a cost-response component, whereby residents have points taken away for engaging or not engaging in specific target behaviors. (This is discussed in greater detail under Token Economy)

2. Contracts

Contracts are a flexible and creative means to address individual needs. For many individuals, a contract specifying a specific problem or an area to be strengthened makes more sense than a behavior program that encompasses an entire day's activities. Perhaps a resident is starting to take public transportation to get to work. A contract stipulating weight maintenance as a condition to using public transportation may be appropriate.

Or you are setting up a program to allow a resident to spend some time without supervision in a particular setting. A contract could stipulate what activities were to be accomplished during that time and the consequences for fulfilling or failing to fulfill the contract requirements. Simply, a contract can be used for any purpose. It is a written document, it's official, and it should be signed by appropriate staff, including an administrator who would serve as the final arbitrator on contract issues if needed. Like any other behavior management system, contracts should be reviewed daily and revised as needed; otherwise, they will lose their effectiveness. The resident should have periodic meetings with the contract manager to review progress and

provide feedback. Keep it simple, but make certain it's serious.

3. Token Economy

This is a form of behavior modification using positive reinforcement and consequences. Expectations are defined, and target behaviors are identified along with associated rewards and punishments on an individual basis. Examples of daily expectations might include engaging in exercise, performing household chores, using good table manners, and adhering to other group living routines.

Examples of target behaviors might include physical aggression, property destruction, stealing, or leaving a designated area. In many such programs, the individuals earn tokens at specific time intervals if they have fulfilled the expectations and did not engage in the target behavior(s). The residents may “cash in” their tokens on a daily or weekly basis (depending on how the program is set up) for items or activities that had been agreed upon initially.

Often, token economy programs include a “cost-response” component which means that if the resident does not fulfill expectations and/or engages in a target behavior, he not only cannot earn tokens, but he must “pay back” a specified amount. I'm not a big fan of the cost-response model. I see a great deal of potential for problems, such as the resident refusing to accept the loss of previously earned tokens and having a meltdown. I have also seen individuals who had so much invested in earning the tokens that they were too scared to engage in a particular activity for fear of failure and losing out on the reward. These individuals sometimes assumed an “I don't care” attitude when, indeed, they cared very much. Many providers contend that the cost response component of their program works well and has had no negative effects on the residents. I would argue that it probably varies depending on the individual and any groupwide program needs to consider individual responses to this and similar punishment based interventions.

4. Positive Behavioral Support (PBS)

In general, we develop behavior management plans for two reasons: to develop or strengthen a desired behavior, or to reduce or eliminate an undesirable behavior.

Positive behavioral support refers to changing behaviors by focusing on the positive behaviors you wish to increase, (e.g., managing anger) which then naturally reduces the likelihood of the problem behavior occurring, such as verbal outbursts. It employs environmental modifications and teaching desired skills and behaviors, along with positive consequences for exhibiting the desired behaviors.

In most residential programs I have visited where more traditional behavior management programs are used, they incorporate some version of positive support plans, along with the use of negative consequences for problem behaviors. For example, there may be a reward for talking instead of screaming about something to a staff person, but there would also be a negative consequence if the resident did

engage in screaming.

Developing a positive behavior support plan, or any kind of behavior management plan, entails a thoughtful and carefully executed process if it is to be effective. Generally, someone in the role of behavior specialist will assist in the process.

The first step is to identify target behaviors—those you wish to increase. It could be completing chores or exercising. Using the positive approach means you would teach the person how to perform the desired behavior. Too often we make assumptions about a person's skills, only to find out that some of the resistance has to do with ability. You would also identify a person's assets and strengths, so you can build on them.

For example, if a resident is good at and enjoys organizing things or putting things into some kind of order, use that to develop greater involvement in housekeeping. He could even assist you or others in specific organization tasks. If a resident is good at time and writing, perhaps part of his role in the exercise program could involve keeping track of how long people spend on different machines. Utilizing a person's strengths to expand his involvement is the simplest and most positive way to engage people. Everyone wants to be acknowledged as especially good at something, especially when living in a group situation where individual attention is often difficult to come by.

But what about those especially problematic behaviors such as verbal and physical outbursts or running away? Each case is unique and the circumstances surrounding these behaviors are person-specific, so a functional behavior assessment (or analysis) (FBA) should be conducted. Again, this would be designed and monitored by a behavior specialist. An FBA involves gathering information in a systematic way about the target behavior—what typically occurs just prior to the behavior (antecedent) and what occurs immediately following the behavior (consequences). A careful examination of this and other information, collected over a period of time, can help us understand why and how the person uses this negative behavior to get (or get out of) something. And what is the something? Is it usually a tangible item? Is it attention from a particular person? Is it to get out of doing chores? We often make assumptions, but they can be verified only through some kind of systematic collection of information. Once we understand the why's and wherefore's, we can develop a plan that incorporates teaching, modifying antecedent conditions and providing consequences that encourage more positive ways to handle life's problems and get what is desired.

While most negative behaviors can be ignored, including some degree of yelling and screaming (note that I said "some degree"), others cannot, like breaking items or hitting people. In addition to some kind of intervention, whether it involves removing other residents or intervening directly with the resident involved, there is usually some kind of negative consequences. The individual loses a privilege or, at the very

least, fails to earn something that would have been forthcoming in the absence of the behavior. Still, the focus of a positive behavioral support plan is on teaching replacement behaviors for those which, while perhaps effective for obtaining what the person wants, are not appropriate.

In my experience, behavior modification programs where the focus is on eliminating undesirable behaviors using rewards and punishments in the absence of a positive behavior support plan is largely ineffective. In addition, behavior modification plans that attempt to change those behaviors which are part of the PWS behavioral phenotype are also largely ineffective. However, that is not to say that many behaviors cannot be modified to some degree with the right supports, so it is well worth your effort to hang in there and keep trying.

5. Natural Consequences

I'm a strong believer in consequences, particularly natural consequences, and encourage you to utilize whatever typical consequences you would use for any other person who gets into the same kind of trouble. The difference is that consequences don't seem to have much, if any, lasting effect on persons with PWS with regard to food or other genetically driven behaviors. Here are some examples.

There was a young man living at home. He was quite capable and could handle emergencies, so he could be left home alone as long as food sources were locked. His folks went out for dinner one evening. Shortly after they departed, he called the locksmith to come and unlock the fridge, explaining that his parents forgot to take his meds out (untrue).

The locksmith came, unlocked the refrigerator, and left the bill for dad. (It's not unusual for parents of children with PWS to have a personal relationship with the local locksmith.) The parents came home to find the fridge totally cleaned out. There were consequences, and undoubtedly the young man knew exactly what they would be when he initiated his plan, but the availability of getting the food was too immediate and far too powerful a force.

A young woman who had been living in a community residence for a couple years awoke one night, left her home through a window, and found her way to a very unsafe part of the town. There she found a man, negotiated a fee, had sex with him, took the money and spent it on food. Upon her return to the residence, the staff questioned how she could do such a thing knowing full well all the risks involved, from STDs to abuse or even murder. The woman acknowledged those risks, but said, "I just woke up and I was very hungry." Obviously, this woman knew that if she asked the staff for food, she wouldn't get it, so she did what she felt she had to do. By the way, this is not a woman who heretofore had a history of eloping or engaging in any such behavior for food, so be warned that the unexpected can happen!

I recall a similar situation where a young man who lived in an institution for

individuals with developmental disabilities would walk out of the facility, which was located in a metropolitan area on a busy street, panhandle and then buy food. On more than one occasion, this man was accosted, beaten and raped, but he did not stop panhandling. The drive for food overrode the pain and suffering of the consequences he endured.

Aside from food, there are many other areas of life where it would seem that consequences can and should make a difference, yet some residents just don't "get it." For example, a typical young adult will learn to clean his room on Saturday because he wants to go out on Saturday night. The person with PWS will avoid cleaning his room week after week in spite of losing privileges. Why? Why aren't they learning from experience, from negative consequences? It could be a power struggle, and the person with PWS has found a way to exert some control over some aspect of his environment. Or the person simply may not be interested in the activity for that day and prefers to be home or spending time in his room.

In other words, what we may consider a negative consequence may not be to the individual involved. This is a common problem with many behavior programs I review. Consequences have been selected based on our experience or what we expect would have an impact. Then, after months of implementing the behavior plan, it is determined that the behavior can't be changed as "we've tried everything!" In this instance, I would be looking for a meaningful motivator for the individual to clean his room, or a privilege or activity that, if withdrawn, would have some impact. Consequences should be individualized and need not be negative. There are positive consequences to our behavior which, when consistently experienced, can have a long lasting effect.

Here's something we tried in a residence I developed years ago. It was our homemade natural consequence program! It may seem odd, but sometimes "natural consequences" need to be somewhat contrived. We engaged in much discussion on establishing appropriate responses to certain problem behaviors. For example, a resident is prone to verbal tirades, which are disturbing to the others in the house. What should the consequence be for that behavior? When you involve the residents in making decisions regarding appropriate consequences, you will hear some interesting ideas (most of which are far more punishing than what staff would come up with).

Certainly, the offending resident owes everyone an apology for disturbing their peace, but perhaps that's too easy and the resident should be required to "make it up" to his housemates. In the residence I am referring to, sometimes the offender was asked to do another resident's chore by way of showing remorse, or give up his turn to select the weekly DVD to a housemate he offended. When stealing or property destruction is involved, making restitution should be a given, but perhaps here, too, an additional, positive act on the part of the offender makes sense. You and the residents can be very creative (within reason) in establishing your own set of

“natural consequences.” Even “natural consequences” need to be tweaked a bit to make them effective for different people!

You may recall that I have stated rather strongly that consequences have little to no effect in changing behaviors that are associated with the syndrome. Maybe you are wondering what the benefit is of a program using natural consequences. First, there are plenty of behaviors that we can help the residents to manage. Second, it's the right thing to do. In a group living situation, it's especially important that there be a standard of behavior for all and mechanisms to maintain a peaceful environment and good relationships.

Typically, we have several people living together, each with an individual behavior plan, and when something happens that affects the household, we treat it as an individual problem when it's actually a community problem as well. Some of the problematic behaviors in residential settings are not necessarily syndrome related; they are group living related.

One rationale for using this approach is to provide an opportunity for the offender to maintain relationships with housemates, particularly those repeat offenders who are not well-liked by the others. While an approach such as this may or may not reduce problem behaviors, it does teach positive life skills with regard to relationships.

6. General Discussion about Behavior Management Programs

I have reviewed hundreds of behavior strategies and programs over the years and, as a result, have come to believe that the following principles should be applied if we are to see any success, both in staff implementation and resident change

KEEP IT SIMPLE: Use language the resident, all family members, and staff can understand. While I acknowledge that good data must be maintained in order to assess effectiveness, recording forms should be self-explanatory without complicated codes and jargon and tiny little boxes for data and percentages and all that other unnecessary stuff that looks intimidating, encourages fake data, and makes people feel stupid. The resident should be fully aware of his program and have input with a goal of self-monitoring .

KEEP IT SHORT: The more words used, the greater the likelihood of misinterpretation and confusion on everybody's part. Does anyone ever read those eight-page behavior programs besides the person who wrote it? People with PWS are quite adept at finding loopholes in sophisticated plans. Indeed, the more sophisticated (i.e., wordy) the plan, the more potential loopholes. Unlike traditional behavior modification plans, precise definitions of “undesirable behaviors” can work against you, as the individual will be quick to identify those behaviors not on the list (and use them) and let you know that they were not part of the plan.

BE POSITIVE: The real goal is to increase those behaviors that the individual needs

to get along, not just to decrease problematic behaviors; so identify existing skills, abilities, and interests and build on them. (Example: if you have someone obsessed with cutting and collecting food coupons, shape the obsession into a meaningful and useful activity for the person.) Make sure that any consequences for troublesome behaviors are appropriate to the situation, are known to the individual ahead of time, and can be administered easily (i.e., not just threats). Punitive responses to behaviors should be used judiciously, while positive responses to specific behaviors should be used in abundance.

If using a daily “report card”, chart system, or other form of communication between home/residence and work, do not add negative comments about a particular behavior or event—save that for some other means of communication with those who need to know. Otherwise, the individual will begin to destroy and/or “lose” the report card and become discouraged about participating in the program. Wouldn’t you?

BE REALISTIC: You are not going to make “it” go away...whether “it” is foodseeking, perseveration, lying, skin-picking, stubbornness, or outbursts over minor changes. So making these your primary target behaviors for elimination is likely to result in failure. You can, however, create situations that are more likely to prohibit or inhibit some of those behaviors. In their absence, you should introduce and teach alternative behaviors, problem-solving, and self-management skills. Be sure that your success criteria are achievable so that the person wins. Most important, set up “preventive” measures (environmental controls re: food and money, having alternate plans when something gets cancelled, “rehearsing” before entering new situations, and so on.). This gives everyone involved the best shot at having a good day.

ONE DAY AT A TIME: Daily reward programs give the individual a chance to start each day with a clean slate, which is important for those individuals who have frequent difficulties. Having to wait an entire week to receive a reward is too much for many individuals. If you do utilize a “savings” program of some sort where the person can earn a really “big” reward at the end of a week or month, still acknowledge an individual’s progress on a daily basis. Using only longer term rewards can “backfire” for some who may “blow it” early on in the reward cycle. Others may become increasingly anxious as the date for the big reward gets closer and “blow it” just before the promised event.

Think about what sorts of positive outcomes can happen on a daily basis. Rewards don’t always have to be big—just meaningful. Extra phone time, staying up a little bit later, a choice of snack are examples of rewards that are typically available and easy to implement. It is counterproductive to promise big rewards that can’t be consistently implemented, such as outings or special time with someone, even though these are important experiences and strong motivators for some individuals. Just make sure you have an agreed upon back-up plan should you not be able to deliver.

BE SURE IT WORKS: How and when is the data examined to determine if the target behaviors have changed for better or worse? What happens if there has been no change over time? Often, programs are just kept in place year after year with minor revisions that don't have much effect on behavior. It's not fair to the individual or you, the staff member, to be engaged in an ineffective program month after month. Ask questions about the residents' behavior programs. Find out what's working and what's not and what you can do to make the program more meaningful.

Most important, as a staff person working with an individual with PWS, don't underestimate the power of your relationship. Your time with him/her can be very meaningful, especially if you keep things positive, productive, and respectful and not a recitation of past failures. Sometimes all the rewards in the world cannot compete with one-to-one time with someone who understands and cares.

There are many behavior strategies and management models available to you. Research new approaches; but don't be convinced that any one approach is the right approach. Change your strategies over time. Don't assume everyone needs a formal behavior plan. It's also true that some persons may come into a residence with lots of needs, but adjust over time, and then no longer require a behavior plan. Stay open and recognize change as well as stagnation. Always start with environmental management and prevention planning as that may preclude the need for a more formal approach.

VI. Additional Useful Information

A. A Brief Overview of Prader-Willi Syndrome

PWS is a complex neurobehavioral genetic disorder. It affects approximately 1 in 12,000 – 15,000 newborns. It results from an abnormality on the 15th chromosome. It is seen in all races; equally in both males and females. Symptoms of PWS are present at birth and remain life long. Currently, there is no cure. Research is underway to broaden our understanding and treatment options.

Because of the advances in genetic testing, it is believed that most affected persons can be diagnosed with this disorder. There are cases where an individual can “acquire” PWS as a result of damage to the hypothalamus. This may be seen in a person who has a brain tumor or suffers injury to that area of the brain. There are also situations where people show all of the signs and characteristics of PWS but lack genetic or other clinical confirmation. No matter the cause, support needed for these individuals remains the same.

Characteristics and Stages

A syndrome is a group of signs and symptoms that collectively may indicate a particular disorder or condition. In most cases, not all person affected by a disorder have all of the symptoms and the symptoms may differ in degree and severity.

Genetics and Diagnosis in PWS

PWS results from an infant not receiving critical genes from a specific section of chromosome 15 that comes from the father. This happens for no reason. The risk of reoccurrence is extremely low. There is nothing either parent did to cause it. Genetic counseling is advised. There are three different ways this can happen. The following descriptions are very brief.

1. Paternal deletion (also referred to as Common deletion) occurs in approximately 70% of cases. It is the most common form. Part of the chromosomes inherited from the child’s father—the part containing the PWS imprinted genes—is missing or broken.

2. Maternal Uniparental Disomy (UPD) occurs in approximately 25% of cases. In this form of PWS, a child inherits both copies of chromosome 15 from the mother.

3. Imprinting mutation occurs in less than 5% of cases. In rare cases, the PWS genes on the father’s chromosome are present but do not work because the process that normally switches them “on” does not work. If a person with PWS has an imprinting mutation, genetic counseling is strongly recommended. This type of mutation may be seen in siblings and other family members.

Diagnosis is made by having a DNA Methylation (99% accurate) test or a FISH (may be negative and then the DNA test is given) test. Both tests are simple blood draws.

The Hypothalamus and Prader-Willi Syndrome

Altered Functions in Hypothalamus in Persons with PWS	Explanations and/or Manifestations of Abnormalities
<p>Altered Pituitary Gland Function</p> <ul style="list-style-type: none"> • Decreased Growth Hormone • Altered Reproductive Hormones 	<p>This accounts for short stature, poor muscle tone, low metabolism and higher risk of osteoporosis. Growth hormone also helps to regulate blood lipids—putting people with PWS at higher risk for cardiovascular disease. A person with PWS can gain weight on half the calories of another person their age. They do not have the normal amount of muscle mass, which helps people burn calories. It often takes a diet of 600-800 calories to lose weight. Many children and young adults are receiving growth hormone therapy so many of these abnormalities are being prevented or minimized.</p> <p>Very few people with PWS produce normal or even near normal levels of reproductive hormones. These young adults often start puberty but do not complete it. Women may never menstruate, and if they do, it is often irregular. Men may start to have voice changes. Beard growth may be sparse. They often have early onset of pubic and underarm hair growth. Hormone replacement therapy is often used. There have been a few—very rare cases where women with PWS have conceived and given birth to a child</p>
<p>Disruption in Appetite Control</p>	<p>The hypothalamus houses the appetite control center. Depending on the individual, the drive for food can be mild to very severe. Typically individuals must rely on external support to help them control this. Such supports must be present in all environments where food is present. The hypothalamus houses the appetite control center. Depending on the individual, the drive for food can be mild to very severe. Typically individuals must rely on external support to help them control this. Such supports must be present in all environments where food is present.</p>
<p>Abnormal Emotional Expression</p>	<p>The hypothalamus is one part of a system that helps with expression of anger and rage. Persons with PWS may have extreme fluctuations in emotions especially in the area of anger. This too, is very individualized.</p>
<p>Altered Regulation of the Autonomic Nervous System</p> <ul style="list-style-type: none"> • Temperature Regulation • Water Balance Regulation • Sleep Pattern Regulation 	<p>The hypothalamus controls our “thermostat” and other biological rhythms. Body temperature may elevate very quickly due to illness or high environmental temperatures. There are also cases where fever is absent in serious illness or infection. The hypothalamus also monitors and regulates body fluids by production of ADH (antidiuretic hormone). Researchers have documented abnormal sleep patterns in persons with PWS. This may contribute to daytime sleepiness.</p>
<p>Poor Auditory Short Term Memory</p>	<p>The hypothalamus has input into our memory process. Persons with PWS often experience difficulty with short-term memory. One of their strengths however, is their long –term memory. Once something is learned and stored in the long-term memory—it can be retrieved for years.</p>

B. Medical Terms

Adrenarche	Premature development of fine pubic hair, underarm hair, odoriferous sweat and sometimes acne
Cryptorchidism	Undescended testicles
Delayed Milestones	Delay in walking, talking, speech, etc.
Diabetes Mellitus	Most common form of diabetes (PWS usually has Type II, adult onset with obesity, non-insulin dependent; Type II diabetes can also appear in childhood)
Dysmorphic	Unusual appearing
Endocrine Glands	Pituitary/thyroid/ovaries/testes
Etiology	Study of causes of diseases or disorders
Gastroparesis	A slow emptying of the stomach which may result in achiopexybdominal distention or bloating, pain and/or vomiting may be signs of life-threatening gastric inflammation or necrosis. A general weakness of the stomach. Eating while the stomach is distended can be very dangerous
Hypogenitalism or hypogonadism	Genital organs are undersized or nonexistent
Hypoplasia	Underdevelopment or incomplete development of a tissue or organ (small hands and feet, small genitals)
Hypotonia	Poor muscle tone, muscles weak/floppy
Hyperphagia	Excessive and insatiable appetite which may lead to life-threatening weight gain
Lordosis (swayback), Kyphosis (front to back curve) and Scoliosis (lateral, or side to side curve)	Forms of spinal deformities
Malocclusion	Abnormal positioning of the teeth so that the bite is abnormal
Metabolism	Body's process of absorbing the nourishment from food and either turning it into energy or storing it
Morbid Obesity	Extreme overweight (danger of causing severe health problems and even death)
Myopia	Nearsightedness
Narrow Bifrontal Diameter	Narrow forehead
Orchiopexy	Surgical correction of cryptorchidism
Rumination	Storing food in the mouth and continuing to chew on it
Satiety	Feeling that one is "full", has had enough to eat
Secondary Sexual Characteristics	Body changes accompanying the onset of puberty, such as growth of underarm hair, changing of the voice, beard growth, breast development
Strabismus	A person cannot align both eyes simultaneously under normal conditions (crossed eyes)

Additional Terms Related to PWS

BIA	Bioelectrical impedance analysis; use of an electrical charge to measure fat in the body; considered to be less accurate than DEXA
Body Composition	Proportions of body weight made of fat, muscle, bone, etc
Bone Age	Stage of development of the bones, evaluated by comparing a hand x-ray to a series of reference x-rays for specific chronological ages; used to determine skeletal growth potential
Bone mineral density (DMD)	Thickness, strength of internal bone structure
BMI	Body mass index, a formula used to determine obesity; calculated by dividing a person's weight (in kilograms) by the square of their height (in meters)
CAT scan	Computerized axial tomography, now known as computer tomography or CT scan; a type of x-ray that films cross sections of the body to measure masses and body composition
Control group	Participants in a study who receive no treatment; used to compare results with the treated group
DEXA scan	Dual-energy x-ray absorptiometry, a low-level x-ray used to measure body composition and bone density
Endocrine	Referring to the body's system of hormones and the glands that produce and release them in the bloodstream
Elopers	A person with PWS that runs away frequently
Hypothalamus	The part of the brain that connects the nervous system and the endocrine system; the hypothalamus is connected to the pituitary gland and gives it the commands to make and release growth hormone.
Resting energy expenditure (REE)	Metabolic rate (calorie usage) during rest

C. A Medical Reference Guide for Parents and Caregivers

What Is Prader-Willi Syndrome?

A disorder of chromosome 15

Occurrence in the Population: 1:12,000 to 1:15,000 (both sexes, all races)

Major Characteristics: low muscle tone, poor growth in early infancy, small external sexual organs, excessive eating developing in early childhood which could lead to obesity if not externally controlled, learning difficulties and difficult behaviors

Major Medical Concern:

Extreme obesity and consequences relate to overeating.

Cause and Diagnosis of PWS

Prader-Willi syndrome (PWS) is caused by a loss of genes on chromosome 15 normally contributed by the father (paternal). This can occur in three ways: (1) approximately 70% of PWS cases have a deletion of part of the long arm (15q11-q13 region) of chromosome 15, thus missing these genes on the paternal side of chromosome 15; (2) approximately 25% have maternal uniparental disomy (UPD), meaning two chromosome 15s from the mother (maternal) and no paternal chromosome 15; and (3) 2-5% have an error in the “imprinting” process that makes these genes from the paternal chromosome 15 to be present but nonfunctional.

PWS is not inherited, but occurs by chance, and there is no known cause. The reoccurrence of PWS in the same family happens only in rare cases of the “imprinting” error referred to above. All children in whom PWS is suspected should have genetic testing, which is very accurate using current techniques. If diagnosis is confirmed, it is recommended that the family receive genetic counseling.

Weight and Behavior

Weight

Individuals with PWS have excessive appetite

due to failure of the brain to tell them when they are full.

Overeating and obsession with food usually begin before age 6. It is important to understand that this urge to eat is an actual physical disorder, overwhelming, difficult to control and requiring almost constant supervision.

Individuals with PWS require fewer calories due to their low muscle tone, low metabolism and inactivity. To create the proper calorie diet, seek out a registered nutritionist / dietitian who is familiar with the syndrome or willing to learn. Regular weigh-ins and a periodic diet review are needed. The best meal and snack plan is one that the family and caregiver are able to apply routinely and consistently. Weight control depends on restricting food from the individual with PWS and may require locking the kitchen and food storage areas. Daily exercise (at least 30 minutes a day) is a must for weight control and health. To date, no medication or surgeries have been found that would eliminate the need for strict dieting and supervision around food. Growth hormone treatment, because it increases muscle mass, may allow for a higher daily calorie intake and a better quality of life.

Behavior

Infants and young children with PWS are usually happy and loving, showing few behavioral problems. Most older children and adults, however, do have difficulties with behavior control, often happening when going from one activity to the next or with unanticipated changes. These behavioral problems usually begin at about the same time as the obsession with food, though not all behavioral problems are food related. Behavioral difficulties usually peak in adolescence or early adulthood. Daily routines and structure, firm rules and limits, “time out,” and positive rewards work best for behavior management.

Developmental Concerns

Physical Development

Average developmental milestones are typically delayed one or two years. Although the low muscle tone improves, problems with strength, coordination and balance may continue. Physical therapy and occupational therapy help to promote muscle development and improve coordination. Foot and/or ankle supports may be needed, Growth hormone treatment, which increases muscle mass, may improve muscle development. Exercise and sports activities should be encouraged.

Speech Development

Low muscle tone may create feeding problems and delayed speech. Speech therapy should be started in infancy to help with feeding issues and speech development. Sign language and picture communication boards help to reduce frustration and aid communication. Products to increase saliva may help with pronunciation problems. Speech development is usually delayed, and articulation problems may persist throughout life. However, speech may become an area of strength for some individuals with PWS, particularly those with UPD (both of the chromosome 15 pair from the mother).

Understanding

Individuals with PWS typically have learning problems. Areas of concern may include short attention span, inability to understand simple directions and difficulties with abstract thinking. Common strengths include long-term memory, reading ability and understanding language. Early infant stimulation is recommended; special education services and support should be started in infancy and continued through adulthood. By federal law, physical, occupational and speech therapies should be available and covered by your local school system.

Growth

Failure to thrive in infancy may require tube feeding. In order to ensure proper nutrition, infants may require special bottles or nipples (e.g., the Habermann feeder). Infants should be

closely watched to make sure they get enough to eat for proper weight gain. Growth hormone levels in individuals with PWS are typically low, causing shortness, lack of puberty and increased body fat, even in those with normal weight, The need for growth hormone therapy should be considered in all individuals with PWS.

Sexual Development

Sex hormone levels (testosterone and estrogen) are typically low. Undescended testicles in boys may require HCG, testosterone, or if needed, surgery. Early pubic hair is common, but puberty is usually late and incomplete.

Other Common Concerns

Having crossed-eyes is common and requires early intervention and possibly surgery.

Curvature of the spine (scoliosis) can occur unusually early, and may be difficult to detect without x-rays. The curvature may speed up with growth hormone therapy.

Weak bones (osteoporosis) may occur much earlier than usual and may cause fractures. Provide adequate amounts of calcium, vitamin D and weight-bearing exercises. Bone density tests are recommended.

Non-insulin dependent diabetes can occur. This is usually caused by excessive obesity and will improve with weight loss. Routine screening is recommended.

Other obesity-related problems include decreased breathing, high blood pressure, right-sided heart failure, bed sores and other skin problems.

Sleep disturbances include decreased breathing with lower blood-oxygen levels during sleep, and/or daytime sleepiness. Airway obstruction may occur with or without obesity.

Skin picking is a common characteristic. It usually occurs in response to an existing sore or itch on the face, arms, legs or rectum.

Dental problems may include soft tooth enamel, thick sticky saliva, poor teeth brushing and teeth

grinding.

Quality of Life Issues

General health is usually good, and life expectancy may be normal if weight is controlled. The constant need for food restriction and behavior management may be stressful for family members. Adolescents and adults with PWS can function well in group and supported living programs if the necessary diet control and structured environment are provided. Employment in sheltered workshops and other highly structured and supervised settings is successful for many. Residential and vocational providers must be fully informed regarding management of PWS.

Medical Alerts for Treatment of Individuals with Prader-Willi Syndrome

Negative Reactions to Medications

Individuals with PWS may have unusual reactions to standard dosages of medications. Use extreme caution in giving medications that may cause sleepiness because longer and more severe responses may occur. Water intoxication (too much body water) has occurred with the use of certain medications, as well as from drinking too much fluid.

High Pain Tolerance

Lack of typical pain signals is common and may cover up the presence of infection or injury. Someone with PWS may not complain of pain until infection is severe, and they may have a difficult time telling you where the pain is. Report any slight changes in condition or behavior to a medical professional for investigation into the cause.

Breathing Problems

Individuals with PWS may be at increased risk for possible breathing problems, such as low muscle tone, weak chest muscles and airway obstruction while sleeping. Anyone with significant snoring, regardless of age, should have a medical evaluation to look for obstructive sleep apnea.

Lack of Vomiting

Vomiting rarely occurs. Medications used to induce vomiting may not work, and repeated doses may cause poisoning. Due to the excessive eating and the possible eating of uncooked, spoiled or otherwise unhealthy food items, lack of vomiting is of particular concern. The presence of vomiting in someone with PWS may signify a life-threatening illness; therefore, if vomiting does occur, a medical professional should be contacted.

Severe Stomach Illness

Abdominal bloating, pain and vomiting may be signs of life-threatening stomach problems which are more common in individuals with PWS than in the general population. Rather than localized pain, there may be a general feeling of unwellness. If an individual with PWS has these symptoms, contact a medical professional immediately.

Body Temperature

Unexplained high or low body temperatures are common. High body temperature may occur during minor illness and in surgical procedures requiring anesthesia. Fever may be absent even with severe infection. Blood work, including a CBC (complete blood count), may be helpful in determining the severity of the illness.

Sores and Bruises

Because of the common habit of skin picking, open sores may be present and prone to skin infection. Individuals with PWS also tend to bruise easily.

Excessive Appetite

Excessive appetite and overeating may lead to lifethreatening weight gain, which can be very rapid and occur even on a low calorie diet. Individuals with PWS must be supervised at all times and in all settings where food is available. Those who have normal weight have achieved this because family and/or caregivers enforce strict control of their diet.

D. The Everything Book

Suggestions for a record keeping book where staff can keep everything they need to know — but don't' always know who to ask

Information specific to the individual

I. Resident Profiles

(Everything you wish you had known about this person during your first week or two on the job. It should be developed by staff members who know the person and family. Be positive, so that new staff start off with good feelings about the resident and focus on their assets rather than their problems. Revise as things change or at least annually).

- Personal attributes, likes, dislikes, unusual behaviors, fears, habits, rituals, routines (in and out-of-house)...
- Describe what you know “works” in terms of encouraging or discouraging certain behaviors.
- Note any behavior plans, if relevant (and where to find them)
- Note any special medical concerns or special procedures to follow regarding health related issues.
- Describe the degree of supervision the person requires for in-house activities, goals, chores, etc., as well as community activities.
- Describe the degree to which the person can be involved with food shopping, food prep, and money management.
- Note friend and family involvement/contact and any special considerations with regard to family.
- Describe any especially significant behaviors, such as eloping, and what procedures are to be followed for the particular resident.
- Absolutely anything else you can think of that would provide new staff with the most critical information necessary to work well with the resident.

II. Families

- Names, addresses, phone numbers
- When families typically call or visit
- Under what circumstances families do and do not want to be called (good news and bad news)
- How resident should be prepared for family visits (appearance, packing, other...)

III. Where to Find Things

- Gas credit card/mileage sheet
- Resident/house money
- Medicaid/other health insurance cards
- “Grab & Go Book”—Medical information on resident
- Emergency on-call lists (phone and beeper numbers)
- List of Physicians, Psychiatrist, and other health professionals used

- Pharmacy
- Incident Report forms
- Goal Books/other data records
- Behavior/Incentive plans
- Communication logs
- List of important abbreviations
- Other program/agency contact people and numbers
- Miscellaneous: lamps, flashlights, first aid kit, extra toilet paper, toiletries, etc...
- Information specific to the residence and the agency

I. Policies

Agency

- Staff phone use
- Smoking: staff and residents
- Alcohol/drugs/weapons
- Personal visitors: staff and residents
- Use of personal vehicles
- Breaks
- Other

House

- Resident phone use
- Degree of supervision required by residents
- Chore Charts
- Exercise Program
- Shower schedules
- TV schedules
- Front seat of vehicle schedules
- Staff meals
- Room searches
- Resident searches
- Physical contact between residents and residents and visitors
- Other

Documentation

- Menu substitutions
- Money: residents and house
- Residents' goals
- Record of visitors
- Meds: on-site and off-site
- Medical/Clinic visits
- Notes on activities and behaviors
- Food/supplies needed
- Time sheets
- Communication logs

- Other

What To Do If... (Routine household problems)

- Plumbing problem: Who to call, how to turn off water
- Heating problem: Who to call (gas, oil, electric)
- Electrical Problem: Who to call, master switch box
- Vehicle problem: Who to call, where vehicle manual is kept
- Other: Recall things that have happened in the past

What To Do If... (Emergency situations)

- Fire Alarm goes off: Who to call, how to assist residents, turning off alarm, resetting alarm, documentation...
- Security Alarm Goes Off/Not: Who To Call, turning off alarm, resetting alarm, documentation...
- Natural Disaster: Floods, hurricanes, tornadoes, snow emergency, etc... Who to call, evacuation procedures, emergency supplies...
- Vehicle Accident: Who to call, care of individuals involved, documentation
- Other

Using the On-Call System

- When to use the on-call system: medical, resident missing, staff not showing up...
- When not to use the on-call system: can't find the toilet paper, do I get overtime for...?

Routine Weekday and Weekend Activities

- Home: Who does what, when, with how much supervision
- Community: Who does what, when, with how much supervision

II. Directions To...

- Main Office of Agency
- Vocational programs
- Church/Synagogues
- Library
- Bank
- Pharmacy
- Food Store
- Physicians
- Dentists
- Other Clinicians/Health Professionals
- Barber Shop/Beauty Parlor
- Dry Cleaner
- Places of Recreation (Parks, YMCA, theatres, restaurants...)
- Other commonly visited places

The Primary Counselor System

The primary counselor system is one way to ensure that each resident is receiving full and individual attention. Each resident is assigned to one full-time counselor (a counselor may have more than one resident assigned to him/ her, depending on the size of the program).

Decision-Making

The primary counselor is the decision maker for the assigned resident. In other words, if Joe wants to buy a new stereo, the first person he speaks with is his primary counselor—not a manager. It is the primary counselor's responsibility to ensure that the request is reasonable and to develop a plan with the resident to implement it. In this way, you don't have staff members undermining each other's decisions unknowingly.

Documentation

Where there is data collection or record keeping, the primary counselor would be responsible for that which is related to the resident assigned to him/her. This does not mean that no one else is responsible for these tasks for the resident—but the primary counselor ensures that data and record keeping is current and accurate.

Support

The primary counselor is the major support system for the resident. The counselor routinely spends time with the resident just talking—keeping abreast of whatever might be going on for him/her. In some homes, the counselor specifically has what is termed a “five-minute talk” when the resident arrives home from his/her work or vocational program. The point is to identify any issues or problems that may be bubbling and head them off. This is especially important for individuals with PWS who obsess over many things the staff might not consider important or problematic.

Daily Living

Any adult has a full life and a busy schedule, and that is no less true for adults with PWS. The primary counselor assists the resident in managing the business of everyday living. Does the resident have adequate clothes for the season? Does his coat need to be dry cleaned? How are her personal hygiene supplies? Has he changed to a new toothbrush after six months? Have holiday shopping plans been made? Did a Mother's Day card get purchased and sent? Is the motivational system being reviewed on a daily basis? What happened at the psychiatrist appointment? Has the resident packed properly for the holiday visit with his family? The list is endless. Leaving the small details of every day life to a manager just doesn't make sense. Parents are usually quite pleased to know that someone is looking out for the very things that they concerned themselves with when their son/daughter lived with them.

Individual Attention

One of the downsides of group living is that it involves a group. Very often, plans are made and rules enforced to serve the needs of the group and not necessarily those of each individual. It's the nature of the beast and can't be helped. However, as part

of an agency's obligation to provide a high quality of care, it would seem that a critical component of that care would be time without the group, to enjoy the company and attention of (we hope) a well-liked staff person without interruption. The time may be spent in a coffee shop, a movie, or a dance recital... What's important is that it the resident can look forward to having that special time on a weekly basis.

Liaison

As the residential person who may know the resident the best, the primary counselor is often the appropriate person to represent the resident at meetings with day programs, planning meetings, family meetings, etc. They may even serve as the liaison to health care professionals and vocational providers or employers. Very often, the primary counselor is the right person for the parents to communicate with regarding day to day issues and concerns.

Summary

Finally, while the manager will always have the greatest oversight and responsibility, direct service counselors can and should be empowered to play a meaningful role in the lives of the people they serve. One way of ensuring that role is to develop and implement a primary counselor system. There are a variety of ways of designing such a system. The counselors may rotate on a pre-determined basis, or re-assignments may be made upon the request of the counselor or resident. Not every counselor works equally as effectively with every resident and there is no point in trying to pretend that they can. And, there is such a thing as plain old chemistry.

I have found the primary counselor system to be an effective training tool for inexperienced and young staff to develop their skills and abilities in the helping profession. It also makes them less dependent on management for constant direction and "permission." When a poor judgment call occurs (and they will occur), it can and should be treated as a learning experience. When direct service staff feel valued and experience their positions as that of professionals, they have increased job satisfaction and are less likely to leave their position. As a manager, giving direct service staff professional responsibilities along with the necessary supports makes management easier and accountability simpler.

E. Words to Live By

If it ain't written, it ain't so. Use a communication notebook whenever possible—it will save you lots of time and aggravation in the end. This notebook serves a couple of important functions: 1) it reduces anxiety for individuals who are obsessive in their thinking when they see that you have recorded their concern and 2) it serves as "the final arbitrator" when the individual tells you that "so-and-so said she could..." If everyone is on top of things, you will be able to verify the statement (or not) by referring to the notebook. If nothing is written regarding the issue, then you can only respond with, "I'm sorry, but there is nothing about that in the notebook, so I'm afraid that unless I

can contact so-and-so, you'll have to abide by my decision". (If so and so forgot to write in the notebook and the individual was correct, then so-and-so owes an apology.) The individual will learn very quickly to remind you and/or any other staff member to write things in the "special notebook" if it's something they really want others to know (e.g., "My mother is taking me home this weekend.").

Did you discuss that with _____ (manager/identified decision-maker on that issue)? The individual will make every effort to obtain the desired response, so it is important to identify who's in charge of what decisions and refer the individual back to that person.

When/Where/How did you get that candy bar?—Not—Did you steal/eat a candy bar? Remember—you know what happened, so why set the person up to lie? And if you happen to be wrong, then the person is entitled to a sincere apology.

I can't answer that question. You need to ask [manager/counselor/nurse/dietician...]. I'll help you write down the question (in the special notebook, if appropriate) and remind you to ask it of the right person.

You can go ahead and tell your mother about _____. I will also speak to your mom. Or, Why don't we speak with your mom together and explain what just happened.

Use open and inviting language rather than directives. Instead of "Go upstairs and clean your room ."—Try "What's on the chore chart for right now?" Instead of "Put on your walking shoes as soon as you're finished with lunch"—Try "What's on your schedule after lunch"

You have a choice: Try and preface everything possible with those words. It makes a world of difference to the individual. Helps them to save face if need be or simply feel that they have some control over the situation. Examples: "You have a choice...You can eat that cookie you took from Mary and I'll call the residence to have equivalent calories deducted from your evening meal or you can give me the cookie and have your complete dinner tonight"... "You can do your laundry or dusting chore now."... "You can take your shower now or in ten minutes"... "You can have one packet of oyster cookies or 4 saltines." Let the person know that you'll be back in a few minutes for their decision and literally move away so they have time to think about it. This makes the decision their idea, not yours. (Controlled choices about food are really helpful in teaching the individual about their food plan and food exchanges.) Don't spend time trying to engage the person in a rational discussion on the issue, as it will only escalate into an argument at which point you have lost the battle. Simply identify the problem—present the options (if any)—provide the individual with a moment to decide and follow through on whatever action is warranted. Never-ever attempt to forcibly take food away from the individual once they have it, unless you want to deal with a really major outburst and potential physical harm to either or both of you.

Yes, you have rights. You also have responsibilities as a member of this household. Would you like to go over them? (Have rules/responsibilities in writing.)

And don't forget to use the old reliable—I don't know the answer to that, so I'll have to get back to you tomorrow. [It buys you time. Just be sure to get back to the person as promised.]

Add your own standard expressions as they develop. It's not helpful to engage in a great deal of discussion over controversial issues. You will rarely reach "consensus". It is respectful, however, to direct people to the right place for answers, speak in understandable language, and to remind them of the agreed upon rules and guidelines.

F. Providers: Some Do's and Don'ts for Improving Parent/Provider Relationships

DO

- ... say positive things to the parents about their child—they've heard plenty of negatives over the years. Make routine phone calls with good news.
- ... arrange the individual's team meetings at a time and place convenient for the family and allow a realistic amount of time for meaningful discussion
- ... work with families in coordinating home visits so that you can plan house activities accordingly. Remember, a special family occasion trumps any policy on visitation.
- ... provide the family with the program's policies and procedures in writing and discuss them up front. Make sure to provide a good rationale for your policies.
- ... take the initiative to contact families about any unusual happenings involving their child. You can be sure they are going to hear about it in any case!
- ... communicate thoroughly and regularly with your supervisor about any issues you are experiencing or foreseeing with parents and families. You may need guidance in order to be proactive, not reactive
- ... ask the parents questions about their child. They possess a wealth of information and would love nothing more than to share it with those who need it most—you.
- ... be sensitive to parent concerns over restrictions regarding calling and visiting. While such policies serve an important function for the program; they can alienate some parents, especially those with children who are unable to articulate their experiences.
- ... tell the truth and take responsibility for your mistakes. (You will make a few.)
- ...work together to establish balanced and realistic expectations

DON'T

- ... be disrespectful or lose your temper with family members no matter how upset you may be. Instead, respectfully end the conversation.

... discuss internal agency or personnel issues with family members. It only serves to confuse and create ill will.

... discuss confidential matters pertaining to other program participants or discuss the family member in front of other program participants

...contradict a parent's decision in front of their family member

... believe everything an individual reports about their latest home visit...like the apple pie and quart of ice cream their mom let them eat.

...say you are going to do something and then not do it. Parents count on you to follow through.

... be afraid to ask for help...Whether it's a new approach to managing a behavior or needing a new treadmill, most parents will do whatever it takes to support their child's program

...make assumptions

Finally...

Don't expect that parents are going to understand all the complications and intricacies in managing a program for several people. That's not their job. Do recognize that most families are very grateful for your support and care of their family member, even if they don't always show it.

G. Parents: Some Do's and Don'ts for Improving Parent/Provider Relationships

DO

...say positive things to the staff—your support means more than you can imagine

...attend your child's planning meetings

...coordinate your child's home visits with the staff so they can plan house activities accordingly

... ask for the program's policies and procedures in writing and discuss any questions or concerns up front

... follow-up with staff when your child tells you about something terrible that happened to him or her at the program

... follow the communication chain—creates good faith with the staff (and doesn't preclude you from going straight to the top when you really need to)

...ask questions

...adhere to program guidelines regarding calling and visiting

...work together to establish balanced and realistic expectations

DON'T

... blame, threaten, or yell at direct service staff—bring your concerns to the

appropriate supervisor

...question a decision made by a staff person in front of your child or other program participants

...do your child's household chores for him/her

...forgo his diet plan entirely during home visits

... believe that absolutely every behavior issue that arises is a result of PWS and isn't subject to

change (after all—do we really know for sure?)

... believe everything you hear from a staff person about an incident—check it out with a supervisor who usually has the bigger and more complete picture

...give cash or credit cards directly to your child (and worse yet, neglect to tell staff about it!)

...make assumptions

FINALLY...

Don't expect that any program can provide all that you provide as a loving parent, but do acknowledge what your child gains by being in a work or residential program. There may be several trade-offs, but most are very worthwhile.

PWSA | USA and the author give permission to make copies of the "Do's and Don'ts for Improving Parent/Provider Relationships", containing more specific ideas on communication and relationship building. This may be a useful handout to give to staff and to parents of new residents.

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In Honor of Sophie Grace Coggeshall

PWSA | USA and The Friedman Foundation... ***Working
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