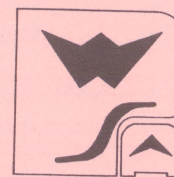


The G

athered View



January-February 1992

Volume XVII
Edition 1

National Newsletter of the Prader-Willi Syndrome Association

What is it to be "Normal"? Misconceptions about normalization.

Paraphrased from an article in the Canadian Journal on Mental Retardation, by Burt Perrin.

While the principle of normalization evolved in Scandinavia during the 1960's, in a very short time it became one of the most influential and widely quoted concepts internationally in the field of mental retardation.

The Normalization Principle as defined by Nirje: "The Normalization Principle means making available to all mentally retarded people patterns of life, and conditions for everyday living, which are as close as possible to the regular circumstances and ways of life of society". Others describe it as the acceptance of mentally handicapped persons with their handicap, offering them the same conditions that are offered to other citizens, inclusive of treatment, education, and training needed to provide for optimal development.

These definitions are fairly wide-based. What could possibly be

misconceived? Well as any parent of a PW child knows, there are many things that you tell others, which they truly do not comprehend, or misperceive what is truly needed in a situation. Here are three common misconceptions which may arise when applying "normalization" ideas to children with PW:

Misconception #1- Normalization means making your child normal, or just like everyone else.

This is probably the most common misinterpretation of the principle of normalization. It is the mistaken belief that mentally handicapped people must be expected to indeed be forced to act "normal;" to conform in all respects to society's statistical norms for all dimensions of behavior. Normalization frequently has been confused with normalcy. It does not mean people should be normalized, or forced to conform to any particular standard, such as getting married and having children.

With persons with PW, many non-parents harbor thoughts of "teaching an individual not to steal food or other items, or having negative consequences for temper tantrums." The overriding perception that individuals with PW can be just like everyone else can really prevent one from reaching the true goal of normalization, which is letting your child lead as normal a life as possible given the confines of PWS.

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Misconception #2- *Special services are inconsistent with normalization--it supports dumping people into group homes or institutions.*

The normalization principle has been falsely interpreted to mean that people should not be placed into "non-normal" situations.

The perception of a group home as being an institution with rigid regulations, or a babysitting service, or simply a place to keep them away from others. Within the principle of normalization, the ideal placement is one which provides for special needs, as well as integration with the community. The most important questions concerning living arrangements are:

"what most closely matches the lifestyle to which this individual has become accustomed?"

"Has this person been living alone or with others?"

"Has this person ever been allowed free access to food?"

"Has this person ever managed his/her own financial affairs?"

"Has this person ever made all his/her own decisions as to what their day would entail?" (Most all of us have a greater majority of our days dictated to us by others.)

These questions are major components of determining what is "normal" in all of our lives. Isn't it logical that a "normal" environment for persons with PW would include what has become "normal" in their lives?

Misconception #3- *Normalization is a humanistic concept, but idealized and impractical.*

On the contrary, one of the major benefits of normalization is that it is very practical. It provides guidelines for routines, implication for actions, and establishes the patterns for what is most acceptable. What ends up being impractical is to handle a PW person just like everyone else.

How many times have you tried to have a "normal" argument over a very logical matter? If your goal is to have a PW child be "normal," you would repeatedly continue to have such arguments, and never reach a conclusion. In the principle of normalization, you have a logical argument, and then you ask yourself what does it matter if my PW child thinks today that the sky is green instead of blue; and the argument concludes. Using the principle of normalization also, parents and providers accept that PW individuals will have at least a stubborn streak and at times temper tantrums. This is acceptable because it is what is "normal" to a person with PW.

Conclusions

Our society is very much into being "normal." Thinking about individuals with PW, the principle of normalization is so much more desirable, and makes for a much happier and fulfilled individual. Even within a normalization concept, good programs, and capable and interested care providers or volunteers, need to be supportive, courageous, and open to learning from parents and friends. A proper understanding of "normal" for individuals with PW goes a long way towards providing the best in services and in life for all involved.

You Have the Power!

Words are more than a few letters pieced together to form a concept. They are our primary source of communication.

Words can comfort or unnerve, praise or scold, encourage or belittle. They are powerful tools to be used with care and with the awareness that words make a difference. Words are most positive and fulfilling when spoken with love.

With love as a basis, words often help you bring positive change into the life of another person. When you speak with love, you give a much-needed dose of praise, encouragement, gratitude, apology, or forgiveness to an eager listener.

Our words can cut or comfort, hinder or help, harass or heal, injure or inspire. Each time we speak we deliver our own state of the heart address.

To speak with love is to plant "flower seeds" within. Negative words beget "weed seeds." Here are some phrases that are music to the ear and spirit.

*Thank you.
I love you.
Good work!
I forgive you.
Let me help you.
Congratulations!
I'm sorry.
You can do it!
We're proud of you.*

Important Words

The six most important words ...

"I admit I made a mistake."

The five most important words ...

"You did a good job."

The four most important words ...

"What is your opinion?"

The three most important words ...

"If you please."

The two most important words ...

"Thank you."

The one most important word ...

"We."

Word Choice

Words stem from the heart, are processed by the mind, and are transmitted by the lips. Although they often are a commentary on others, they also reveal a great deal about who you are as an individual.

Do your words say you are:

You're Great!



An optimist or a pessimist? A doer or procrastinator? An encourager or a discourager? Joyful or sorrowful? Content or dissatisfied? A giver or a taker?

You and I

by Elaine Popovich

(Lutheran School Services in
Midland MO.)

(An interesting perspective on
the language and terms we use.)

I am a resident. *You reside.*
I am admitted. *You move in.*
I have behavior problems.
You are rude and obnoxious.
I am noncompliant. *You just
don't like being told what to
do.*

When I ask you out for
dinner, it is an outing. *When
you go out for dinner it is a
date.*

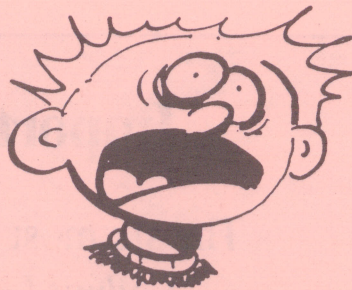
I don't know how many
people have read the
progress notes people write
about me. *You didn't speak
to your best friend for a
month after they read your
journal.*

I make mistakes during my
check writing program,
which is to help make me
independent, and maybe
someday I will have my own
account. *You forget to
record something or over-
draw your account the bank
calls to remind you.*

I am on a special diet all the
time to help my weight.
*Your doctor gave up telling
you of your need to lose
weight.*

I am learning household
skills. *You hate housework.*
I am learning constructive
leisure skills. *Your shirt
jokes about you being a
couch potato.*

My case manager and other
professionals set goals for
me for this year. *You
haven't decided what you
want out of life.*



Frustration

It's the feeling we get when plans and efforts go haywire. Many times frustrations are produced by others' interference. More often however, we do it to ourselves. Somehow it's easier to deal with when others are the root of our stress. We can point a finger and say, "it's your fault." It's the craziness we bring upon ourselves that is most difficult to bare. Self-criticism is often the first choice for venting our anger. However, positive methods exist to deal with frustration. Individuals with PW are especially prone to frustrations and should try the following beneficial stress relievers.

Talk it out - Meet with your school or group home nurse, teachers, counselors, parents, siblings, friends, clergy person or anyone with a sympathetic ear. Speak with several people to get a variety of views. Problems left to bounce around in our head often grow as we go over them again and again. Talking them out not only reduces our anxiety, but often clarifies the issue so it doesn't seem so bad after all.

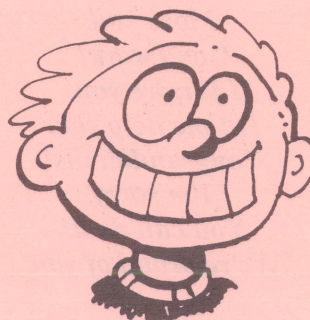
Be involved - Check the activity schedule at school or at your group home for movies, plays, or concerts. Plan to

attend and give your brain a rest from your troubles. You're not forgetting your problem, you are just regrouping so you can deal with the concern in a clear manner.

Work off your anger - If you're mad at the world, try some strenuous activity to wear it out of you. Volunteer to help clean the garage or group home. Swim some extra laps or work extra hard in your exercise sessions. Group sports, like kick ball, are an excellent way to distract yourself from your frustrations.

Write it away - Try writing a letter expressing your every feeling to the person or thing that annoys you. BUT - don't mail it. Reread it the next day and file or throw it away. Spill your emotions on the paper and don't dwell on them.

Do something for others - Take the focus off of yourself. Help a friend who is struggling with a project. Write a letter to your grandparents, parents, or a long distance friend. Create several Valentines for those who may not receive any. Remember to thank the special people in your life.



Overweight vs. Obesity

What is the difference between a PW child being overweight or being obese? And does this matter in their lives?

Someone with dense musculature may be overweight--that is, exceed the "desirable weight" on a weight chart--and yet not be fat (an athlete, for example). It is also possible for an individual with PWS to exceed what is considered "desirable weight" on a weight chart, due to the uniqueness of the functions of their body; functions which are as yet not fully understood. In the PW population, if weight exceeds 15-25% of the desirable weight, an individual is considered slightly overweight. If the weight is in excess of 25% of the desirable weight, this would be considered obese.

What does actually being obese mean? All the fat that causes either excess weight or obesity (stored fat which is more correctly called triglyceride) is located in a special tissue called adipose tissue. This type of tissue is present in everyone's body. In a normal adult male weighing 150 pounds, as much as 20 pounds of that weight is adipose tissue. In an obese individual, there would be roughly 40 pounds of fat.

Why is the extra fat tissue in an obese individual bad? In most individuals, fat tissue lies just beneath the skin; the remainder is in the deeper depots found in the abdomen, and surrounding the vital organs of the body,

such as the kidneys, heart, and lungs. Thus the extra pounds of fat directly affect the functioning of the vital organs in the body. You can think of it in terms of trying to breathe with a twenty pound weight on your chest, or remember how your heart pounds after carrying a heavy object for some time. In the PW population, it is proven that the effects on the vital organs begin more quickly than they do in the general population. Young adults with PWS have been known to have heart attacks, and develop diabetes.

If the weight is in excess of 25% of the desirable weight, this would be considered obese.

This is not to say that individuals with PW are healthiest if they stay within a "desirable weight range".

Nutritionists who have worked with the syndrome agree upon a formula of 8-11 Kcal per cm of height to maintain ideal growth and weight. To explain this formula in more practical terms, one inch equals 2.5cm, or 30cm roughly equals one foot. If your child is 36 inches tall, an ideal caloric intake would be between 720 and 990 calories. Maintaining this dietary intake would keep your child within a healthy and happy weight. If you have further questions, contact PWSA for possible names of nutritionists.

Do you know your fats? Fats occur in animals and vegetables, but cholesterol is found only in animal products. Vegetable products can be labeled cholesterol-free, even if they are 100% fat, such as vegetable oils.

Animal fats are mostly saturated, in both meats and dairy products. Vegetable oils vary from mostly unsaturated (olive, canola, and others) to mostly saturated (palm and coconut).

Although your level of blood cholesterol can be increased by cholesterol in the diet, saturated fats have a larger influence. This is because your body can make cholesterol from saturated fats. Some scientists estimate that two-thirds of your blood cholesterol can come from saturated fats.

Fats and oils can be hydrogenated (processed) to reduce their tendency to turn rancid (stale) so they keep longer. This also makes them more saturated. Not more than ten percent of daily calories should come from saturated fat.

It is so encouraging to know so much these days about nutrition and weight management. Less than ten years ago, doctors were convinced that no one with PWS would live beyond their early thirties. Today we know despite the struggles, individuals with PWS are productive members of our society living far beyond their 30's.

President's Message

by Janalee Tomaseski-Heinemann

Parent Power was a term I heard several years ago. At that time I thought it was a little trite, but over the years I have begun to appreciate the significance of that phrase. Like the bricks used in building a house, no brick in itself can be good enough or big enough to make the entire house, but bonded together they can build castles. The same is true of a parent trying to deal with Prader-Willi syndrome. Try to imagine if there had never been a meeting or group for Prader-Willi parents. There would still be the same amount of parents, but how many people would be educated about the syndrome? Also, how many group homes would there be in existence? Would we have brochures, films, camps, or conferences? If not parents, who else would come forward and exert the time, energy, and money it takes to make these things happen? Would we know how to lock up food, and would we know that the behavior problems specific to Prader-Willi syndrome are not our fault? I doubt it. How many professionals would get a true understanding of the syndrome if they only talked to an individual family? How many parents alone would be able to convince legislators, community boards, etc. that building a Prader-Willi group home should be a number one priority? From a personal perspective, ten years ago when we were just a few parents meeting in our home, no one would have convinced Al

and myself that today we would be working on our third group home! At that time we didn't even have the foresight to know what we needed, we just knew we weren't dealing with the syndrome very well alone. We wanted to know if anyone else's kid stole boxes of cereal, or had frequent temper tantrums. Gradually as our group grew, we went from sharing problems to wanting to find solutions. Perhaps it's good that we didn't have a crystal ball to see exactly what we needed to do, because it may have been a bit overwhelming. For example, when we first began with the concept of a group home, it seemed to take forever to figure out where to start. We finally thought of it like climbing a mountain. If you look too far up the mountain, you lose perspective. But if you never look up you'll never know the height to which you can reach. It's a matter of taking one step (or piece of a project) at a time, with each person bringing their own set of skills to the group.

Bravery is also something that is born out of parent power. There are many things that a person will do as part of a group that they wouldn't have been brave enough to do alone. For us, our greatest triumph was taking a bus load of parents and friends to "storm" the capitol in Jefferson, MO. On the entire bus, only one of us had been to the capitol before--and that was in the eighth grade! Many went to great efforts to be there--taking time off from work, traveling great distances, making child care arrangements, etc. If nothing else,

the capitol was educated on the syndrome. We did 300 mailings that day, plus our group handed out brochures and talked to everyone they met, including people on the elevators. Doors opened that we didn't expect to open and legislators not only listened to us, but ultimately supported our cause. We ended up being the only new program approved in the budget for the Department of Mental Health! This wasn't because we hired a lobbyist or because some generous outside professional decided to take on our cause. It's because each person in our group did their part.

As we enter a new year, we are greatly encouraged by the many news articles regarding the progress in the field of genetics. In the next few years, we hope to be directing our "parent power" in many new directions. If the problems of compulsive eating and behavior were eliminated, the remaining areas of concern would be greatly reduced. In the next few years, we hope to have new and exciting directions to focus our "parent power!"

As a social worker, after years of leading and being part of many groups, I never cease to be amazed at the flow of ideas that the group process brings out, and how scattered threads of thought can be woven into a constructive, insightful plan. As parents we often feel we are in powerless situations in our own homes, but as a chapter or a member of PWSA, we can help each other find the strength and the pathway to climb the mountains we face for a better future.

SPECIAL THANKS TO OUR SUPPORTERS

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Thank you!

As a conclusion to the year 1991, we particularly want to thank those members who continue to remember PWSA through the various funds, and the additional dues paid through Contributing and Patron dues. Naming the organization as recipient for Memorial funds is also very helpful to our growth and Research Fund.

To honor two families that have contributed immensely to this organization, your Board of Directors have changed the names of two of our major funds. The Research Fund will henceforth be the Deterling Research Fund and the Crisis(CIT) Fund will be the Wett Crisis Fund. Donations may be directed to these funds at any time. At the present time we are conducting our Annual Fund Raiser, Be An Angel. As you can see we are nearing the \$20,000 mark on this fund raiser, which is terrific, but additional funds are required in order to maintain the operating of PWSA. We hope contributions to this fund will continue. In 1989 this fund raised a much needed \$31,000. Last year the total went down to \$28,000, which is going in the wrong direction. We hope our membership will come through and top that 1989 total of \$31,000.

Extended Office Hours

Help us to Help others.

The Gathered View often asks for your suggestions and experiences in managing the individual with PWS. We record your tried methods and offer them to other parents and professionals who need fresh effective techniques to incorporate into their daily schedule. We need your input each month to continue our network of communications between members and others who are truly desperate for new ways to deal with old problems.

To accomodate those who are unable to take work time to talk with us and to encourage your important questions, funny stories, or unique behavior management techniques, we will have new hours on a trial basis.

For February and March, PWSA will be open on Tuesdays and Thursdays until 6:00 PM Pacific, 7:00 PM Mountain, 8:00 PM Central, and 9:00 PM Eastern.

The last few issues of the Gathered View have posed questions such as the following:

Toilet Training Methods

Acting as a trustee for a person with PWS

Successful Vocational Placements

Exercise Plans

School Experiences

Medical Problems or Successes

Please call or write, your suggestions do make a difference!

An Easy Way for All to Donate !!

In the next couple of months everyone will receive a mailing from MBNA. This company will be offering Mastercard to our members. For each member who opens an account with them, a royalty will be given to PWSA. Also their cards will have the Association's name and logo.

The deal gets better- each time you use your card a 15 cent royalty is also paid to PWSA.

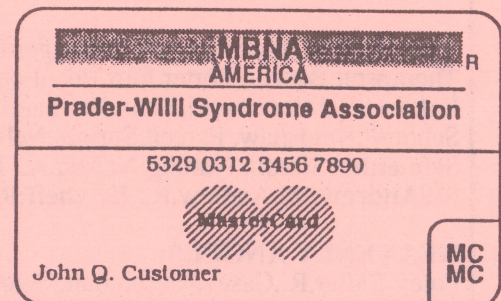
So donating to PWSA can be as easy as using your charge card!!

So to help PWSA make bread, here is the recipe:

1 cup of overflowing desire
1 application
1 pen

Use the cup of desire and the pen to fill in the application and get a MBNA Mastercard.

Continually use your new card and watch the PWSA funds rise.



Your Wett Crisis Funds at Work

I want to extend my deep gratitude and appreciation to PWSA for making it possible to take care of my son with PWS without so many worries.

My three sons and I were getting evicted from our apartment because of the trouble Tony (with Prader-Willi) was causing. The police came to my door every day because Tony was sneaking food from individuals' cars, all night stores, golf courses, etc. Due to the apartment being rental property, I was not allowed to install locks on the refrigerator or the outside doors. I tried everything from sleeping in front of the doorway to setting "booby traps." I honestly hadn't enjoyed a decent nights sleep in two years. Everytime I would hear a car start up, I would jump out of bed. I finally got evicted, so I decided to move to the country where there are no stores or neighbors.

The Association was supportive in a crisis situation and helped me to move and purchase my own refrigerator and locks. For the three months in our new home, it's been great. I rented a house

on 200 acres and locked everything up. There are no stores and no neighbors.

I set up a trampoline and bought some dogs for the boys. Tony adjusted well to the change in homes and schools. He even thanked me for putting locks on the refrigerator and cupboard.

The problem I see with Tony is not only eating, but behavior. I put the phone away at night so he cannot call 911. I also turn off the gas to the stove and now I sleep great. My next step is to fix up his room real nice so he can be occupied in the mornings. He loves to read and listen to his tapes and records.

We all have to find ways to help our children and this was mine. It has taken me time to adjust to the country as I was born and raised in the city, but it is worth it. I also hope I can try and better my life. Again, thank you very much. If I can help anyone, with respite for example, I would be willing to help.

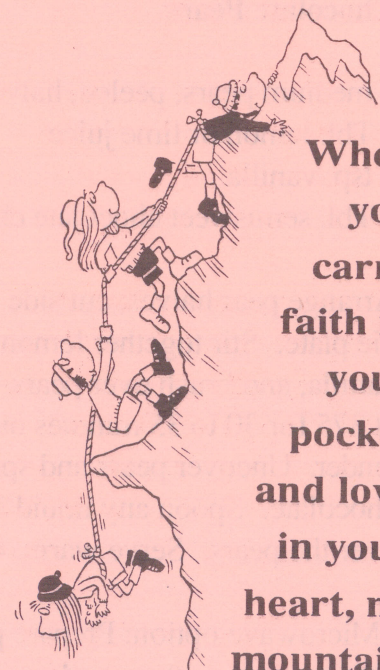
Thank you,
Laura Johnson

WI Parent Group to be the next chapter?

Wisconsin is not yet represented by a chapter, but you can change that. A meeting to address becoming a chapter is scheduled for Saturday, January 25, at 12:30 p.m. at the Physicians Plus McFarland, 5020 Farwell, McFarland, Wisconsin.

A support meeting will follow the chapter discussion. For more information contact:

Barb Dorn
5403 North Pass
McFarland, WI 53558
608/838-9535.



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you
carry
faith in
your
pocket
and love
in your
heart, no
mountain
is too tall**

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Coffee Ice

(44 Cal.)

1/4 c. sugar
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1/2 c. boiling water
1 c. cold water
strawberries (optional)

In a small bowl combine sugar and coffee. Add boiling water; stir until dissolved. Add cold water. Pour mixture into a 9x5x3 loaf pan. Freeze about 2 hours or until firm. Break frozen mixture into small chunks; place in a small chilled mixer bowl. Beat with an electric mixer on low speed till fluffy. Freeze mixture for 2 hours or till firm. To serve scrape or scoop ice into small dessert dishes. If desired, garnish each serving with a strawberry. Makes 5 1/2 c. servings. (It's possible that some of the new sugar substitutes, which can be cooked, may be used.)

Chocolate Pears

(76 Cal.)

2 medium pears, peeled, halved, and cored
1 Tbl. lemon or lime juice
1 tsp. vanilla
2 Tbl. semisweet chocolate chips

Arrange pear halves, cut side up, in a 9 inch pie plate. Stir together lemon juice and vanilla, and brush over pears. Baked covered at 375 for 30 to 35 minutes or until pears are tender. Uncover pears and sprinkle with chocolate. Spoon any liquid in the pie plate over the pears. Serve warm. 4 servings.

*Microwave option: Prepare pears same as above, cover with waxed paper. Cook High 4 to 6 minutes or until pears are tender.

Country Oat Crackers

(17 Cal.)

1 1/2 c. quick cooking rolled oats
3/4 c. whole wheat flour
1 Tbl br. sugar
1/3 c. margerine
1/3 c. water
2 Tbl. sesame seeds

In a food processor or blender, blend oats till powdery. Transfer to medium bowl. Stir in w. wheat flour and br. sugar. Cut in margerine till pieces are the size of sm. peas. Sprinkle 1 Tbl. of water over part of the mix; gently toss with a fork. Push to side of bowl. Repeat till mix is moistened. Form into a ball. Divide in half. Between 2 sheets of waxed paper, roll out 1/2 of mix, about 1/8th inch thick. Remove top sheet of waxed paper and invert onto greased cookie sheet. Use a fluted pastry wheel or knife to cut pastry into 1 1/2 squares. Using a pastry brush, brush with water and sprinkle with sesame seeds. Bake at 325 for 15 to 20 min. until golden brown. Repeat for second half of dough. Makes 84 crackers.

Strawberry-Yogurt Pudding

(79 Cal.)

1 4-serving size package reduced calorie instant vanilla or chocolate pudding mix
1 c. skim milk
2 8oz. plain low fat yogurt
2 c. sliced strawberries

In a medium mixing bowl mix pudding mix and milk with electric mixer or rotary beater till smooth. Gently stir in yogurt and strawberries. Divide among 8 airtight containers. Chill overnight. Makes 8 servings.

1991 Conference Tapes Available

A condensed set of four 90 minute tapes from the 1991 conference in Chicago can be purchased for \$10.00. Each of these four tapes can be purchased individually for \$3.

In addition, a complete two tape set of the session, **Psychological Aspects of PWS**, is available for \$5. A description of each follows:

Opening Sessions: Marge Wett and Gene Deterling provide an overview of the past, present, and future of PWSA.

Government Benefits & Estate Planning: Theresa Varnet presents a practical guide on how to receive government funds for services. Included are qualifications needed for obtaining SSI and Medicare as well as estate planning options.

Laughter after Tears: The Heinemanns, Altermans, O'Learys, and audience members share humorous stories about their experiences with PWS. A very warm, uplifting, and funny session.

Medical Aspects: Suzanne Cassidy, MD describes the basic traits and behaviors of individuals with PWS. A brief discussion on growth hormones is included.

Speech & Language: Deborah Downey, MA, CCCSLP delivers an excellent presentation on the development of the PWS child's communication skills. She also demonstrates tested methods to encourage speech.

Services: Mildred Lacy, Sarah Abell, and Mary Regester explore many service agencies that provide aid throughout the life of the individual with PWS. An overview of the political steps necessary to develop a group home is included.

Employment: Anna Marie Saporito, Mike Brown, and Tere Schaefer describe possible job options for persons with PWS. Results of an employment survey are presented along with tips for successful placement.

Psychological Aspect of PWS: Barbara Whitman, PhD, Louise Greenswag, RN, PhD, Andree Walczak, MD, Bea Maier, PhD, and Jeanne Hanchett, MD offer management techniques that work with the individual with PWS. Their suggestions include giving truthful responses to PWS' questions and the importance of shifting caregivers' frameworks to preventive action.

Please send me the 1991 conference tapes. I have marked my choices below.

Name & address:
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Total enclosed \$ _____

___ Opening Sessions/
Government Benefits
& Estate Planning

___ Conclusion Govt Ben
& Estate Planning/
Laughter after Tears

___ Medical Aspects/
Speech and Language

___ Services/Employment
(Above four double-sided
tapes are \$10 or \$3 each)

___ Psychological Aspects
of PWS
(This two-tape session is
available for \$5)

New Year's Resolution:

Buy PWSA Calendars for family and friends.

Nearly every month of the calendar features pictures of children with PW along with practical tips for managing the unique characteristics of PWS.

Individuals that work with your PW child: teachers, social workers, doctors, group home directors, etc., will benefit from the overview of the many issues associated with PWS.

Please send me _____ (Qty)
1992 calendars at \$5 each.

My name & address follow: (please print)

I have enclosed \$ _____

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