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Fall 2014

The Holidays Will Soon Be Upon Us!

The fall/winter holiday season presents many interesting contrasts, joyful celebrations with delicious indulgences versus healthy eating and dodging temptations everywhere. In a typical household, for example, Halloween brings excitement about costume selection, parties and trick-or-treating. In a PWS household, we go into immediate "investigative" mode. What food and snacks will be served? Will there be unfettered access to treats? What is the agenda for the activities so we can discuss and review ahead of time? Will there be adequate supervision? Repeat for Thanksgiving and Christmas. In our particular house, this becomes our natural routine, we are on autopilot during the holidays to ensure we can anticipate and predict what could possibly happen and plan for a safe and enjoyable event. Our children living with PWS are all different and we as parents and caregivers do what is best and what works!! If you have stories or ideas to share during this season, we would love to hear them! We wish you a happy and healthy upcoming holiday season!

-Edie Bogaczyk, Co-President, PWSA of Iowa

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On the Move Event Celebrated Prader-Willi Syndrome Awareness Month

Prairie View Management, Inc. in conjunction with the Prader-Willi Syndrome Association of Iowa hosted a community open house in Fayette, Iowa on May 3rd, 2014 to celebrate Prader-Willi Awareness Month.

The festivities kicked off at 2:00pm with the "On the Move" Buddy Walk. An enthusiastic and energetic group started the walk at the Fayette Sports Complex, which took them through a park trail walking along side a beautiful horse ranch. Afterwards the "On The Move" activities continued at the Fayette Community Church.

An educational outreach resource fair was held, followed by a catered luncheon, socializing, crafts, dancing and karaoke to round out the evening.

Leading the "On the Move" Buddy Walk is Edie Bogaczyk (front, right), President of Iowa Chapter of the Prader-Willi Association.

Printed Union, May 14, Jerry Wadian photo

It's Homecoming Season...

Edie Bogaczyk

Homecoming is typically an exciting time for most students, for some (including parents) a bit overwhelming! Keeping track of all the events both during and after school leading up to the day of the big game is a feat in and of itself. From a parent perspective, I have to be three steps ahead, soliciting all of the specific details, whether food is involved, supervision, details for theme days, etc...but I truly love the energy this week brings throughout the community!! Hands down, Zachary's favorite activity is the school dance right before the varsity homecoming football game. Thankfully he does not mind having his mom volunteer at the pizza stand! I can be there when he turns his ticket in for snacks to secretly monitor what he eats; and still be far enough away to allow him independence on the other side of the room to dance with his friends. This is his last year in middle school so I am not sure if he will feel the same way about wanting a parent around at future homecoming high school activities! I recognize there will be other options like a respite worker or a Best Buddy, for now, I will enjoy this year's events in case I am replaced!!

Zachary wanted to give a special shout out to his friend and Challenger League soccer teammate Joel Kafer who was just named Homecoming King at Johnston High School on September 26th! We heard the student body in the stands went wild when Joel's name was called. What an incredible moment for this young man, his parents, and for everyone at the football stadium! Keep smiling Joel, keep smiling!!

Competing at the State Special Olympics

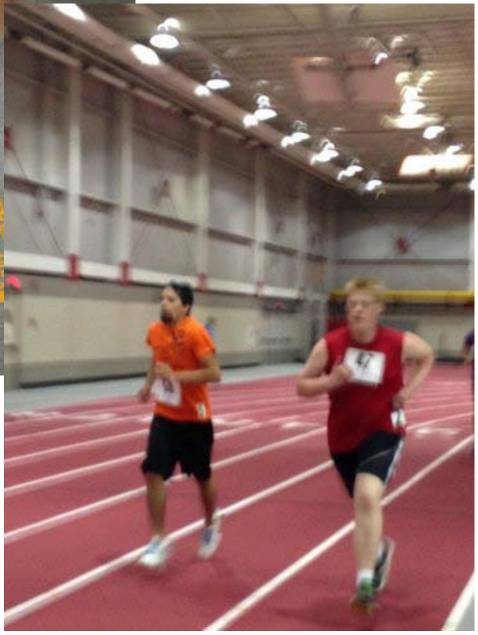
Tammy Davis

In May Eric Davis competed in Special Olympic State Track & Field competition. This was his seventh year competing. He competed in the 100 meter dash and won a first place (Gold) medal with a time of 16.9 seconds. He also took home a second place (Silver) medal in the 1500 meter run with a time of 7 minutes 22 seconds. This was his sixth year competing in the 1500 meter but his first time competing as an adult athlete.

Eric is an avid runner and runs two miles three to four times a week; he also enjoys spin class and Pilates at his local YMCA. Eric will be competing in district bowling this year to try to win a spot at the state competition.

Eric with his silver and gold medal

Eric and Tammy Davis



Running for the win!

No More Secrets

Lisa Peters writes about family life at www.onalifelessperfect.blogspot.com.

I guess you could say, it is the dirty little secrets we hide behind closed doors that make us all human. We believe that if we hide our perceived imperfections and create a more perfect version of ourselves, we will be accepted by others. We can protect our fragile hearts from the excruciating pain of judgment, humiliation and societal scorn.

But when you are the parent of a child diagnosed with special needs you have no more secrets.

You cannot hide your child's differences.

Walkers, wheelchairs, and behavioral outbursts serve as disability trip wires alerting the world to our unwelcomed presence. We are exposed and vulnerable, helpless victims held hostage by the unwanted stares, comments and criticism of an ignorant public.

When you are here to teach the world, you lose the power to be inconspicuous.

You no longer blend.

You become the spotlight.

How you choose to use that spotlight is entirely up to you.

Most days you diffuse the comments and stares with hardened tolerance and polite unresponsiveness.

Then there are those other days, when you meet it with anger,

sadness,

humiliation,

even retaliation.

But whatever emotion you chose...

You lose the ability to protect your heart.`

I was reminded of this last week, at Nick's 6th grade graduation ceremony.

Pete and I arrive early to the school and enter the empty auditorium. We survey the rows of empty seats and chose two chairs next to the aisle way. As parents of a child diagnosed with Prader Willi Syndrome, we know a behavioral meltdown during this kind of event is highly probable. We need easy access to an open exit.

Large public events are difficult for Nicholas. His sensory sensitive body is quickly overwhelmed by loud noises and bright lights. He is unable to connect with someone speaking from across the room. He loses focus and the ability to sit still. But perhaps his greatest challenge is the heightened anxiety issues that accompany his repetitive thoughts about his inability to access food.

Pete and I are nervous, we know we are pushing it. But denial is a powerful drug for desperate parents.

Children and teachers begin to file slowly into the room.

Two of Nick's teachers spot us in the crowd. Sensing our nervousness they part from the group and approach us to calmly explain the plan for handing Nick his diploma. Their small act of kindness soothes our fear momentarily and we are comforted. But their noble effort to shield us from pain is quickly

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shattered as Nicholas enters the room.

"I WANT TO SIT WITH MOM AND DAD!" he screams and every head in the room turns to look at Nicholas.

His sped teacher, Mrs. T is holding his hand and although he is wearing his headphones to deaden the sound of a noisy room, he is already overwhelmed.

In an effort to soothe Nicholas, she walks him over to where we are sitting and asks him if he would like to sit with us. It is a brilliant idea since sometimes simple changes to the routine is all that is needed to prevent such a dramatic response.

It works. Nicholas is quieted and takes a seat next to me.

The room is filled to capacity as the ceremony begins. Several speakers take the stage and begin to call the names of students who have earned special award. I laugh to myself, knowing my child will not be one of them.

The list of names seems endless. Nicholas is hot and sweating and it isn't long before the loud applause and droning sound of nervous speakers begin to erode his patience.

"I CAN'T TAKE THIS ANYMORE!" he screeches.

The woman at the podium stops speaking. All eyes turn to us. My checks start to burn. It is as if our bodies are being targeted by a deadly, red laser beam emanating from the focused and scornful eyes of a room full of angry parents.

It is quiet as everyone waits to see what we will do.

Pete and I lead the crying Nicholas slowly toward the exit.

I feel a hot wave of resentment coming from the parents around me, angry that we have ruined their need of a perfect ceremony. I focus my eyes on the floor knowing that I do not have the strength to control the rage I feel inside toward their overwhelming ignorance.

"NOOOOOOOOOOO. DON'T DO THIS TO ME," Nick screams.

Inside, my heart is saddened as I realize I have asked too much of my son. Selfishly, I have placed him in an environment he is not ready to handle. My need for normalcy and perfection has superseded his ability to endure such a show.

I pay for my selfishness.

Mrs. T leads us out of the auditorium, down the hallway and into the quiet confines of the motor room. Hanging from the ceiling is a large swing used to create proprioceptive input for the students who need it. It is the perfect instrument for calming Nick's outburst.

Pete places Nicholas on the swing and I begin to sing to him quietly.

"Row, row, row your boat, gently down the stream........."

Mrs. T heads up to the classroom and brings down his friend Alex who always manages to make Nick smile. Within a few minutes, Nicholas is quiet and comforted.

We head up to his classroom. Mrs. T sends a text to Nick's teacher Mr. P and asks if he could come to the classroom after the ceremony to present Nick his certificate.

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It isn't long before the kind Mr. P arrives with a group of Nick's "typical" friends. They encircle his chair to officially present him with his diploma and a copy of his yearbook.

Nicholas smiles brightly. He feels happy connecting with this small group of special people. It is a quiet and intimate ceremony. Nicholas is surrounded by all of the people he loves most in the world creating a beautiful moment that is profoundly more meaningful to all of us.

As we drive home from this eventful day, my husband and I reflect on the chaotic experience and begin to laugh.

"You know Lis," Pete says. "There was a moment during the ceremony when Nick was screaming bloody murder and all the parents were shooting us dirty looks. But there was one guy standing near the back by the door. He looked me in the eye as I passed by and smiled at me kindly. That simple gesture comforted me and let me know that there was at least one person in the room who felt compassion for us and appreciated our difficult life."

I do not know the identity of the kind man in the back.

I probably never will.

But I will tell you this.... he helped me to realize that as parents of a child diagnosed with Prader Willi Syndrome, our "secrets" may be exposed to the world. But what is less obvious, and perhaps more important is Nick's unique ability to remove the masks of those who choose to judge him. He is like a mirror, reflecting the energy of the individuals who stare at him. He strips these people of their personal secrets and shows me exactly where they reside on their own spiritual journey.

Most observers who gawk or comment are scared, fearful, frozen or obnoxiously curious, displaying the character and actions of a childlike spirit.

But sometimes....just sometimes we are fortunate enough to find the hidden few who are truly enlightened. Angel-like souls who travel among us here on earth. Faithful, strong spirits unafraid to show compassion or stand beside us on our journey to learn new ways of assisting our special child.

Once again, it is my beautiful son who teaches me that it is we who are disabled, crippled by our need to keep our secrets. We repress our burning desire to embrace our imperfection and celebrate the true essence of what makes us worthy and unique.

and in the process become less human and able to love.

It is our secrets that prevent us from living.

I am tired of being afraid to live.

I am ready to embrace Nick's humanness and desire for no more secrets.

PWS Funds, Awareness Big Winners at Events

By Steve Peterson, Akron Hometowner,
Originally printed June 18 in the Akron Hometowner

A new champion was crowned on the softball diamond and the real winner from the Kramer Co-Ed Slow-pitch Softball Tournament and Auction, and golf outing were those families in Iowa who cope with Prader-Willi Syndrome (PWS), daily. The condition affects Hawarden resident Anneke Kramer, daughter of Stacy and Ryan Kramer.

This year, Iowa PWS Association President Edie Bogaczyk of Clive attended the event. Her son Zach, now 13, was diagnosed with PWS at age one when the family was living in Michigan.

"I attended a scientific conference in Baton Rouge, LA, and they're making progress slowly but surely. There is no cure but we're working hard for everyone who has to cope with PWS so that they can have the best possible quality of life," said Bogaczyk, adding that there are different stages of PWS.

The key is for those with PWS to have active, low calorie lives, said Bogaczyk. For Zachary, the active part is not hard as he is in swimming in Special Olympics, just winning a Gold Medal at the Iowa Games, and also has met PWS researcher Dr. Rob Nicholls, who has completed a 3000-mile coast-to-coast bike ride to raise funds and increase awareness of PWS and obesity research.

At the midway point of the eight-team softball tournament, Stacy thanked all for their support over the years. Anneke will be a second grader this fall at West Sioux Elementary School in Hawarden.

"Anneke would like to say that she is 'almost eight.' You are our eyes and ears in the community and help us," said Stacy.

"This year, all of the funds raised will go to Iowa families who have a child with PWS," said Stacy, who added she has learned of at least one more person who was diagnosed.

As for the softball tournament, the day belonged to the Engleman Team, named Red Solo Cup. They

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ended with a 4-0 record, including dethroning defending champion Millage People, 8-6, a squad that was going for its fourth straight championship.

After downing Anneke's Jewels squad handily, "Red Solo Cup" then beat Randy Renken's team, 16-1, as a storm was rolling in, for the title. The squad consists of West Sioux alumni and current staff. Baseball coach for the Falcons, Brian Engleman, was the winning pitcher in the title game; Chase Vander Feen supplied the home run power; Adam McVay, Erin Schroeder, Hannah Vander Feen, Sam Engleman, Jason Engleman, Jordan Pilcher, Andrew Marshall, and Chris Dicks all contributed.

As for the former champs, Millage People, captain Eddie Segar vowed the squad would be back next year.

The PWS events weekend included a golf outing, "Driving for a Cure," June 27 at Hawarden Golf Course. Golfers then attended a party at Sportsman's Lanes and Lounge.

Proceeds raised at the golf and softball events at "Strike Out PWS" will benefit Prader-Willi Syndrome Association, Iowa and USA. To contact PWS, visit online at www.PWSAIowa.org; phone 1-800-926-4797.

There was a silent auction as well. Some of the items included Iowa Hawkeye football tickets; Sioux Falls waterpark hotel night stays; Adventureland; Arnold's Park, Wild Water West & Great Plains Zoo passes; local restaurant and gift cards; University of South Dakota football season tickets; rounds of golf in Hawarden, Sioux Center and Okoboji golf courses; movie theater tickets; Oak Grove State Park cabin stays and baseball tickets for Sioux City Explorers and Sioux Falls Canaries baseball games.

Kramer family members came from Denver, Colo. and Phoenix, Ariz., as well as area towns.

Swimming for Special Success

Originally printed in MyWaukee Magazine, August/September 2014 Issue

Standing together, waiting for their picture to be snapped, are two boys with gleaming gold medals indicating they have achieved something spectacular. No, not everyone gets these medals for participating. These are winners' medals.

They are evidence of conquered fears. They weigh with the responsibility that comes with overcoming adversity and a race won tried and true.

Like children do, they would rather be playing outside with friends, or making something out of sand and mud, catching bugs, or in this case, swimming. Brooklyn, 11, and Zachary, 13, were fish out of water when it came to swimming

in the deep end of the pool. Then they met Michelle, an adaptive aquatics trainer at Waukee YMCA, and lifelong swimmer with 25 years of coaching experience.

Zachary wouldn't let the water get up to his shoulders and Brooklyn refused to dive into the deep end of certain pools. It was going to be their way or the highway and this is where the work began.

Unique Challenges

Brooklyn, with his sporty tennis shoes and athletic wear, was born with a lesion on the left side of his brain the makes his right upper body extremely weak.

Epilepsy comes paired with the lesion. Brooklyn adds details to his friend Zachary's stories, showing their shared experiences and the impact it's made.

Zachary, with his sweet smile, has extremely low

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Left to right: Michelle Bussanmas (Y Adaptive Swim Lessons Instructor), Brooklyn Pierce, Zach Bogazcyk

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muscle tone as a result of living with Prader-Willi Syndrome. Both boys found themselves in need of a unique aquatics program for therapeutic, health, wellness and youth development reasons.

Great Minds Think Alike

A little over three years ago Michelle was in the beginning stages of organizing an adaptive aquatics program with Brian Longren, Waukee YMCA aquatics program director. It was at this same time Zachary's mother, Edie, was looking for an alternative to group swim lessons for her son.

"We have a lot of family friends who have pools. We knew if he [Zach] was enrolled in a regular swimming program it wouldn't work out," Edie said. "We wanted some sort of program where he could safely learn."

Brooklyn also tried the group lessons but that wasn't working well for his swimming development.

"Swimming with Michelle and experiencing the competition help Brooklyn to take risks, improve his confidence and know that even though he has his differences, he is able to do amazing things," said Brandon, Brooklyn's dad.

The physical and cardiovascular exercise is also beneficial for the boys.

"Swimming is one of the best physical activities," Edie said. "It helps with breathing, puts less stress on the joints than other activities and is a good activity for the whole body."

Swimming Buddies

At the Indianola Regional Special Olympics Spring Games held at the Indianola YMCA, Brooklyn placed first (and achieved personal bests) in his age division

in both of his races—25-yard freestyle and 25-yard backstroke. He advanced to the state completion where he placed first and recorded personal bests in both events again.

In an age group up, Zachary won the 25-yard backstroke at the Regional Games.

This qualified him to converge with nearly 3,000 other athletes at the Special Olympics State Summer Games in Ames. There he swam with everything he learned from Michelle and a powerful, personal strength to a first place finish in his age division as well.

In the end it's not the gold medals, but the camaraderie. Swimming is an individual sport but it's so important to cheer one another on agreed Edie and Jessica, Brooklyn's mom.

"Friendships are built; the whole purpose of the Y is to do teamwork," Michelle said.

"I get nervous before a race, but when I win it feels awesome," Brooklyn smiled.

Next April at the regional Special Olympics meet in Indianola look for the boys who are doing their best, competing with the rest. For it is in these moments that their confidence grows bigger than all of the obstacles placed in front of them from the beginning.

Key Components for Success with a Child with Prader-Willi Syndrome in a School Setting

These notes on working with children with Prader-Willi syndrome in a school setting are taken from the presentation "Behavior Challenges in a School Setting" written by Mary K. Ziccardi. Ms. Ziccardi is an Executive Director with REM, OH and serves as a behavioral and educational consultant for the Prader-Willi Syndrome Association (USA) working with schools across the country to create more effective learning environments for students with Prader-Willi syndrome.

Key Components:

A. Structure and Predictability
B. Staff Competencies and Commitment
C. Supervision
D. Food Security and Controls

Structure and Predictability:

- Use of written and/or picture schedules
- Limiting choices to two
- School personnel who provide assurance are a "safety net," providing a sense of security
- Predictability reduces overall anxiety

Staff Competencies and Commitments:

- Must match personality, training, and desire…"it's not for everyone"
- School staff require ongoing support and updated information
- Build a relationship of trust between home and school

Supervision:

- There is no substitute for consistent visual and/or auditory supervision.
- School teams should identify and discuss particularly vulnerable situations (i.e. transportation, bathroom breaks, substitute teacher or aide) and have a preagreed plan.
- Building a relationship with and wanting to be with the student is preferable to just "watching" him/her.

Food Security and Controls:

- Transportation
- Holidays, birthdays, special occasions
- Avoiding the "just this once" phenomenon

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Four (4) Challenging Behaviors and Solutions:

Issue #1: Transitions

- Sudden change in routine or schedule, particularly around food
- Difficulty accepting the change, even if it is a "preferred" activity

Strategies

- Keep schedule and routine predictable
- Have a staff dedicated to the student in order to take the time necessary to work through the changes
- Use logical sequence of events throughout the day

Issue #2: Perseveration

- Repetitively asking the same question/saying the same phrase
- Talking about the same topic or event repeatedly
- Playing with the same toy or puzzle over and over again

First Analyze…

- Is the repetition soothing?
- Does it signal stress and/or an imminent meltdown?
- Is it disruptive?

Once these issues are addressed, then…

- Be certain the child does know and understands the answer/information
- Ignore when possible
- Write down/use a picture to affirm the answer
- Give the student the "last word" on the subject

Issue #3: Sleepiness and Trouble Paying Attention

Strategies

Work with the school staff to:

- Accept this characteristic as one you may have little influence over…but manage the environment by…
- Presenting high and low movement/activity levels alternately
- Use highly motivating rewards for particularly difficult times
- Sit the student close to the teacher/center of activity

Issue #4: Food Management

- Searching for food that is not properly secured
- Seeking garbage and other inedibles
- Trading/borrowing/swapping for food
- Being victimized for the promise of food

Strategies

- Keep all lunches out of sight and secured
- Do not use food in the classroom as reinforcers or teaching tools
- Agree with the school that your student only eats/drinks what is sent from home
- Monitor/secure all trash cans
- Discuss in advance and provide additional supervision for holiday parties

Information for School Staff: A Focus on Behavior Supporting the Student Who Has Prader-Willi Syndrome

(Compiled by Barb Dorn, Consultant on PWS)

All students with Prader-Willi syndrome are individuals. Each has varying strengths and needs. This chart does **not** reflect the behavioral needs of all children &young adults.

Common Behaviors Often Seen in Students with PWS	Possible Management Strategies
Rigid Thought Process It is common for people with PWS to receive and store information in a very orderly manner. There is a strong need for routine, sameness, and consistency in the learning environment.	▪ Foreshadow changes and allow for discussion. Do this in a safe area where they can share feelings. (The student needs to time to adapt to this change) ▪ If there is a change -use visuals; put things in writing – lists, schedules ▪ If able, communicate changes in personnel ahead of time – but not too far ahead. ▪ Don't make promises you can't keep ▪ Break down procedures into concise, orderly steps. Limit steps to 2-3. ▪ To resolve "stubborn issues" try using "compromise". Both the student and the educator have to come up with a totally new solution. Serves as a problem-solving strategy – and diversion. ▪ Provide praise when being flexible
Perseverative or Obsessive Thinking This is the tendency to get "caught" on one issue or thought to the point where it overshadows the main theme of the learning or social event. This behavior can contribute to difficulty in transitioning from one topic/activity to another. Students often have a great need to complete tasks. It can lead to loss of emotional control.	▪ Use reflection – have student restate what you said ▪ Put in writing; use visuals. Carry a small notebook if needed. ▪ Less is best – give less amount of work at one time. Add to the work as time allows. ▪ Avoid power struggles and ultimatums ▪ Ignore (if possible) ▪ Don't give more information than is necessary especially too far in advance. ▪ Use "strategic timing" – time the activity that the student has difficulty ending right before activity he/she enjoys (snack or lunch.) ▪ Set limits. "I'll tell you 2 more times, then we move on to next topic. This is #1."
Tenuous Emotional Control Any combination of life stressors can lead to emotional "discontrol". The result may be exhibited as challenging behaviors such as tantrums – yelling, swearing, aggression, destruction, and/or self-injury. During these episodes, reasoning is lost. Recovery of control takes time and is often followed by sadness, remorse, and guilt. Because of a problem in sequence processing, students are **not always able to turn what not to do into what to do.**	▪ Be aware of "hallway over stimulation" – especially before school begins. Have student enter the building at a less popular entrance. If possible, have arrive 5-10 minutes after school starts. Dismiss early. ▪ Start the day by reviewing the schedule; work through any changes. Put new schedule in writing to decrease anxiety. ▪ Set daily goals with the student. Limit to 3 or less. Communicate behaviors you wish to see. Make it a cooperative task that provides concrete behavior expectations. Put goals in writing. Avoid the word "DON'T"… focus on the word "WILL". (EX. "Talk in a quiet voice … instead of "Don't yell". When I feel frustrated, I **will** tell Mr. Smith or another adult.") ▪ Provide positive attention and praise when student is maintaining control, especially in difficult situations. Celebrate success! ▪ Encourage communication and acknowledging feelings. Words are important – LISTEN carefully! ▪ Include the student in behavior plans. Having their input elicits cooperation and a sense of support. Especially true in older children and teens. ▪ Be a role model. "I always say "darn" when I am angry. Let's try that for you … darn, darn, darn". Practice when the student is **not** agitated or angry. ▪ Depending on the student and the situation – use humor. It is often effective. ▪ Anticipate build up of frustrations and help him/her to remove self to "safe area" Create a key word or phrase that will alert the student that it is time to go. Practice using these words/phrases when the student is calm. ▪ Develop a plan and **teach the student what to do** if he/she feels angry or frustrated. Many students substitute a means of releasing this pent up anger – long walks/exercise, ripping paper, tearing rags, popping packaging bubbles… ▪ **Don't try reasoning during times when out of control. Limit discussion.** ▪ Have a plan in place if student becomes more violent. Safety for all is a priority. Consistency in approach is imperative ▪ Provide positive closure. Don't hold a grudge. ▪ If using consequences – they should be immediate and help the student learn from the outburst – saying "I'm sorry", sending a note to say they are sorry …

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Common Behaviors Often Seen in Students with PWS	**Possible Management Strategies**
Food Craving and Diet Restrictions For people with PWS, the message of fullness never reaches the brain – they are always hungry. In addition to this craving for food, food is metabolized at a rate that causes extraordinary weight gain. Food must be monitored and the individual supervised in all environments. Food seeking behavior can vary in intensity. Food security is the most important health and behavior issue that can impact learning and the student's well being.	▪ Make sure lunch is placed with a bus driver and /or an assistant on the ride to school. ▪ Educate and inform all people working with this student – including bus drivers, custodians, secretaries, lunch room personnel and volunteers. ▪ If the student states he/she has not had breakfast – call parents or caregiver before giving more food. (Often times they say this to get more food.) ▪ Supervise in lunchroom and in all food related areas – including vending machine areas. In some cases, student may need to eat in classroom (with peer/friend) ▪ Many require supervision in hallways or near unlocked lockers at all times. ▪ Avoid allowing the student to have money. Lock up all sources of money – including purses. Money buys food! ▪ Address any stealing or trading of food in private. ▪ Follow guidelines for treats or eating of extra food. Communication with home is very important. ▪ Follow calorie-controlled diet. If a special calorie diet is needed and served by the school, a prescription should be obtained from a health care provider and should be a part of the student's educational plan. ▪ Don't delay snack or lunch; if this is necessary discuss ahead. ▪ Limit availability and visibility of food. Be aware of candy dishes. ▪ Avoid using food as a reward or incentive. If done should be part of calorie controlled diet. ▪ Be aware of smells – can cause agitation and extreme distraction. ▪ When going on a field trip or other outing, discuss all food-related issues ahead of time. Will you bring snack along or will it be purchased? If purchased – what will it be? Will the outing interfere with the time of a meal or snack? ▪ Obtain weekly weight by school nurse if indicated. ▪ Daily exercise is a life skill that should be a part of student's program. **IMPORTANT NOTE: If a student with PWS is caught with food in his/her possession that is stolen – DO NOT ATTEMPT TO PHYSICALLY TAKE IT AWAY. Try to compromise, trade or other forms of negotiation. Do not threaten; it could result in aggressive behavior. Evaluate what happened. Institute measures to prevent reoccurrence.** ▪ If it is discovered that student has had a binge episode and eaten a large quantity of food – contact parent immediately. This could result in a health emergency. ▪ Encourage eating slowly – student may choke from eating too fast. Make sure staff trained in the Heimlich maneuver.
Poor Stamina People with PWS tire more easily and may fall asleep during the day. Morning is typically their optimal learning time, when energy level is highest.	▪ Get person up and moving. Send on errand. Take a walk. ▪ Schedule high energy, mobilizing activity after lunch ▪ Offer items /activities which stimulate large muscles and deep breathing - balloon blowing, party blowers ▪ Some require scheduled rest time or a quieter activity.
Scratching and Skin Picking These two behaviors are often seen in individuals with PWS and may be worse during times of stress. Combined with a higher pain threshold, these behaviors can result in tissue damage if not controlled.	▪ Use diversion - provide activities to keep hands busy (coloring, computer time, play dough, hand-held games, magazines, book…) ▪ Keep nails short. Apply lotion liberally – it keeps skin slippery and soft making it more difficult to pick. Applying lotion can also be an effective diversion. ▪ In extreme cases, provide constant supervision – even in the bathroom. Limit time in the bathroom. ▪ Cover area with bandaide or similar covering. ▪ Don't just tell him/her to stop picking – it won't work. ▪ Apply mosquito repellant before any walks or outside activity.
Difficulty with Peer Interactions While children want and need other children and value friends, they often lack age-appropriate social skills. They often face challenges in issues of fairness and comparing themselves to others, often resulting in frustration and anger.	▪ Many do better in small groups. Benefit from verbal cues and guidance. ▪ Pre-plan outings. Keep time short ▪ "Supported recess or social outings" – planned activities with a friend ▪ Include child in planning activities that are of interest to him/her (board games, puzzles, computer games…) ▪ Provide social skill classes that emphasize sharing, taking turns… ▪ Role play and practice appropriate social situations. ▪ Clearly state and write do's and don't for social interactions w/ friends of opposite sex.
Students with Prader-Willi syndrome are very caring, sensitive and conscientious. They want very much to be successful, have friends and be a part of their school community. Although they face some unique challenges, with proper support and understanding … they can play, learn, work and live successfully in our communities.	

Behavior Plans

*From **Pittsburgh Partnership,** Specialists in Prader-Willi Syndrome, written by Linda M. Gourash, MD, Developmental and Behavioral Pediatrics and Janice L. Forster, MD, Developmental Neuropsychiatry*

Some General Points

- You know you have a good behavior plan when the child enjoys the plan and does not rebel against it.
- A behavior plan makes a child more aware of his behavior, but he will still need lots of help to change it. FEEDBACK
- A "star chart" is not a behavior plan; charts are one type of on component of behavior plans
- Virtually every behavior plan needs to be modified or "tweaked."
- When a behavior plan is not working, it needs to be modified, not abandoned
- The work is not done by the behavior plan so much as the people implementing the behavior plan.
- Starting a behavior plan is not as difficult as maintaining it.
- Behavior plans have fewer side effects than medications.
- If medication is needed, it will work better WITH a behavior plan.

Most parents come equipped with the same tools that their own parents used: scolding and punishment. Neither is especially effective in the hypersensitive child nor do they help the child with strong and problematic impulses.

Don't forget the basics. Behavior plans are always best implemented using basic behavior management skills: low expressed emotion and low attention to undesirable behaviors.

Benefits of a Reward/Incentive Behavior Program:

One of the main benefits of an incentive behavior program is that it completely changes the dynamics between parent and child. Without an incentive plan, the parent becomes the "punisher" and "scolder" while the child becomes "wrongdoer" and "victim". They are working against each other. With an incentive plan, parent and child are working together toward success as defined by the plan. The child's effort is motivated by the incentives and rewards; the parent provides the necessary support for the child's success. The support may be considerable.

- All children (and adults) work better for rewards than to avoid punishment.
- Rewards and consequences are predetermined. This decreases anxiety for the child because they know what to expect. It also allows the parents to avoid bribery and threats which are counterproductive and can have the perverse effect of encouraging the undesirable behavior.

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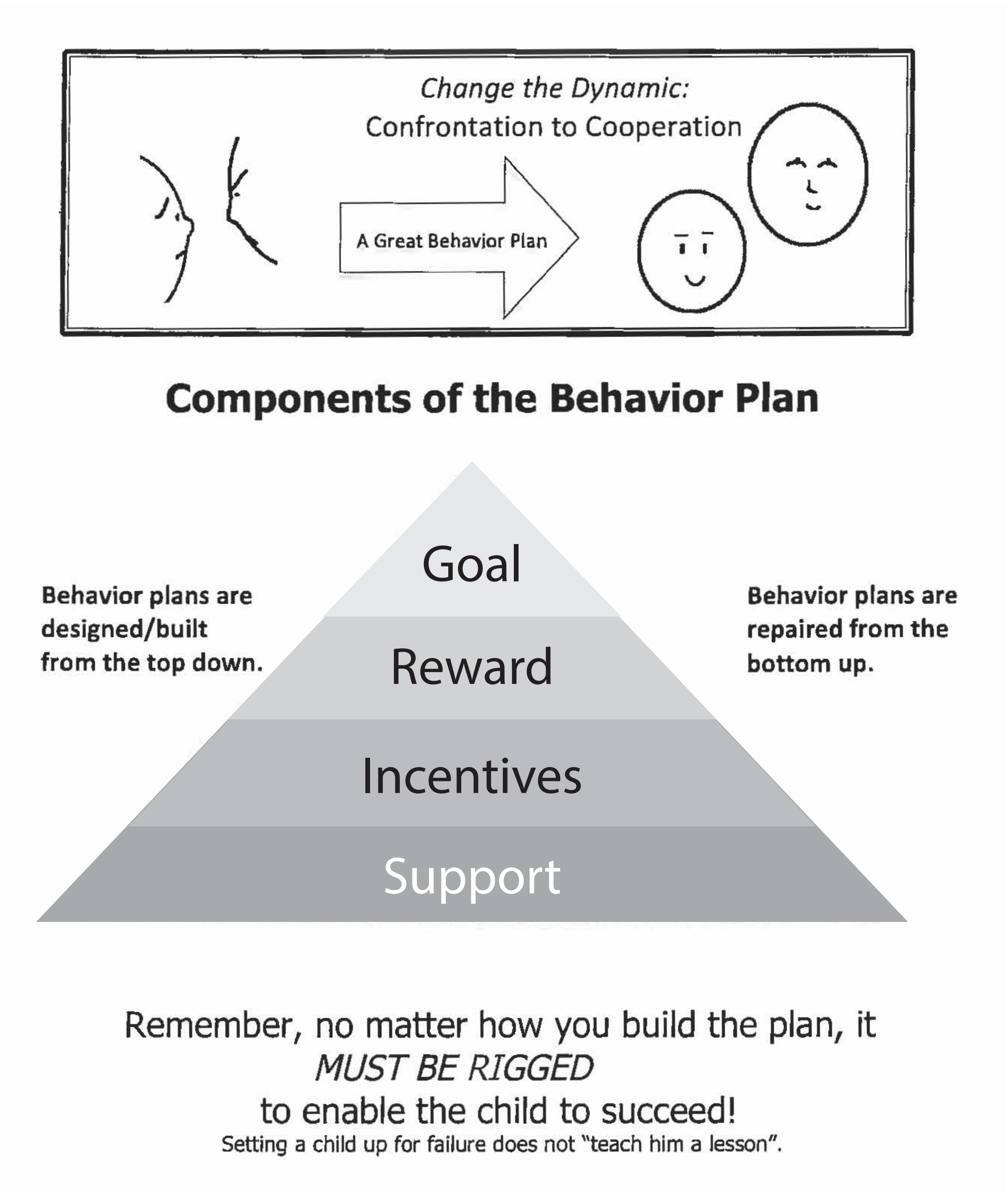

Change the Dynamic:
Confrontation to Cooperation

A Great Behavior Plan

Components of the Behavior Plan

Behavior plans are designed/built from the top down.

Goal

Reward

Incentives

Support

Behavior plans are repaired from the bottom up.

Remember, no matter how you build the plan, it
MUST BE RIGGED
to enable the child to succeed!
Setting a child up for failure does not "teach him a lesson".

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Goal

The goal is your desired behavior; it is stated in a positive format. This is done as a means of giving low attention to the problem behavior. Therefore, instead of "not fighting with your brother," the goal will be stated "playing nicely with your brother".

Problem Behavior	Goal
Falling asleep at school	Paying attention in school
Using rude or bad language	Being respectful
Pushing, shoving, pinching	Good hands to self
Running away	Staying safe
Destroying or stealing others property	Respecting others' property
Screaming yelling/tantrums	Staying calm
Getting up at night	Staying in bed all night

Special Cases (a digression)

Lying

Lying is a nearly universal and complex behavior in Prader-Willi syndrome and a reward system for "telling the truth" is not likely to be helpful. Strategies include:

- Emphasize the truth and not the lie.
- For children who are newly trying out their deception skills, low~key correction is a good option: "I think you meant to say, Mom did give you your snack. Does that sound more like the truth?"
- Avoid getting fooled: A successful lie strongly reinforces the behavior
- Be skeptical: when something sounds a little suspicious, verify with other parties involved.
- Keep asking questions and for details. They often rat themselves out.
- Stall for time: I'll have to think about that"
- Be noncommittal: "Interesting"
- Avoid confrontations. Don't bother pointing out the lie once this has become a repeated behavior. This creates escalation.
- Create diversions instead. Do you remember what we are going to do now?"
- Use humor: "Nice try!" or "I don't think so." Said with a smile is more likely to let you child know to give it up without escalating him.

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Stealing food

Behavioral Goal: Asking for help when food is around.

Food stealing is a self-rewarding behavior in persons with PWS, and behavior plans must take this into account. Behavior plans will not "teach" a person to NOT steal food, especially if they have been successful at it in the past; it is too rewarding. This is why persons with PWS need to have controlled food access and FOOD SECURITY, even when weight is under excellent control.

- Food theft should be addressed with low attention, a low keyed, matter of fact response, and a token consequence involving the next meal or snack e.g., loss of bread or other starch, or substitution of water for the next beverage.
- Checking weights 2 times per week is a helpful and proactive way to detect food stealing. As your child becomes older, food exposure and opportunities will expand. If he/she is already accustomed to being weighed regularly, this valuable tool will be already In place when you need it. Obtaining body weight is critical information at the beginning of each school year. If a weight gain occurs and new behavior problems emerge, you will be able to detect the source.

Skin picking

Goal: "getting healed up". We have a separate handout on Skin Picking on our website.

How to weigh a person:

Weigh him or her on a digital scale with a 0.2 lb. increment. Weigh first thing in the AM in underwear or PJs after toileting and before drinking. Weigh on Monday AM and Saturday AM. MAKE NO COMMENT ON THE RESULT, good or bad. Write down the weight in a notebook with the date. Water weight will fluctuate up and down by 2 pounds in a single day but new highs and lows help you know if there is a trend.

Children who are getting food at home tend to gain weight on the weekends. If they are getting extra food at school or work, the change in weight will be noted from Monday to Saturday.

Rewards

Your child will be focused on the reward associated with the behavior plan. A reward is different from an incentive in the scheme of behavior plans in that it is rewarding in and of itself, while an incentive (See below) may be only an encouragement or a reminder of the child's progress toward the reward.

It is crucial that you give careful thought to choosing the reward prior to establishing the behavior plan. This usually requires consultation with members of the family and a considerable amount of foresight. Small rewards may be given daily and are usually necessary for younger children or children who are of a mental age less than first or second grade. Older children can work for one to four weeks in order to obtain a particularly desirable reward but are likely to need daily incentives to support their effort. Whatever the reward, it must be something that can be repeated in another one to four weeks.

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Do not combine the reward of a behavior plan with a Christmas or Chanukah present, or birthday gift as these are not repeatable. Gifts are not contingent on good behavior. But you may keep your reward system in mind when planning these special occasion gifts, because giving the behavioral reward as a gift lessens the power of the item to motivate behavior.

The child who "has everything" may be difficult to motivate. "Taking away everything" and making him earn it back is counter-productive and puts the child into a foul mood. He feels he is being persecuted when favorite items he is used to having are no longer permitted. Rather, going forward, you prepare the child that certain desired items will be earned and then purchased but kept in the parents' custody; then, "time" with the item will be earned using the behavior plan. Here it is very important to schedule guaranteed time with this activity and then encourage working for BONUS time. This approach eliminates the ineffective punitive approach of "taking way" used by parents and some behavior therapists.

Keep the rewards associated with the behavior plan separate from other desired activities, small and in general, try to avoid "stuff". Ideas for good rewards include frequent activities which the child enjoys:

- An extra story at bedtime
- An opportunity to choose the Friday night movie for the family
- An outing
- One-to-one time with parent
- TV time
- Extra time on the computer or video game
- Time with a favorite craft; opportunity to buy small addition to crafting supplies
- An opportunity to make a long distance call to a favorite relative (these should be prescheduled)

CAUTION

- Expensive toys, outings or privileges are not useful as they cannot be used on a continuous basis. Trips out of town are not repeatable.
- One-time events (an opportunity to see a show that is in town for a limited period) are not good rewards because the loss of the reward is permanent and irreplaceable and creates too much anxiety or frustration in the child.

Older Children/ Adolescents and Adults:

If your child enjoys computer or video game time, they will tend to perseverate on it and overuse it. For this reason using these activities as a reward is not only desirable but necessary. It is best to give the child some guaranteed time and then design the behavior plan around his earning "bonus time" with a favorite activity. This diminishes the negative emotions associated with "taking away" a desired activity and reduces anxiety over losing the reward. The maximum amount of time the child can earn should be no more than you want him doing is,e.g., 1 hour of TV or time on the Internet. (Consistent with APA guidelines).

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Behavior Plans

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For older children with fundamental number concepts, these rewards can be banked and saved for the weekend if another family activity (sporting event or doctors appointment) interferes with his getting to enjoy the daily reward activity. In fact, the contract will state that rewards are redeemable on the weekend. Older children and adults can earn small amounts of money and the opportunity to go shopping. The amount of money must be carefully considered to be small enough to be used continuously by the behavior plan but large enough to be motivating.

MOST Dieticians are not PWS behaviorists. In PWS there are no "FREE FOODS." Even calorie-free foods must be provided only as part of the meal plan or the behavioral plan.

Food Rewards

Food rewards are generally avoided in PWS, but for children who have a great deal of difficulty getting through their day without tantrums or shutdowns, and when other rewards have not been motivating, food incentives can be offered as a reward, not to exceed four times per day. It is very important that the food incentive is not any more exciting than a pickle, flavored water, a sugarless mint or Flavor Spray. The possibility of earning the food reward must be frequent enough (e.g. 3-4 times per day) so that the individual does not become overly anxious about losing the reward and always has a new opportunity to earn the reward. Verbal reminders are very effective, directing the child's attention to his next opportunity to earn a reward. Children who cannot be counted on not to swallow their gum, of course, cannot use this reward until they are taught to spit the gum in a paper cup for the parent to see. If your child is not receiving sweets (sugar or artificially sweetened food), then it is highly desirable that you do not use sugarless sweets as incentives as this will undo the benefits of having eliminated those foods that are most likely to cause cravings.

Sometimes food rewards, such as sugarless candy and a preferred beverage, are used successfully to reinforce an exercise schedule.

A major disadvantage of food rewards is that your child will never grow out of expecting them and they can increase anxiety if they are likely to be lost.

Earning, Not Losing Rewards

As noted elsewhere, losing the reward is not instructive or motivating, especially for the child with Prader-Willi syndrome. Behavior plans that emphasize losing the reward create increased anxiety and some form of rebellion such as tantrums or declarations of "I don't care". For this reason, threats or warnings of losing the reward will destroy the effectiveness of a behavior plan. All of this is avoided by designing the behavior plan in a way to assure that the child is successful.

Incentives

In the behavior plan, INCENTIVES are reminders of the reward and therefore reminders of the goal and the plan. They help your child on track. Incentives include praise, encouragement, as well as visual feedback of success, such as stars, sticker, poker chips, check marks or "points".

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TOKENS are tangible objects given to the child or placed in a visible location. These can be cashed in for a reward. For younger children the token may also be the reward, such as a star or sticker. Even young children, however, can understand that they receive a token (a point or a chip) for each star or sticker earned, and that these can accumulate to a reward activity at the end of the day. Their number concepts can go up to 3 when visible aids are used.

Points are incentives and can be used for children who can understand the numbers and the accumulation of points toward a goal. They should have to earn most but not all of their daily or weekly points to achieve a reward. Success promotes good behavior. Children love to carry their own point card from class to class to be signed by each teacher or therapist.

For all ages, even adults, SOME visual demonstration of progress/success is essential in the form of a chart and/or a jar or box of tokens a thermometer chart etc.

Frequency

A key decision will be how frequently the child must experience an incentive to keep him on track for reward. Frequent behaviors such as whining, tantrums, not listening, fighting with siblings, which may occur multiple times per day, will require incentives multiple times per day.

The child's age is also a factor. Younger children will need tangible incentives, 3 or more times per day. Younger children will work for stickers or shiny stars, both as incentives and as rewards. Older children can keep track of tokens and work for a daily or weekly reward.

It is not unheard of for a young child with a frequent undesirable behavior (every 5-10 minutes) to densely reinforce for performing the goal behavior. This usually requires a structured behavioral team, if only to provide manpower.

Weekly Rewards

Older children often need a longer-term reward in addition to daily feedback. Achieving the reward is based on points earned during the week, e.g., points for each daily incentive earned. The arithmetic should be such that it is an almost certainty that the child will earn the reward by the end of the week and if he does not, he is given more time to earn it, it is not lost.

Effectiveness

The effectiveness of the token economy depends on a number of factors. Many times behavior programs do not work because they need to be adjusted slightly, not because they are completely wrong. Other times they are not implemented properly or consistently.

Effectiveness is enhanced greatly by the following:

- Frequent opportunities to earn recognition for desired behaviors (3 times a day for most children for frequent behaviors)
- Daily opportunity to "cash in" for a reward
- Weekly goal and opportunity to "Cash in"
- No reward is lost forever. The child should have additional opportunity to earn rewards in subsequent periods of time/days/weeks. One time events, such as concerts or parties, therefore should not be used as rewards unless they can be rescheduled.

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Support

Support is one of the most overlooked components of a behavior plan, but in PWS it is one of the most important components. Support consists of all of the things that you must do to help your child do what is difficult for him to do (with or without a behavior plan).

As a PWS parent, you are already giving your child lots of support. So when introducing a behavior plan, you will look for ways to give him extra support to succeed. Supports include:

1. Lower expectations
2. More help
3. Increased feedback
   a. Verbal
   b. Visual

Lower Expectations:

You have already learned how to do this around food issues. You do not expect your child to stop eating on his own; you know that you must limit his access to food. That is an example of SUPPORT.

Example: If you child does not do well with long outings/errands you can

1. Shorten the outing; this is often the only solution and is best done proactively instead of in response to an outburst or whining.
2. Help him to tolerate it by providing rests, or breaks, or entertainment (toys etc.)
3. Remind him of the incentive scheduled at the end of the time period involved, and give him lots of encouragement that he can be successful
4. Use visuals to show him his success after the fact (star chart, grade card etc.)

Support, therefore, consists of recognizing your child's limitations. If you know your child fatigues easily or gets bored after 30 minutes of an outing or activity, you must plan for it and help him to succeed. If you child becomes bored easily and starts whining, then you must help him find ways to entertain himself even as you target the whining behavior with a plan.

Summary of Support Strategies:

Shorter time periods for difficult situations (school tasks, boring visits to family/friends [boring for him not you!], errands).

More hands-on assistance even when the child can sometimes complete the task himself; he may need help when asked to perform it on demand.

More supervision in difficult situations (time with siblings; be there before it deteriorates! Be quick to separate him without assigning blame!)

More diversions (Portable crafts, games, books)

More visual and verbal encouragement (pointing out charts, score cards, praise, reminders of incentives and rewards)

More verbal and visual feedback after the fact.

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Tips and Reminders On Using Behavior Plans

- DO: Discuss the plan with the most sage members of the household FIRST. Ask them to offer suggestions or comment if they foresee problems with implementing the plan. Adjust the plan according to everyone's input.
- DO: Keep your TEAM (everyone in contact with the child) up to date on his plan.
- DO: Introduce the plan to your child in upbeat tone and during a time when he or she seems most receptive. Say something like "We have an idea for how you can earn ," Older children can contribute ideas to what rewards they would like to work for. The PRICE (Cost in tokens) of the incentive is not up to the child.
- DO: Communicate frequently. Give the child frequent verbal and visual reminders of 1) what behavior you are looking for 2) the reward 3) what incentives or credits (tokens/points) toward the goal he has already earned.
- DO: Emphasize the behavior you are seeking, not the one you are trying to avoid, e.g., "You did a very good job playing nicely with your sister. You earned your star!" Not: "You get a star for not hitting your sister."
- DO: Give frequent encouragement and praise. If the child is not earning his points, do not scold* but do tell/remind him of what you prefer for him to do. Remind him of the incentive and encourage him that he can earn it during the next time period.
- DO NOT: Use the loss of incentives as a threat. Use the possibility of earning the incentive as encouragement. Avoid all negative statements. Do not announce the loss of a star or other incentive at the time of the behavior, never announce it in anger. ONLY mention the loss of an incentive when the child asks or at the end of the period when the incentive could be earned. State matter of factly. "You did not earn a star this morning, but let's see if you can get one this afternoon."
- DO NOT: Take away incentives or rewards once they are earned, regardless of the behavior. The consequence for the behavior is not earning the next incentive.
- DO: Expect the angry or volatile child to become frustrated when he first fails to earn an incentive. Expect him/her to say, "I don't care about .... " Ignore this statement. Do not abandon the program. Wait until he or she is calm and speak encouragingly of the next opportunity to earn tokens. You can comfort him/her for the loss but do not give in or change your mind.
- Expect to use this plan or a variation of it for months or years. Do not expect to "fix" a behavior problem, and then abandon the program.
- DO NOT: Abandon the plan if it does not seem to be working well. Adjust the plan based on your recent experience with It or seek help (from other family members or therapist who helped you to design the plan) to modify the plan.
- DO NOT: Bribe, cajole, tease or bargain. It will provoke retaliation or revenge from the child.

Interested in Joining the Prader-Willi Syndrome Association of Iowa?

We'd love to have you!

Fill out this page and 1) mail it to:

Prader-Willi Syndrome Association of Iowa
15130 Holcomb Avenue
Clive, Iowa 50325

OR 2) email it to: edieiowa@gmail.com

OR 3) sign up online at: PWSAIowa.org/contact

Questions? Email us or call us at 515-770-5297

Suggested membership annual dues: $20
**Membership can still be accepted if this is not financially affordable.

Checks can be made payable to "PWSA of Iowa".
Send payment to: PWSA of Iowa, 15130 Holcomb Avenue, Clive, IA 50325

Name: ____
(required)

Mailing Address: *(required)*

____

Street City State Zip

Email: ____
(required)

Phone Number: ____
(required)

Tell us about yourself!
(Does someone in your family have Prader-Willi Syndrome? How old are they? Would you like additional information? Etc.)

____

____

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____

The Krumm Family Fund
for the Advancement of Persons with Prader-Willi Syndrome in Iowa

PURPOSE:

This fund will make grants available to individuals, families and service providers to promote the well-being of persons with Prader-Willi Syndrome who reside in the State of Iowa. The interest generated from this Fund can be used for grants with the principal staying in an interest-generating investment.

ADMINISTRATION:

The current Board of Directors of the Prader-Willi Syndrome Association of Iowa and a Krumm family member will have control over the dissemination of this Fund. The grants and their eligibility requirements can be changed with a majority vote of this Administering Board.

GRANTS:

Application can be made on an annual basis for each of these grants. A limit of $100 applies per individual, family or service provider to each grant. An individual, family or service provider can receive up to two grants per year.

HOME MODIFICATIONS:

Grants are available for home modifications that are not covered by other services, including but not limited to locks and installation of locks for the purpose of protecting a person with Prader-Willi Syndrome from access to food. Receipts as proof of purchase of supplies and charges for installation will be considered. This grant is available to individuals, but will be limited to two grants ($200) per house per year.

TRANSPORTATION:

To assist persons with Prader-Willi Syndrome in traveling in the community to and from work, taxi fees (punch cards) can be reimbursed with proof of purchase.

HEALTH CLUB MEMBERSHIP:

To promote the good health of persons with Prader-Willi Syndrome, reimbursement of membership to a health club can be reimbursed with proof of purchase.

CONFERENCE REGISTRATIONS:

Registration for conferences sponsored by the PWSA-USA and PWSA-Iowa can be reimbursed with proof of registration and attendance.

TRAINING FOR SERVICES SPECIFIC TO PRADER-WILLI SYNDROME:

Opportunities for individual or group trainings specific to Prader-Willi Syndrome are eligible for funds. Submission of full information to the Administering Board prior to the event is recommended.

GRANT FOR RESEARCH:

At the discretion of the Administering Board, an amount of up to $500 per year can be given to the PWSA-USA Research Fund.
Krumm family members serving on this Fund: Wanda Askelson, Carlene Krumm, and Valerie.

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PARTING WORDS

from the Prader-Willi Syndrome Association of Iowa:

> The only *disability* in life
> is a *bad attitude.*
>
> *-Scott Hamilton*

Has Your Home or E-mail Address Changed?

If you change your home or e-mail address, please notify the PWSA of Iowa chapter office at **edieiowa@gmail.com or 515-770-5297.** We want to stay connected, keep you on our newsletter mailing list and also inform you of all upcoming PWSA of Iowa events; including socials, fundraisers and mini-conferences.

Share this newsletter! Find it online at PWSAIowa.org/fall2014