



Positive Behavior Support in PWS

Strategies, Challenges and Solutions



Objectives

Define behavior

**Understand how
anxiety and sensory
needs affect
behavior**

**Strategies for
managing
challenging
behaviors**





What is Behavior?



Behavior is defined
as anything a living
organism does

Behavior is not
good or bad, it
just is

Everyone
engages in
behavior

POSITIVE BEHAVIOR SUPPORT



What you see is just the tip of the iceberg

What a person with PWS feels is below the surface:

Fear

Anxiety

Irritation

Overwhelm

Anger

Disappointment

Sensory
overload



Genetics / Subtype Generalities



Hypothalamic
dysfunction causes
emotional
dysregulation

Deletion subtype –
more skin picking, ability
to match emotions with
others, good spatial
abilities / puzzle skills,
may be better at
recognizing other's
emotions, intense
hyperphagia

UPD / Imprinting – more
ASD features, increased
risk for psychiatric
comorbidities, better
verbal skills, can
become obsessed with
others, gain more skills
with age



How Anxiety Affects Behavior



Anxiety is NOT a behavior, however it can cause maladaptive behavior

Most individuals with PWS have high levels of anxiety

POSITIVE BEHAVIOR SUPPORT



How Anxiety Affects Behavior

Maladaptive behaviors that can be a result of anxiety



Perseveration

Skin picking

Aggression

Defiance

Meltdowns

Elopement

POSITIVE BEHAVIOR SUPPORT



Managing Anxiety



Food security

Calm
environment /
responses

Trust

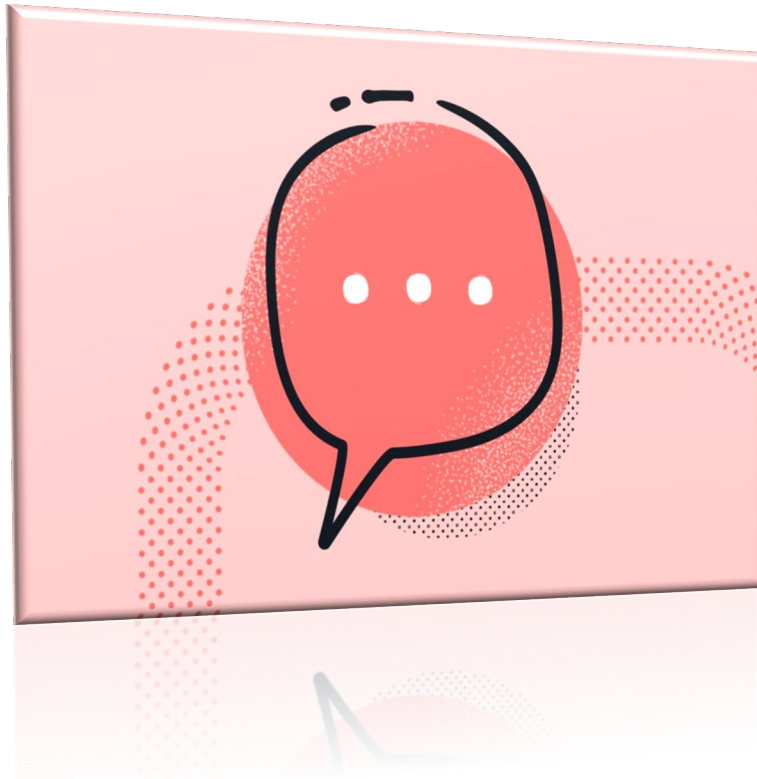
Consistent meal
and snack times

Rules

Boundaries /
expectations



Principles of PWS Behavior Management



PWS friendly
environment

Establish clear
boundaries

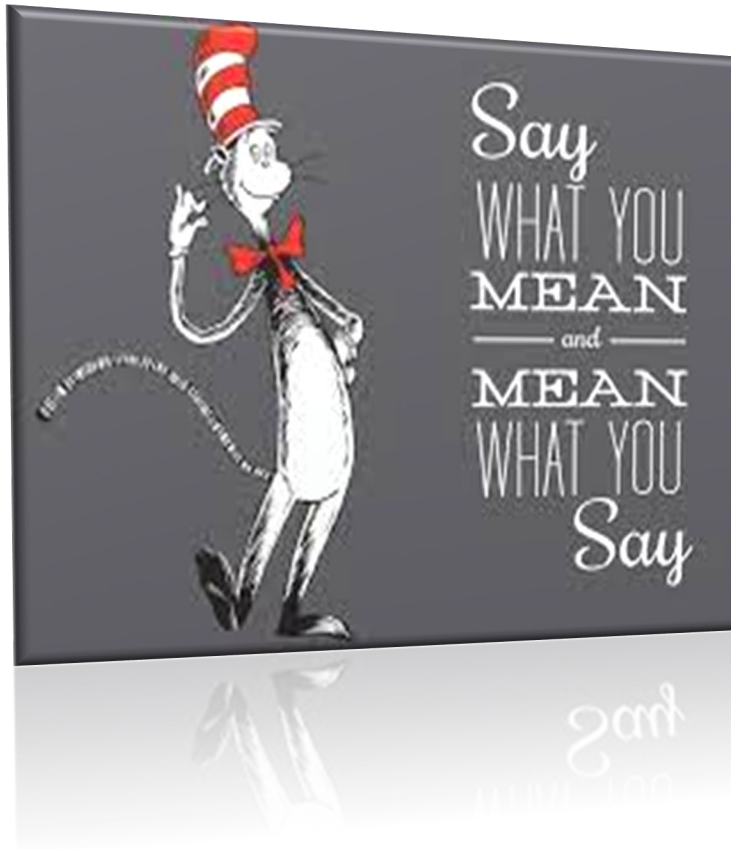
Create consistent
routines and
expectations

Communicate
rules

Prevention is
key



Establish Clear Boundaries



Be authoritative
not authoritarian

Establish boundaries
around acceptable
behavior – what you
expect

Say what you mean
and mean what
you say

Give limited,
preferential
choices

Be clear, avoid
ambiguity “we’ll see”

Do NOT give in
to a tantrum

Do NOT lie or
make threats

POSITIVE BEHAVIOR SUPPORT



Create Clear Consistent Routines and Expectations

Get Dressed 	Eat Breakfast 
Clean Up 	Brush Teeth 
Screen Time 	Baking 
School 	Play Outside 
Color 	Play Dough 
Walk 	Play Time 

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Consistency and routines help people with PWS feel secure

Use picture schedules

Reward systems

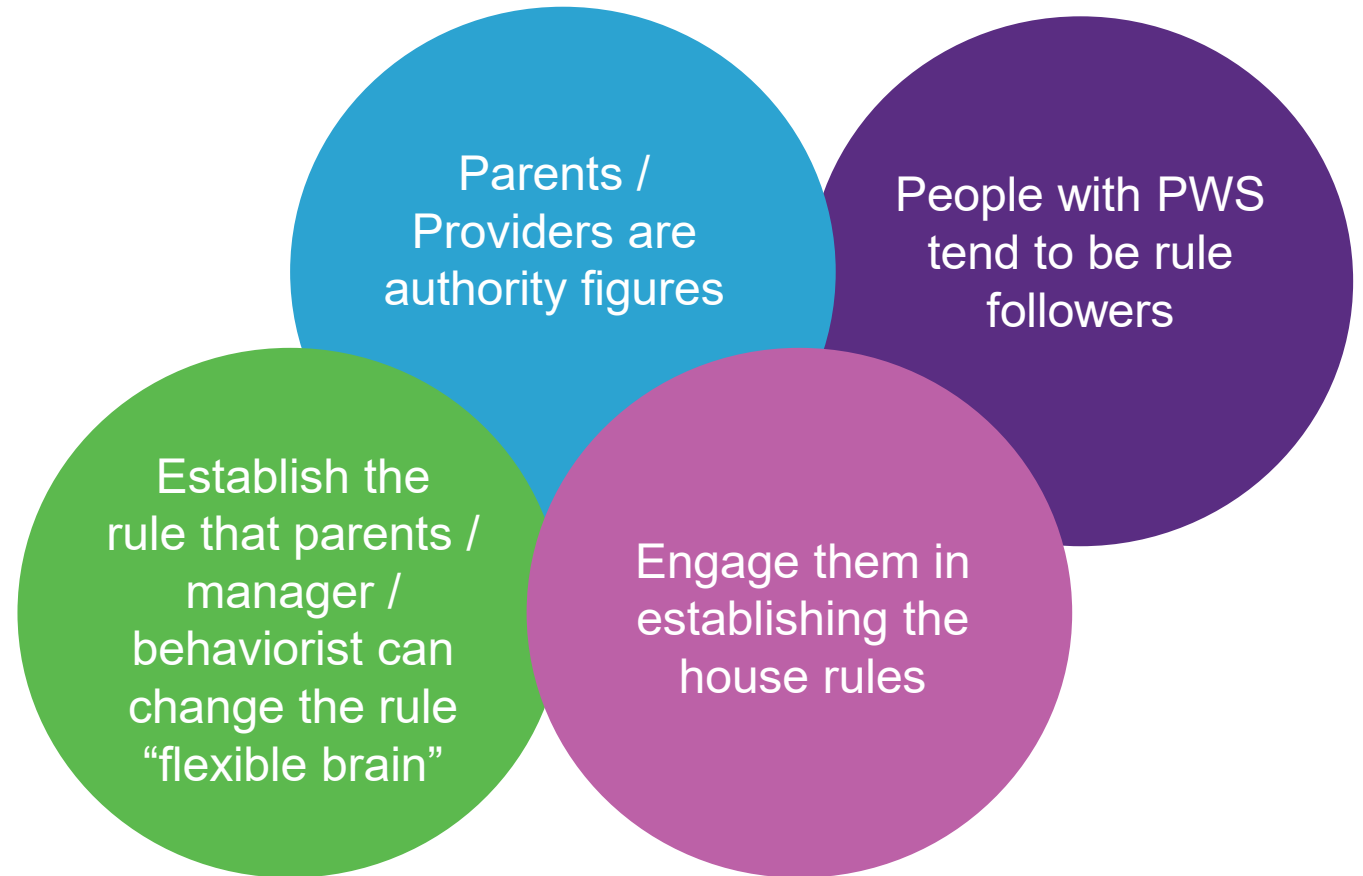
Preset and paint the picture

Create rituals

Use social stories



Communicate the Rules





Empathy as a Preventative Strategy



Empathy is not
agreeing nor
disagreeing

What does the
situation look like
from their
perspective

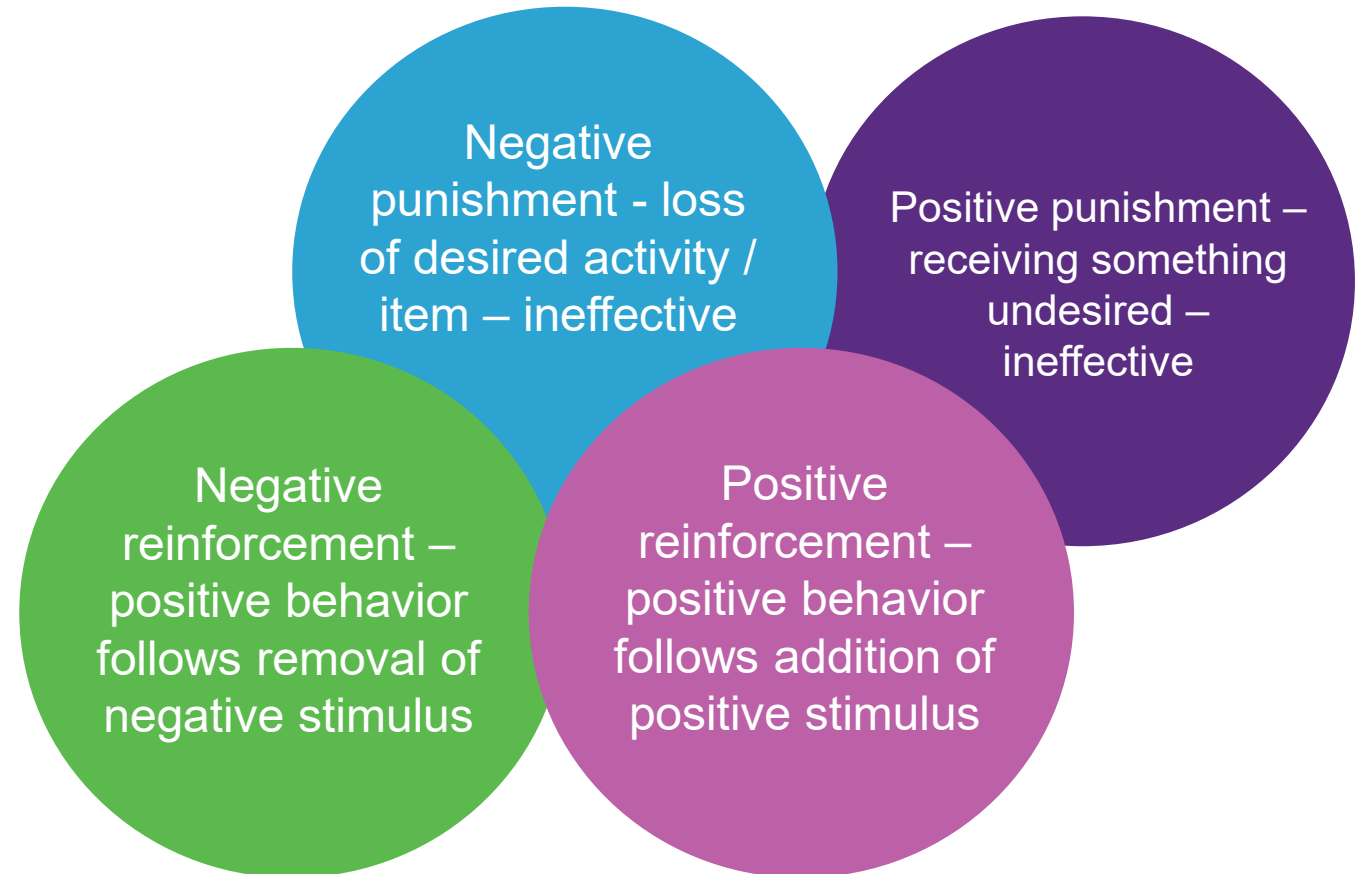
Be genuine!

Be sure the individual
knows that you
completely understand
their concern before
you share your
concern

Empathy will
reduce anxiety,
disappointment,
fear and frustration



Consequences



POSITIVE BEHAVIOR SUPPORT



Tips for Specific Maladaptive Behavior



Meltdown or
tantrums

Aggression

Skin picking

Perseveration /
repeated
questions

Power struggle



Tantrum



Give time and
space

Maintain safety

Remain calm
and quiet

Be aware of your
body language

Do NOT give in

Listen to what
they are saying

Look bored /
disinterested



Aggression



Praise the use of
a calm voice

Do not rehash the
behavior

Physical aggression -
SAFETY FIRST.
Remove items that
may be thrown, keep
your distance -
Do not respond with
aggression

Verbal aggression –
use empathy and
validate feeling not
behavior



Skin Picking



Skin picking can happen for several reasons: boredom, anxiety, sensory

Keep bug bites and wounds covered

Keep nails short and use a thick lotion to prevent dry itchy skin

Keep hands busy

Use positive reinforcement for not picking

Avoid saying "stop picking"

OT evaluation for sensory needs

Medication may be beneficial



Perseveration / Repeated Questions



Provide
reassurance and
empathy

Redirection

Refer back to
rules and
schedules

Only answer the
same question
three times

It's okay to say "I
need 10 minutes
of quiet"

[illegible]

Model the
behavior you
want to see



We ALL Make Mistakes



Admit when you
are wrong or have
made a mistake –
modeling this is so
important



We ALL Make Mistakes

How to fix a wrong



Remind them of specific incident -
“Remember when I ...”

Use empathy –
“last time we ... and you ...”

Remind them of benefit – “I care very much about you, and I always want to do what’s best for you”

Introduce the fix – “this time we will do ... instead of ... because that will be much better for you”



Open Discussion

Q & A



RESOURCES



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