Psychosocial Well-Being of Siblings of Children with PWS:

Findings from qualitative research and support groups
Thank you

A special thanks to the siblings who participated. You are AMAZING and generous!

Thank you to the Utah Developmental Disabilities Council and the Utah Prader Willi Syndrome Association for funding the project.

Thank you to Lisa & Sid Thornton, and the University of Utah PWS team.
SPECIAL THANKS TO KATE
We are not promoting any products or services.

We have no financial conflicts of interest to disclose.
BACKGROUND
Bronfenbrenner’s Socio-Ecological Model (1979; Kazak, 1989)
Bronfenbrenner’s Socio-Ecological Model (1979; Kazak, 1989)
FEW STUDIES, LIMITED DATA
Siblings of children with chronic illness have higher rates of distress than the general population

• Siblings have higher rates of depression & anxiety than peers with healthy siblings

• Peer activities and cognitive development scores are lower

• Illnesses and treatment regimes that affect daily functioning have the most negative impact

• However, these findings are modified by lots of factors (family cohesion and control, flexibility, age, birth order, gender).

• Parent reports show worse functioning than child reports

In some groups, parents and siblings are more vulnerable than the ill child

• Dunn et al. (2012) found that 41% of mothers and 30% of fathers report PTSS exceeding clinical cut-offs

• Kaplan et al. (2012) found 60% of siblings scored in the moderate to severe range of PTSS and 22% met full criteria for PTSD
• The Millennium Cohort Study (MCS; UK) found that 14% of older siblings of children with intellectual disability had adjustment problems compared to 9% of those whose siblings did not have ID (Hayden et al., 2019)

• In general, siblings of children with intellectual delays are at greater risk for psychological and social difficulties (Kovshoff et al., 2017)

• Results are typically small and modified by factors like gender, SES, single parent household, and whether or not sibling took care of the child.
Not surprisingly, siblings of children with autism have more psychological, behavioral, and social problems than their peers where all family members are developing typically.

Ross & Cuskelley (2009) report that about 40% of siblings developed clinically significant challenges, usually of the internalizing type (anxiety, depression).

The more aggressive the child with ASD, the more the typically developing sibling struggled, *EVEN THOUGH* they typically attributed the aggression to the illness, *not* child or self.
Is PWS so different?

- Yes
- Because the child with PWS often has intense and complex health, developmental, and behavioral concerns, siblings are chronically confronted with challenges in multiple domains of life.
- The needs and the demands change over time with development – Both the development of the child with PWS and the sibling.
- Two studies suggest that siblings of children with PWS suffer more than those with Down’s Syndrome or non-specific delays, even as adults. This is not modified by parenting style or attachment to parents (O’neill & Murray, 2016).
Mazaheri, and colleagues (2013) compared 13 siblings of children with PWS to inpatient and outpatient samples of siblings of chronically ill children:

Family Quality of Life is notably low

<table>
<thead>
<tr>
<th></th>
<th>PWS</th>
<th>Inpatient</th>
<th>Outpatient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>47</td>
<td>81</td>
<td>62.5</td>
</tr>
</tbody>
</table>

Symptoms of PTSD are notably high

92% reported moderate to severe symptoms
"I FEEL LIKE A PIECE OF DUST"

9-year-old sister of a child with PWS
AND STILL....
Some evidence of positivity and resilience

- Kaminsky & Dewey (2002) found that siblings of children with autism reported greater admiration, less competition, and less quarreling with their sibling with ASD

- “I like that he always shows who he is.” (Petalas, et al, 2009)
Research suggests that siblings are at risk for:
- Loneliness,
- Anxiety,
- Depression,
- Less interpersonal intimacy,
- Lowered academic achievement

AND
- Greater compassion
- Greater tolerance
- ???
“It’s a roller coaster ride”
·study participant
Dilemma

- There are not enough data to guide clinical practice.
Family Functioning
- Cohesion
- Conflict
- Control
- Organization

Child Characteristics
- Resilience
- Emotional Functioning
- Psychological dx
- Temperament
- Age relative to sibling

Parent Characteristics
- Well being
- Psychological adjustment
- Marital Relationship
- Social relationships

Psychosocial Environment
- Access to health care
- Funding
- SES/financial resources
- School
HOW DID THIS PROJECT COME TO BE?

It all started with Kate
METHOD
GATHERING DATA

Quantitative Surveys    Qualitative Interviews
PARENT SURVEY

Family Environmental Scale
Youth Outcome Questionnaire
14-Item Scales of General Well-being
SIBLING SURVEY

- Positive and Negative Affect Scale for Children
- Connor-Davidson Resilience Scale 10
- Child Report of Post-Traumatic Stress Symptoms
<table>
<thead>
<tr>
<th>INTERVIEWS</th>
</tr>
</thead>
</table>

**What is it like for you being a sibling to your brother/sister with PWS?**

**Do you have friends over at your house?**

**What are your feelings toward your brother/sister with PWS?**

**What are some good things about being a sibling to someone with PWS?**
FINDINGS AND THEMES
“You just want to be normal.”

“I love being his sibling, but I feel bad all the time.”

“I feel useless if I am not involved in helping her calm down.”

“I feel guilty asking for attention because she needs it more.”
EMOTIONS

- “I am grateful for what she adds to the family.”
- “It is impossible not to love her.”
- “When he is happy, we are happy.”
- “She can always make me happier.”
Relationships With Sibling with PWS

• “She is the royalty and we are her servants.”
• “I wouldn’t want a life without him.”
• 90% of interviewees enjoy being with their sibling with PWS
“I worry about my sister’s safety. She doesn’t have common sense; she might wander off by herself.”

“I always have to be aware. Ten eyes need to be on her at all times; it is stressful and straining.”

80% of the interviewed siblings claimed they worried about their sibling’s safety often.

77% are often hurt by their sibling.
“It is all worth it.”
“I don’t like the disability, but I love her.”
“We are more mature and handle things better.”
“I can look at different ways to solve a problem.”
“I’m thankful because he brings blessings and hardships.”
Growth and Resilience

- Patience
- Responsibility
- Understanding
- Gratitude
- Maturity
Descriptive Data

- Family Cohesion: 45 (4-59)
- Family Conflict: 47.5 (33-80)
- Organization: 49 (21-69)
- Family Control: 57 (27-70)
- Parent Well Being: 45 (0-70)
Descriptive Data

- Resilience: 25 (9-38)
  Average for a US youth is 30

- Child P:N Emotion: 4.5:1

- Sibling Distress: 44 (-4 to 135)
  > 45 is clinically significant
  (Outpt – 79, Inpt -110)

- PTSD: 59% clinically significant
Predicting PTSD & Sibling Distress

The only variable to predict child trauma in siblings is the ratio of reported positive to negative emotions.

Family control and organization predicted overall distress, i.e., anxiety and depression.
Parental Well-Being

• Predicted by family cohesion and sibling positive emotions
DISCUSSION
There is no “one” family environment

- Siblings may each experience the family differently depending on their age, gender, age relative to the child with PWS, genetics, temperament, etc.
- Families exist to support the development of all members
- Resources are limited
Build Resilience

- Individual Relationships
- Strengthen Positive Emotions
- Encourage Humor
Recognize Distress

Open channels of discussion

Listen, debrief

Allow expressions of negative emotions

Find professionals when needed
• Work with medical systems, educational systems, local and national groups to find connections for your healthy children


