

Prader-Willi Syndrome Services: A National Survey

Latham Centers is committed to brighter futures for individuals with PWS and their families. We reached out to members of our PWS community nationwide through a recent survey, and we're pleased to share the results.

The Goal:

The PWS Services National Survey was designed to give parents, guardians, professionals, and chapter members from across the country the opportunity to learn — based on the survey results — what is needed in our PWS community nationwide. In this survey results page, you'll find answers to questions such as:

- What are questions often asked within the field?
- What are the needs of parents and guardians?
- How have people from within the community found guidance, and where do they need more support?

Survey Setup:

The survey asked 30 questions and included six sections, including:

- Demographics,
- Medical,
- Residential,
- Educational and Social,
- PWS related advocacy and parent/guardian support, and
- Vocational.

Survey respondents were given the option to skip questions or to provide details about their personal experiences.

Demographics:

Who took the survey? One-hundred and fifty people from across the nation completed the survey. While most respondents were from the Northeast states and California, other states and regions worth noting are Puerto Rico, New York/New Jersey, the Southeast including Florida, and the North-central states including Wisconsin.

Results:

We include common responses to questions in each of the above listed categories. If you have more questions related to a specific geographic area, please contact Katrina Fryklund at kfryklund@lathamcenters.org. Latham Centers' team would appreciate the opportunity to learn more about your experience and needs.

Individuals were asked **“What is the age of the person that you know with PWS?”** The majority ranged between 0-5, 11-20, and 25-30. They were also asked their relationship to that person with PWS, and the overwhelming response was from **mothers**. The two other most common answers included **legal guardian** or **professional in the field**.

Medical and Behavior Management

- **Helpful Therapists, Endocrinologists, and Medical Professionals included:**
 - Children’s Hospital of California
 - Franciscan Medical, Dr. Fatima Watt and Maria Fragala
 - Independent Consultant, Dr. Jennifer Miller
 - Independent, Lisa Graziano, MA, LMFT
 - Latham Centers, Patrice Carroll, LCSW
 - LOMA LINDA, Dr. June-Anne Gold
 - Lurie Center, Massachusetts General Hospital
 - Rady’s Children’s Hospital (Clinic), Dr. Lynne Bird and Dr. Michael Gottschalk
- **Where respondents have learned helpful coping mechanisms for medical appointments and transitions:**
 - Facebook Groups and Social Media for PWS: Parental Support
 - Latham Centers
 - Literature/Online Searches/Personal Experience
 - PWS Conferences
 - PWSA (USA)
 - PWCF
 - PWS NE
 - School based services
- **Behaviors in which parents/guardians need the most guidance include:**
 - Aggression
 - Anxiety
 - Confabulation
 - Emotional Outbursts/Tantrums
 - Food seeking
 - Non-compliance
 - OCD/Compulsion
 - Obsessive Tendencies/Repetition
 - Perseveration
 - Skin-picking
- **Services are most needed in the following areas:**
 - Behavior Support/Training
 - Education to parents/guardians about potential vocational opportunities
 - Events that are food-safe
 - Food Issues/Security
 - Meal Times/Nutrition
 - Vocational Training for individuals

Residential

- **Necessary resources that are currently unavailable:**
 - Housing specific to people who have a PWS diagnosis
 - Outside community supports and opportunities
- **Residential support is needed to...**
 - Identify well-trained and well-paid support staff for programs geared towards people who have PWS
 - Identify transitional planning ranging from childhood to adulthood



- **Transitional Plans:**
 - Most survey respondents who know someone under the age of 21/22 with PWS have learned about:
 - 18-22 transitional placement
 - Residential placement
 - Son or daughter living at home after graduation from school with at-home supports and day-program
 - Many survey takers who had children within the 1-10 age range had not yet looked into transitional plans
 - Most people who took the survey that know someone over the age of 21/22 with PWS identified:
 - Successful resources:
 - State departments such as DDS (Department of Developmental Services)
 - Visiting residential and day programs to learn program dynamics and enrollment necessities
 - The most successful types of placements:
 - Day Programs (*where parents/guardians are finding the most opportunity*)
 - Residential Housing
 - Volunteer Work Opportunities
 - Paid Work Opportunities (*where parents/guardians are finding the least opportunity*)

Educational and Social

- **Necessary supports needed by the Educational System include:**
 - An open-mindset to learn from parents and guardians about PWS (many survey takers mentioned how he or she – parent or guardian – becomes the educator)
 - Education for the staff about a PWS diagnosis
 - Funding for PWS specific consultation
 - Supportive IEP Teams to build a program in which children with PWS can be successful in non-food secure environments
 - Understanding the meaning of “food secure”
- **Needed socialization opportunities include:**
 - Aquatic programs
 - Athletic programs and classes specific to someone with PWS
 - In-school events that are food safe
 - Out-of-school events that are food safe
- **Concerns about finding a peer group:**
 - Overall, the individuals who took this survey shared a common concern about appropriate peer groups. Some mentioned that the struggle exists because of behaviors as a result of the diagnosis, as well as lacking opportunities. One person said, “The best socialization is with other individuals who have PWS which takes a lot of planning and travel.”

PWS Related Advocacy and Parent/Guardian Support

- **Survey takers would like to learn the following about PWS Advocacy:**
 - How to involve local politicians and state legislators
 - Rights as parents/guardians
 - Rights of the person with PWS in school and residential settings
 - Trusts and other financial options for someone with PWS once parents/guardians pass
- **Survey takers have used the following advocacy techniques:**
 - Appeal to politicians and people who have influence in providing residential placement
 - Collecting data, such as behavior, that are a direct result of poor placements, and presenting data to influential persons
 - Communication with State Chapters
 - Consultation with the Disability Law Center
 - Involvement in state and local committees invested in better opportunities for the Developmental Disabilities population
 - Understanding the laws and your rights
- **State Chapters help our survey takers by:**
 - Learning legal requirements for transitional planning for which most schools seem to be out of compliance
 - Obtaining information about resources and events
- **Survey takers wished their State Chapters would provide more information on**
 - Financial planning
 - Housing options
 - Transitional planning

Vocational:

- **Survey takers needed vocational guidance in the following areas:**
 - Career planning: better tools to assess skills and interests
 - How to advocate for rights in work settings
 - Information about other successful job placements
 - Paid employment as opposed to volunteer opportunities
 - More opportunities in general!
 - Where to find vocational opportunities
 - Where to find employers who understand a PWS diagnosis
- **Helpful vocational tools included:**
 - Easter Seals
 - Person-centered planning
 - Three-Year Re-Evaluations
 - Vocational Specialist

Thank you to the survey respondents for taking the time to share your experiences and needs with others in the PWS community! We'll continue the conversation through ongoing collaboration.

Stay in touch with the network of PWS resources near and far:

- Find a PWSA Chapter in your region: <https://www.pwsausa.org/find-a-chapter/>
- Follow Patrice Carroll's Tip of the Week on Latham Centers' blog: <https://www.lathamcenters.org/blog/>
- Subscribe to our Latham's quarterly "Living Healthy with PWS" newsletter: Please email kfryklund@lathamcenters.org to be added to our email list.