Caregivers’ Forum

IPWSO
International Prader-Willi Syndrome Organisation
LathamCenters
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Meeting Notes | Thursday 25 September 2025, 8pm UK time

Meeting 04.

Attended

From IPWSO: Shelly Cordner (UK)

From IPWSO’s PPC Board: Neil Gumley (Australia), Patrice Carroll (USA), Lynn Garrick (USA), Myles Kelly (UK), Lynsey Moorehouse (Ireland)

Caregiver Delegates: Bastian Bühler (Switzerland), Kim Herivel (Australia), Mark Lister (USA), Julie-Anne Quinney (New Zealand)

Other Forum Members attending the meeting represented Argentina, Bulgaria, Costa Rica, Denmark, France, Germany, Hungary, Mexico, New Zealand, Russia, Sweden, UK, USA

45 people in total attended.

Please note in accordance with IPWSO’s Privacy Policy we do not release the Zoom recording of the meeting, or list the names of general Forum Members without their express permission. PPCB and Caregiver Delegates have given advance permission to have their names listed in the Forum.

Members should contact Shelly Cordner scordner@ipwso.org in the first instance if they wish to connect with specific Forum Members over email.

Agenda

8pm: Welcome to the Forum

Shelly and Neil gave a brief welcome and introduced speakers. Topic of ***How to establish a PWS residential home.***

Background to the meeting:

Any PWS residential home must meet the core needs of people with PWS.

- **Food management:** Locked kitchens, structured meal routines, staff training to ensure food security.
- **Medical care:** Monitoring for obesity, diabetes, sleep apnea, scoliosis, osteoporosis; access to endocrinology and hormone therapy.
- **Behavioural support:** Staff trained in managing rigidity, anxiety, outbursts, and obsessive behaviours within structured routines.
- **Mental health:** Monitoring for mood disorders, skin picking, and risk of psychosis.
- **Social inclusion:** Balancing autonomy and safety through community activities, employment, and recreation.

There are country-specific challenges

- **High-income countries:**
    - Strong regulations, funding through state/insurance, and access to multidisciplinary teams.
    - Accredited staff training required.
    - Stronger emphasis on safeguarding and individual rights, with tension between food restriction and autonomy.
- **Middle-income countries:**
    - Limited funding and specialist expertise.
    - Greater reliance on family or NGOs; residential homes less common.
    - Barriers in dietetic food access and suitable housing modifications.
- **Low-income countries:**
    - Low awareness and underdiagnosis of PWS.
    - Very limited medical resources (growth hormone, obesity care).
    - Care mainly family-based; group homes rare.
    - Funding reliant on charities or international support.

There are also ethical considerations.

- **Food restriction vs. autonomy:** Essential for health but raises rights concerns.
- **Disability rights:** Countries interpret differently; UNCRPD provides global guidance.
- **Transition planning:** Lifelong support must be considered, not just childhood care.
- **Family role:** Degree of family involvement varies widely by culture.

Overall:

- **Everywhere:** Services must provide strict food control, structured routines, trained staff, and regular medical monitoring.
- **High-income settings:** Regulation, autonomy, and multidisciplinary care dominate.
- **Middle-income settings:** Resource limitations and family-based care are central.
- **Low-income settings:** Awareness, funding, and medical access are major barriers; support is often informal.

8:05pm: Brittni Kliment, Executive Vice President, Latham Centers, USA, supported by Lynn Garrick, Program Director, AME Community Services, USA.

Brittni's Presentation, Building Safe and Supportive Homes for Individuals with Prader-Willi Syndrome is available to watch here.

Overview:

- Understanding PWS Behaviours
- Environmental Design
- Staffing & Programming
- Practical Applications

Lynn Garrick has also provided two presentations and further reading to refer to:

The Establishment and Management of a PWS Group Home (American Experience)

Patient Care Issue of a PWS Group Home

Supporting Adults with Prader-Willi Syndrome in Residential Settings

Notes from Q&A with Brittni:

Latham Centers operates about ten homes on Cape Cod, with a few more located off-Cape to help address staffing needs. These homes are integrated into ordinary neighborhoods within the community, rather than being set apart, and each one typically houses four to five individuals.

Staffing levels are an ongoing challenge. Most homes operate with a ratio of one staff member for four to five residents, though some individuals require closer support, even on a one-to-one basis. Ideally, the ratio would be two or three staff to a home, but this is difficult to achieve consistently due to funding limits and staffing shortages. Brittni emphasised that while the physical setup of the houses is important, staffing is critical to the success of residents. She sees it as a balance: well-designed homes create the right environment, but it is the staff who truly make the difference in supporting individuals' daily lives.

Kitchen design is one area where this balance is especially visible. In homes developed about five or six years ago, the kitchens were built as enclosed spaces with locked fridges and cabinets. Staff prepare all meals, ensuring safety for residents with PWS, while still allowing some degree of access through sliding doors or windows. Deliveries are brought in directly through the garage into the kitchen, avoiding disruption inside the home. Brittni noted that while these measures are effective, they also try to maintain a sense of normalcy so that the homes feel like any other household.

Brittni explained strategies for meal preparation with people with PWS: using a sliding glass window for visibility into the kitchen and timing staff shift changes during meal prep so one staff member can cook while others supervise. This ensures safety, supervision, and engagement during meals.

Different countries approach this issue in different ways. In Australia, for example, there are legislative requirements that any locked fridges or pantries must be formally approved by the government. In the USA, similar restrictions must be approved by a Human Rights Committee and written into residents' individual care plans.

A safe and thoughtfully designed environment matters, but it is the staff who bring stability, care, and quality of life to residents.

8:15pm: Open Forum Discussion

Question 1: In Pennsylvania, USA, a team described challenges with a resident who frequently elopes, putting herself in dangerous situations like walking into traffic. Staff often have to follow her closely, and police are regularly called to manage safety. Although she hasn't been arrested, she is well known locally, and both stores and law enforcement are familiar with her. The team has considered moving her to a more rural setting where temptations and risks are less accessible.

Others in the discussion shared similar experiences from Ireland (Lynsey) and Australia (Neil). In both places, building proactive relationships with local police proved essential. Teams introduced themselves to law enforcement, provided training about PWS, and created ongoing connections so officers understood the unique challenges and motivations of residents. This helped prevent situations from escalating and fostered trust. Police in one Irish town now visit at Christmas, while in Australia, officers have been given background information through training and even technology tools like an alert app.

Regular retraining for police is vital, given turnover in both staff and law enforcement. The goal is to ensure officers approach individuals with PWS from an informed, empathetic perspective, recognising that their actions stem from the syndrome rather than typical behavioural issues. This proactive approach not only improves safety but also strengthens community support and understanding.

Links to some resources suggested are:

When a person with Prader-Willi syndrome is in trouble with the law

To: Law Enforcement Personnel Regarding Adults with Prader-Willi Syndrome

Question 2: A team from New Zealand shared that in their small region they have struggled to support adults with PWS locally. Currently, people must move out of the region into specialised PWS homes, but there might be a need to create mixed housing models where individuals with PWS live alongside people with other intellectual or physical disabilities. They asked whether such models have worked elsewhere and how challenges, particularly around food access, are managed.

In response, colleagues from the UK (Myles) and Australia (Neil) explained that mixed homes do exist and can work well, though outcomes vary. Some people with PWS prefer not to live with others who also have the syndrome, while others do better in specialist settings. The main challenge in mixed housing is balancing food security for residents with PWS without unfairly restricting the rights of others.

Strategies that have helped include grouping residents with similar needs (for example, others who also have issues around food); ensuring expectations are clear from the start (e.g., if a house has food restrictions, new residents understand this before moving in); and putting safeguards and support plans in place to protect all residents' rights. While managing locked fridges and cupboards can be complex, pairing compatible individuals and building homes around the needs of people with PWS has allowed many services worldwide to make mixed models successful.

Julie-Anne in New Zealand explained that their services include both specialist PWS homes and mixed homes, and that success is often easier when the person with PWS is placed in the house first. In higher-functioning houses, they use biometric systems such as fingerprint locks. These allow residents without PWS to access food and belongings freely, while preventing unsafe access by the individual with PWS. With some coaching and guidance, non-

PWS residents adjust well, though staff also need to manage potential coercion from the person with PWS.

Others compared approaches. In New Zealand, biometric systems have proven reliable, with only rare failures thanks to battery backups, and are relatively inexpensive to install. They also eliminate issues like lost or noisy keyrings, making the environment smoother and more pleasant. By contrast, some services elsewhere, such as in the USA, still rely mainly on keys or key fobs, partly out of caution about technology failures.

Question 3: As a follow-up to the above discussion, a parent described how they currently manage keys at their son's home by numbering them but raised concerns about the reliability of biometric systems, asking whether they are wired into electricity or only battery-operated. Julie-Anne responded that in New Zealand their biometric locks are connected to the electrical system with a battery backup, and they also include a backup code system in case the fingerprint scanner fails. For example, one resident who had worn a thimble for years couldn't use her fingerprint, so staff relied on the code. Casual staff can also use the code if they haven't been preloaded into the system. Each user is typically registered with more than one fingerprint as an added safeguard.

It was noted that biometric locks don't always need to be wired into the main electrical system. Simple standalone versions can be installed on individual cabinets or pantries, and many families now use them at home. For example, one family fitted a biometric lock to a sliding pantry door so siblings could still access food while keeping it secure from the person with PWS. These systems are increasingly common in family settings.

Comment: Lynsey described Resilience's model for PWS specific homes, where each resident has their own self-contained apartment within a larger shared house. The apartments include a sitting room, dining space, kitchenette, bedroom, and ensuite, alongside communal areas like a dining room. This setup reduces the stigma of traditional group homes, giving residents independence, privacy, and a personal space they can decorate, while still offering shared community living.

Locked kitchens are standard in these homes, but the design emphasises more than just security. The goal is to create a warm, homelike environment that avoids an institutional feel. Personal space helps residents manage emotions and reduces anxiety, while thoughtful design and atmosphere give the house a vibe that encourages comfort and stability. Balancing security with homeliness is key: residents need safety, but they also need their homes to feel normal, welcoming, and truly their own.

Question 4: Neil asked how different countries are approaching (or struggling with) PWS specific group homes.

Many nations still lack such facilities. Representatives from Argentina and Brazil described being at the very beginning of the process. In Argentina, a small group of families has formed a foundation and started the legal groundwork to establish a residence, but they face challenges convincing others about the need for strict food control. In Brazil, the national Association has identified assisted living as one of its key goals for the next four years. They currently have no group homes, and while they are committed to building one, they are concerned not only about funding construction but also about ensuring sustainable long-term financing.

The Forum highlighted that every country with PWS services once started from scratch. There is no single model that works everywhere. Some places have apartments for individuals, others group homes, and some mixed models. The key message was encouragement: even though it is difficult, many examples worldwide show it can be done, and this international community can provide guidance, shared knowledge, and support for countries just beginning their journey.

Comment: Myles and others highlighted a study by Professor Brian Hughes on dedicated PWS residential services. The study found that residents in specialised PWS services experience significant weight loss and improvements in behaviours of concern, with these benefits appearing within a year and continuing over time. Key factors contributing to these outcomes include staff specialisation, food security, and the size of the service, with service specialisation particularly important for BMI, and smaller service sizes linked to behavioural improvements. The data came from six countries, providing a substantial evidence base.

The discussion emphasised the importance of research to support funding and policy decisions, noting that while medical interventions for PWS are widely studied, more focus is needed on the effectiveness of residential care. Providing safe, structured environments in specialised group homes is critical for managing behaviours, anxiety, and hyperphagia, enabling individuals with PWS to thrive. The consensus was that further studies on the benefits and limitations of specialised group homes are essential for advancing care.

The study: Body weight, behaviours of concern, and social contact in adults and adolescents with Prader-Willi syndrome in full-time care services: Findings from pooled international archival data

The Report on the Joint National Pilot of the Health Service Executive and the Prader Willi Syndrome Association of Ireland was also noted as a helpful example of work with the government around education in relation to PWS and securing funding for PWS specific services.

Comment: Myles also raised challenges with regulators around managing food for people with PWS. In the UK, the Care Quality Commission has begun questioning practices like locking kitchens, even in PWS-specific homes, requiring providers to continually educate new regulators. In the USA, similar issues arise when new psychologists or officials question established practices, sometimes altering care plans in ways that complicate food management.

Participants emphasised the need for standardised documentation, guidelines, and best-practice policies to explain why certain measures like locked kitchens are medically necessary for PWS.

A sibling of a person with PWS in Michigan, USA, highlighted a supported independent living situation where a behaviour specialist reviewed restrictions and confirmed they were appropriate, with the person with PWS was able to explain their necessity.

In Australia, a “least restrictive” model is used, starting with minimal restrictions and gradually adding them as needed, with annual reviews to remove any unnecessary limits. Norbert, an experienced psychologist, emphasised that individuals with PWS should be gradually included in responsibilities like managing key so they can learn competencies over time.

Question 5: Norbert was asked by Forum members to expand on how to involving people with PWS in food-related activities - by reflecting on both positive and negative behaviours. Early diagnosis allows parents and staff to communicate normally, guide, and train individuals to understand the consequences of their actions, build empathy, and recognise their own competencies. Instead of rigidly structuring everything, caregivers should ask individuals what strategies they find helpful and support them in decision-making. It was noted that even for adults who have had highly structured routines for years, this reflective and participatory approach can still be applied. Norbert stressed that while practical measures like locked kitchens are sometimes necessary, the focus should also be on empowering and involving the individual.

Teach people with PWS self-advocacy so they can speak for themselves, explain the need for group homes, and participate actively in decisions. Working with individuals rather than for them helps build competencies, independence, and better long-term outcomes, and enables them to help lobby for services and support within their communities.

One example provided was Helping Carers to Understand: Kate’s Story.

8:25pm: Close and Thank you

The next meeting of the Caregiver’s Forum is scheduled for **Thursday 22 January, 1pm UK (London) time,** on the topic of **Ageing in PWS**.

For detail on upcoming IPWSO events visit: https://ipwso.org/news-events/