



IPWSO
International
Prader-Willi Syndrome
Organisation

Family Meetings

Meaningful occupation and activity for adults with PWS: Promoting well- being and community

Wednesday, 7 October 2026

Meeting Summary

We were delighted to welcome parents, professionals and advocates from around the world to discuss how meaningful activities can support the well-being, independence and community participation of adults with PWS.

Fred Nicolai, Director of Prader Willi Huis (the Netherlands), shared his experience of developing specialist residential and day services. His approach focuses on building trusting relationships, providing predictable routines and creating a safe, welcoming environment. Activities such as gardening, creative workshops and producing items for sale help residents develop skills and experience a sense of achievement. Fred emphasised the importance of tailoring activities to individual interests and abilities, with caregivers working alongside residents to help them succeed.

Janice Agarwal (USA), a parent and paediatric physical therapist, discussed the importance of developing practical skills from an early age. Through a farm-based programme she established with her husband, young people and adults with intellectual disabilities gain vocational experience through activities such as gardening, weaving and property maintenance. Participants work alongside others, build on one another's strengths and have opportunities to earn wages. Janice highlighted how everyday responsibilities in childhood can help prepare individuals for employment and greater independence in adulthood.

Maria Benedevoka (Slovakia) shared her family's experience of supporting her 24-year-old son, Tomáš, to participate in his local community. Through a day programme, he enjoys activities including music, theatre, swimming and Special Olympics. Personal assistance has also helped him develop everyday skills and build friendships. However, Maria highlighted challenges including limited staff understanding of PWS and insufficient crisis planning, reinforcing the importance of appropriate training and consistent support.

During the discussion, participants explored how to create meaningful opportunities where specialist services are unavailable. Suggestions included handmade arts and crafts based on individual interests, while one participant shared an example of a local day centre in Brazil offering daily living activities, outings and workshops. Maria's experience also demonstrated how families can build connections through associations and make use of community services.



Speakers encouraged families to start developing practical skills early, connect with others and explore local opportunities.

Funding and access to suitable services were recurring themes. Janice explained how including people with a wider range of intellectual disabilities can help programmes become more sustainable, while Fred described the government-funded support available for disability services in the Netherlands. Participants also discussed emerging treatments such as VYKAT, which is prescribed in the US, with speakers expressing optimism while emphasising that meaningful activities, supportive relationships and appropriate care will remain important for adults with PWS.

Overall, the meeting reinforced that there is no single approach to meaningful occupation for adults with PWS. Whether through paid or voluntary work, structured day programmes or creative and recreational activities, opportunities should reflect individual interests, abilities and support needs. With appropriate support, planning and collaboration, families and communities can help adults with PWS develop skills, build relationships and enjoy fulfilling, meaningful lives.

Questions? email us office@ipwso.org