



**IPWSO**  
International  
Prader-Willi Syndrome  
Organisation

# Family Meetings

## Supporting success at school: Planning for PWS throughout the school years

Wednesday, 15 April 2026

### Meeting Summary

We were delighted to welcome parents, professionals, and advocates from many countries to discuss how best to support children and young people with PWS in education.

The presentation made by Barbara J. (BJ) Goff, Ed.D., and Elizabeth Roof, M.A. (USA), explained that many children with PWS cope well in early schooling but often face increasing academic, social, and behavioural challenges from around ages nine to eleven, when learning becomes more abstract and peer relationships change. These difficulties were described as arising from anxiety, frustration, and neurological factors rather than wilful behaviour. Appropriate school placement, realistic expectations, and regular assessments - especially at transition points - were emphasised as key to supporting both learning and well-being.

A strong focus was placed on preparing schools effectively. Parents were encouraged to share clear, manageable information about their child's strengths, needs, and health considerations, and to work with schools gradually rather than overwhelming staff. Training delivered by recognised PWS specialists was highlighted as particularly valuable. Health and safety issues, especially strict food security, sleep problems, temperature regulation, and low muscle tone, were identified as essential areas for school understanding and planning.

Classroom strategies discussed included predictable routines, visual schedules, advance warnings for change, direct teaching of social skills, movement breaks, and positive behaviour supports. Consistent, constructive communication between home and school was seen as critical to preventing problems and building trust.

Parent speakers Michael Rubin and Cathy Mallove (Canada), and Salman Shaban (Qatar) shared lived experiences from different education systems, stressing a holistic, lifelong view of education that balances academics with social, emotional, and vocational development. Active parental involvement in schools and community settings helped strengthen advocacy and inclusion. Alternative pathways, adaptive activities, and real-world experiences such as volunteering, travel, and vocational learning were shown to build confidence, purpose, and belonging.



In the Chat, parents talked about mainstream schools, special schools, small private settings and home education, agreeing that there's no single right path. Many shared how hard it can be to find schools that truly understand PWS, and how often families end up explaining the condition themselves and pushing for the right supports.

People also swapped ideas and resources, with associations describing materials and projects that help schools and families work better together. Topics like IQ testing, social relationships, communication, and planning for the future all came up, showing common worries but also practical, hopeful approaches. Throughout the chat there was a lot of encouragement, gratitude and shared optimism, reinforcing a strong sense of community and the belief that, with understanding and teamwork, children and adults with PWS can thrive.

Overall, the meeting reinforced that there is no single educational pathway for individuals with PWS. Flexibility, collaboration, and ongoing reassessment are essential. With informed advocacy, appropriate supports, and a focus on wellbeing as well as learning, children and young people with PWS can experience fulfilling and meaningful lives.

Questions? [email us office@ipwso.org](mailto:office@ipwso.org)