

IPWSO MENTAL HEALTH ECHO



IPWSO Mental Health ECHO Summary

June 27, 2023: The design of services to meet the behavioural and mental health needs of children and adults with PWS

IPWSO presented the 4th Mental Health in Prader-Willi syndrome ECHO on the 27th of June, 2023. At this ECHO meeting the objective was to discuss Mental Health services for people with PWS:

- What should they look like?
- What skills are needed?
- How might they integrate with other services, such as education, endocrinology, and social care?

Dr. Louise Gallagher, Chief of the Child and Youth Mental Health Collaborative at the Hospital for SickKids in Toronto, Canada, presented on the design of mental health services for children and youth with PWS.

The learning objectives for this presentation were:

1. Understand how to conduct a gaps analysis of service provision with stakeholders.
2. Understanding the behavioural, emotional and psychiatric needs of children and youth with PWS.
3. Learn about the development of an integrated approach to care delivery involving psychiatry.

Maximillian Deest, Psychiatrist, Outpatient Department for Mental Health in Rare Genetic Disorders, Hannover Medical School, Germany, presented on the design of mental health services for adolescents and adults with PWS.

The presentation included:

1. Learnings from the Outpatient Department for Mental Health in Rare Genetic Disorders at Hannover Medical School, Germany.
2. The most important things you need to be aware of when treating people with PWS and mental health issues.
3. The ideal setup of services for mental health in PWS.

Tony Holland, IPWSO President, shared a Clinical Challenge to stimulate discussion on what happens when PWS mental health services fail.

Reflections on the meeting can be heard in the video summary linked below.

Video links

Louise Gallagher: [Co-designing mental health and social services for PWS in Ireland](#)

Max Deest: [Mental Health services for adults with PWS](#)

Tony Holland: [Clinical Challenge: When Services Fail - The prevention of avoidable deaths](#)

Patrice Carroll: [IPWSO Mental Health ECHO Summary June 27, 2023](#)

A letter on PWS Services in France

Below are reflections on the meeting written by François Besnier, IPWSO Vice-President and Prader-Willi France.

First of all, I just want to say how I found this session interesting, stimulating and rich, with the emphasis on the environment and the importance of listening to families.

Concerning the challenges, I just want to share what we are setting up in France, following the critical situation of a young girl with PWS some years ago.

The starting point is to affirm that there is collective responsibility of all parties involved. Which means that any person, family, caregiver, social worker, doctor, etc., considering that there are enough alert signals, may or must ask, when they believe there is a critical situation, that a working group is set up and meetings organised to work on the case and determine actions. Of course, they cannot perform miracles but at least something is done, and the case is not ignored.

The discussion about PWS specific solutions is a complex one. In France, there is only one specific home with 10 rooms but many adults with PWS live in mixed institutions, with one or several others with PWS. If the team is properly trained on PWS and sets up a solution for food security, adults can have a happy life. This was the case of my daughter. They meet with other persons with PWS during vacation packages organized by the association, families regional meetings or in Hendaye hospital during respite stays. There PWS is the norm, and they discover they are not alone.

So, for me it is a societal or social problem and political policy to make mixed solutions possible for people with PWS.

Tony said that more and more adolescents or adults claim a “normal life”. I confirm there is a clear emerging demand for this along with the associated frustration of facing difficulties to achieve this goal. But they also wish to have a meaningful occupation and not just to be occupied. They want a project for their life. We have to seriously consider this important point regarding what society offers to them and the individual level of support needed to answer this legitimate demand. Crises and psychiatric episodes can be triggered by this distance between what they think they are able to do and what is offered to them.

PWS is a rare disease with neurodevelopmental disorders. This means a dynamic vision of the trajectory of the person. From birth to adolescence, the family exercises a rather full control of the child, mainly due to the food related needed control, but also in other situations where the child could progressively make their own decisions and choices. As the child grows, it gets harder and harder in an open environment. Some families prefer to still control all, resulting in a lack of socialisation for all the family, and restriction of any freedom. Adolescents try to escape this rigid framework, sometimes with extreme behaviour. This transition period we know is critical.

So, the main challenge is how to evolve the necessary framework? How to introduce self-determination, individual choices but with the needed protection and support? What kind of risk is acceptable?

This transition from rather strict control to relative autonomy, in some situations, according to each individual, is a complex question, but for me and many families, crucial.

Upcoming Mental Health ECHO sessions

July 25	The application of psychological models in the understanding of adaptive and maladaptive behaviours in people with PWS	Norbert Hödebeck-Stuntebeck, PhD, Psychologist, PWS-InterNational, Germany Kasey Bedard, BCBA, University of Florida, USA
	Challenge: Putting psychological interventions into practice	Marguerite Hughes, CEO, IPWSO
September 26	Early intervention for children with PWS	Anastasia Dimitropolis, Professor of Psychology, Case Western Reserve University, USA Kate Woodcock, Reader in Applied Clinical Psychology, University of Birmingham, UK
	Challenge: Early intervention in practice	Karin Clarke, Chairperson PWS Support Group, South Africa

Thank you very much to everyone who attended the session and participated. We look forward to seeing you again at the next session on 25 July.