



Summit on

Preventing obesity and other risks, and promoting a good life: global experiences of restrictions and supporting independence

Sunday 14 May 2023, 11am London, UK time

IPWSO was delighted to welcome participants to the 2nd Summit Meeting on Sunday May 14, 2023. During the meeting families and health and social care professionals shared their experiences and reflected on how such issues and crises are managed in their country. Two additional video presentations were also recorded and made available for viewing in advance of the discussion.

These presentations are now available, and we hope those of you who were not able to attend will be able to watch them and to share with others who might also find them useful.

Thank you very much everyone for the great presentations and the very stimulating discussion!

-Comment from participant

Video presentations: Global experiences of restrictions and supporting independence

Welcome address: [Tony Holland, IPWSO President, University of Cambridge, UK](#)

[Christina Brydegaard, Healthcare manager, Nurse, Bostedet Solvang, Fejø, Denmark](#)

[Karin Clarke, Parent, Chairperson PWS Support Group South Africa, IPWSO Trustee, South Africa](#)

[Samik Datta, Parent and Committee Member, Indian Prader-Willi Syndrome Association, India](#)

[Lynn Garrick, Parent and Programme Director, AME Community Services, USA](#)

[Georgina Loughnan, Physiotherapist/healthy lifestyle clinician, Metabolism & Obesity Services, Royal Prince Alfred Hospital, Sydney, Australia](#)

[Jorgelina Stegmann, President, Clinical Physician, SPINE Foundation, Argentina](#)

[Jorgelina Stegmann, Versión con subtítulos en español](#)

[Lantz Yap, Parent, IPWSO Trustee, PWS Association, Malaysia](#)

Presentations were followed by Questions and Answers, and group discussion.

Questions

1. Are families of children with PWS in your country informed early in the child's life about hyperphagia and other behaviours that can result in harm and how to manage them?
2. To what extent is it accepted that restrictions on access to food are necessary and likely to be required over a person's lifetime? How restrictive can they be and what happens if an adult with PWS refuses to accept food security and has become severely obese and their health and possibly their life is at risk?
3. A child or adult with PWS is engaging in behaviours that are distressing and dangerous to them and others. Would restrictions on freedom be justified? How would such restrictions be implemented and monitored and how can the quality of life be maintained?

4. There is much debate about the use of psychiatric medications to 'treat' difficult behaviour, such as emotional outbursts, and limited evidence to indicate benefit. Whilst it may be appropriately for medication to be used to treat serious mental illness there are concerns about the excessive use of such medication at times of crisis because of problem behaviours and their on-going use without medication reviews and without clear evidence of benefit. Such medications, when used to treat these behaviours, are seen as restrictive because of their effects on a person's function. Is this a common experience and how might restrictions that are chemical in nature be addressed?

Meeting Summary

This short summary is taken from the meeting transcript. IPWSO President Tony Holland closed with some brief reflections on what we heard at the meeting.

I think what's been really striking is the diversity in the presentations we've had, and that is really important for us in IPWSO because we're not always aware of the struggles that people have in all the different countries that that we're involved with. And so that's been really helpful. I do think that there are some principles that guide how you might intervene in a way that might be seen as restrictive. This is something that I think, as an organisation, we should look, at preparing something that guides people and helps them in thinking about this.

But I think there was general agreement that we are there to try and support independence, to support the person having choice and to be fully engaged in life. Also I think there was general agreement that certainly around food, the restriction there is a very positive restriction, and maybe "restriction" remains a problem word to use. I think we didn't touch as much on some of the issues around what comes with emotional outbursts, or what or what might occur if someone was to become mentally unwell. So I think still discussions to be to be had, but there is never time for everything.

Thank you to those of you who participated. We look forward to holding the next Summit Meeting later in 2023 and will share details in the IPWSO Newsletter when it is announced.