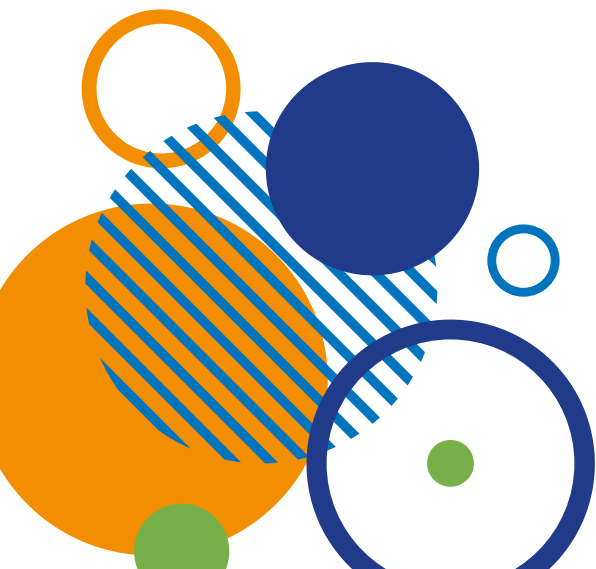




# 6th International Prader-Willi Syndrome Caregivers' Conference

21-23 May 2024, Berlin, Germany

## Balancing rights and restrictions for individuals with PWS



[www.ipwso.org](http://www.ipwso.org)

## Workshop Summary

### Understanding behaviour: Behavioural diagnostic methods for caregivers in the everyday support of people with PWS and the implications for interventions

#### **Workshop Leaders:**

Hubert Soyer, PhD. Psychologist, Germany, Gary Brennan, National Development Manager, PWSAI, Ireland, Johannes Fuhrmann, Germany and Lynn Garrick, Programme Director, AME Community Services, USA

#### **Workshop description:**

This workshop invited all participants to a dialogue to find practical solutions for a central and particularly sensitive issue in dealing with Prader-Willi syndrome (PWS). The workshop comprised four keynote speeches in which basic concepts were presented that served as a basis for the subsequent discussions. These ideas were integrated into the framework of the workshop.

## Workshop presentations

In the short presentations, the topic was examined from different angles to ensure a comprehensive understanding of the complex interrelationships.

### The presentations used to facilitate the workshop were as follows:

1. Balancing individual rights and restrictions - an irresolvable dilemma, Hubert Soyer, Germany. [PDF available here.](#)

Key question:

Is a balance between the individual rights of a person with PWS and (necessary?) restrictions possible or should there rather be a dialogue on how to deal with tensions between individual rights and restrictions that arise?

Focal points in this presentation were autonomy vs. protection, access to food and nutritional control, integration vs. protection from overstimulation, right to education and employment, to name but a few.

2. Balancing rights and restrictions for individuals with PWS, Johannes Fuhrmann, Germany. [PDF available here.](#)

This presentation highlighted personal experiences, to emphasise the importance of independence and the barriers faced in realising aspirations. Johannes' talk advocated for a paradigm shift in caregiving, focusing on nurturing individual potential and empowering individuals with PWS to lead autonomous lives. Collaboration between caregivers and individuals with PWS is essential to bridge the gap between aspiration and reality, fostering inclusivity and empowerment.

The latter half of this presentation was also captured and can be viewed [here](#).

3. Decision-Making Capacity and PWS, Gary Brennan, Ireland. [PDF available here.](#)

In April 2023 the Assisted Decision Making (Capacity) Act (2015) was enacted into legislation in Ireland. The Act supports decision-making and maximises a person's capacity to make decisions. It applies to everyone over the age of 18 and is relevant to all health and social care services. This Act will help ensure compliance with human-rights obligations including the United Nations Convention on the Rights of Persons with Disabilities.

In terms of decision-making, adults with PWS can make decisions about many areas of their life, but dysfunction in areas of the brain that control eating behaviour and energy balance means that they may struggle to have the capacity to independently make decisions about eating.

This presentation looked at how the Prader-Willi Syndrome Association of Ireland is working with local agencies to identify a framework of supports for adults with PWS and their families, that meets their needs around their capacity to make informed decisions and also works within the scope of the legislation.

This presentation focussed on [A Report on the Joint National Pilot of the Health Service Executive and the Prader Willi Syndrome Association of Ireland](#) which can be found [here](#).

#### 4. [Balancing Rights and Restrictions](#), Lynn Garrick, USA. [PDF available here](#).

For many providers across the globe, there can be a tension between rights and restrictions. We may hold tight to our own personal beliefs of what is the best way to support individuals. This may come from past experiences, generalisations, or what we have been taught in the past is the way to successfully manage PWS. Sometimes providers can become stuck in a pattern which begins with a deficit mindset. Each person is unique and will not need the same level of restrictions or support. Taking the time to fully understand each individual you support is key.

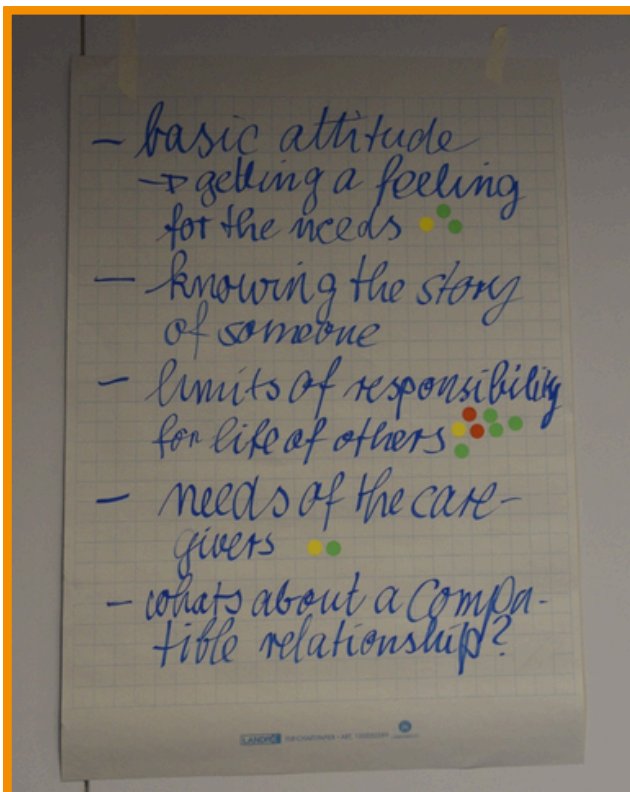
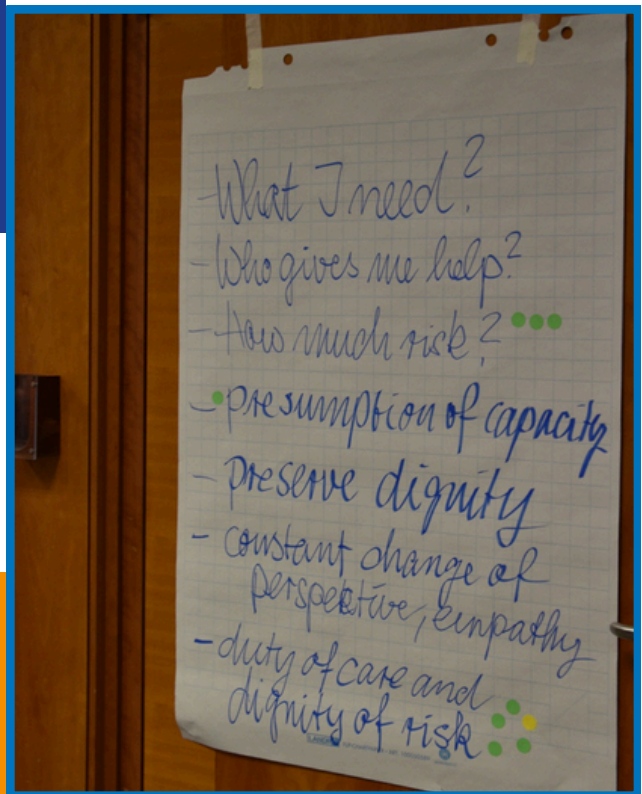
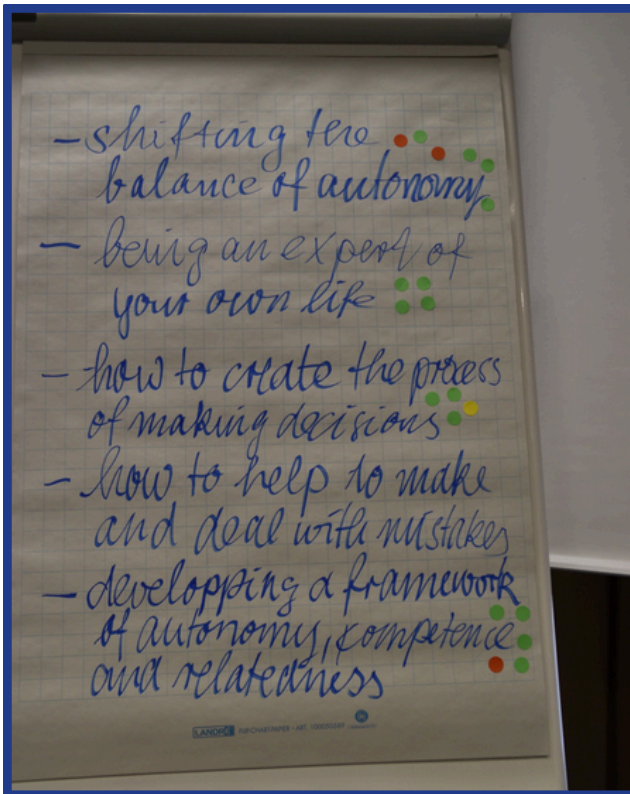
Restrictions may be necessary to maintain health and safety. Conversely, restrictions can bring about behaviours and cause dependence. Does supporting individuals with PWS always include restrictive practices like limiting access to food and money? Before initiating any restrictions, we must consider the UNCRPD and how we can support the individual to lift the restrictions.

This presentation looked at ethics when deciding on rights restrictions, addressing our biases, the fear some of us may have when “loosening the reins” and how to be a partner in support.

#### **Breakout groups**

The participants jointly developed a catalogue of discussion points, which were prioritised according to their importance. These topics were then explored in greater depth in small working groups.





### Delegate report

Bjørn Christensen, Regional Service Manager, Community Connections, Wellington, New Zealand attended the workshop and provided this wonderful summary of his experience.

*This was a fantastic workshop. We worked in groups and it was very much a high focus on removing restrictions and co-creating choice alongside the individual with PWS. We are all aware of the use of restrictive practice that is often in place for someone living with PWS so this very much went in the other direction.*

*A key question was how to habilitate a PWPWS in their communities? To thrive, not just to survive. Habilitation involves teaching skills to live as independently as possible. How do we do this?*

*Collaboration between care providers. Sharing our success and our failures builds further resources across the globe.*

*Optimising positive opportunity for PWPWS. This also includes the encouragement of positive decision making.*

*Having a shared vision for best support with someone living with PWS - Better networking in NZ would be our good starting point.*

*We were incredibly lucky to have Johannes Fuhrman in our group for this workshop. Johannes is a PWPWS and an amazing advocate for the PWS community. He explained restrictions from his lived experience which was really helpful.*

Workshop group: Christina  
Brydegaard, Denmark,  
Sarah Leichsenring, Germany,  
Johannes Furhmann, Germany,  
Bjørn Christensen, New Zealand,  
Lynsey Moorehouse, Ireland  
and Danielle Kerlake, Ireland.



**Report of Bjørn Christensen (continued...)**

*Every person is presumed to have capacity for decision making in their life.*

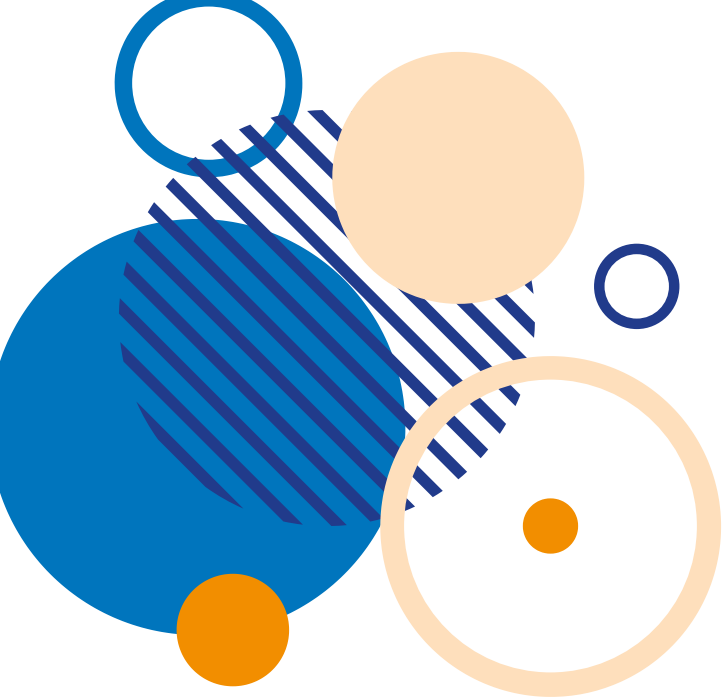
*An unwise decision is still a decision - making progress towards positive choices.*

*We had a great brainstorming session once separated into groups for this workshop. Our topic was 'How to co-create the process of making decisions?' What made this group really great to work in was having Johannes in the group to get his perspective around choice for PWPWS. In the end, we had a great conversation and raised many valid points around what is needed to facilitate autonomous decision making. We came up with a six point plan which is detailed below:*

*Human rights belong to everyone and should be at the centre of what we do. Do we have a deficit mindset?*

*Six Step plan for making decisions*

- 1. What is it that I want to do?*
- 2. What do I need to know and what support do I want?*
- 3. Do I have a plan?*
- 4. Give me some time to think.*
- 5. I am ready to make a decision*
- 6. Reflecting(celebrating) on my decision*



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Salisbury House, Station Road, Cambridge CB1 2LA, UK

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