




**6th International Prader-Willi Syndrome  
Caregivers' Conference**

21-23 May 2024, Berlin, Germany

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



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## Workshop Summary

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

#### **Workshop Leaders:**

Norbert Hödebeck-Stuntebeck, PhD, PWS-InterNational, Germany and Tony Holland, Psychiatrist, University of Cambridge, UK

#### **Workshop description:**

This workshop focussed on two main topics:

1. The use of standardised diagnostic procedures that can provide helpful background information for understanding the behaviour of people with PWS.

2. The development and evaluation of observational methods that can be used in everyday care.

The aim was to develop more reliable and objective information about the basis or background for challenging behaviour affecting people with PWS. The results of the methods discussed form the basis for targeted support and interventions in the support of people with PWS. Examples of such methods were presented, and the participants were asked to draw on their own experiences during the workshop.

During the course of the interactive sessions, brief lectures were given to provide some additional basic information to support the diagnostic process.

These included presentations on the following:

- Subjectively perceived wellbeing
- Mental illness and PWS
- Behaviour analysis
- Physical illnesses in PWS

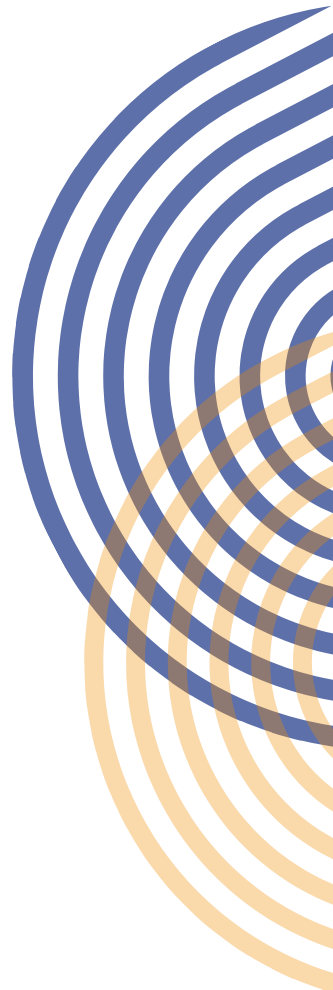
## Workshop content

The presentation used to introduce and outline the workshop is available [here](#). It lays out all of the topics discussed over the course of the workshop.

- Introduction
- Subjectively perceived well-being (short lecture) | This presentation is available [here](#).
- Presentation of a standardized test procedure - IQ test (WAIS-IV) | This presentation is available [here](#).
- Mental illnesses and PWS - recognition and differentiation (short lecture) | This presentation is available [here](#). See slides 1-7.
- Behavioral observation sheet | Available [here](#).
- Behavior analysis (short lecture) | This presentation is available [here](#).
- Survey
- Physical illnesses in PWS (short lecture) | This presentation is available [here](#). See slides 8-14
- Summary and conclusion



Setting up for presentation at the workshop



## Participant comments

These comments were recorded in a post-conference survey sent to all delegates.

THE UNDERSTANDING BEHAVIOUR AND AGEING WORKSHOPS WERE BRILLIANT. THEY WERE BOTH VERY INTERACTIVE AND THERE WAS LOTS OF TIME TO ASK QUESTIONS AND DISCUSS GIVEN TOPICS.

FOR ME, THE WORKSHOPS WERE KEY. CONFERENCES SHOULD BE ABOUT PARTICIPATION AND THE ABILITY TO INTERACT WITH OTHER PARTICIPANTS.

Dinh Thi Thanh Van, Clinic staff, psychologist, at Morning Star Center, Vietnam also shared about her experience of attending the Understanding Behaviour workshop in a post-conference report.

*I participated in workshops such as Therapy options: Art and ABA; Understanding behaviours, Aging, etc. Thanks to the experts' presentation, I learned more about the hidden causes of challenging behaviors and how to help reduce these unwanted behaviours in children and people with PWS as well as the changes in needs and methods of care and intervention for people with PWS in different age groups.*

*At my center, teachers face many difficulties in teaching and providing intervention for children with disabilities and children with PWS because the children with special needs develop many challenging behaviors.*

### Report of Dinh Thi Thanh Van (continued...)

*After returning to my country, I gathered the knowledge I gained about behaviors and ABA therapy and shared it with teachers and clinic staff, to help the caregivers and teachers better understand about the causes of children's behavior, and find the most effective ways to reduce their children's unsocial and challenging behaviors. Therefore, we can contribute to improve the effectiveness of care and intervention for children with intellectual disabilities and children with PWS at the center.*

Van went on in her report to specifically reference working with Norbert in this workshop and how the experience would benefit people with PWS in Southeast Asia.

*While attending the workshop, I connected with experts on PWS. I had an opportunity to connect and discuss with Ms. Phiri, an ABA therapist from the USA and Mr Norbert Hödebeck, an expert on PWS from Germany.*

*I exchanged ideas and discussed with them about training opportunities and the plans of organizing workshops on PWS in the Southeast Asia region in the future, helping to raise awareness about PWS in the Southeast Asia countries and improving quality of life and intervention support services for local people with PWS.*



Dinh Thi Thanh Van and  
Norbert Hödebeck-Stuntebeck





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

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