



**IPWSO**  
International  
Prader-Willi Syndrome  
Organisation

# IPWSO Caregivers' ECHO abstract summary

## May 12, 2021: Basic philosophy of taking care of people with PWS

*Please note this document is abridged from audio transcription of the Zoom session. Some errors resulting from the transcription process may be present.*

IPWSO hosts: Norbert Hödebeck-Stuntebeck (NHS), Hubert Soyer (HS) and Patrice Carroll (TH)

Presenters: Norbert Hödebeck-Stuntebeck (NHS), and Neil Gumley (NG)

### Video link

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[Norbert Hödebeck-Stuntebeck, Basic philosophy of taking care of people with PWS](#)

PDF of PowerPoint is available [here](#).

### [Q&A Following Norbert Hödebeck-Stuntebeck's Presentation](#)

**Q:** During your presentation I thought of genetic differences and also that how someone is brought up can make a difference. Its that something you've experienced?

**NHS:** Do you mean the difference in deletion and dysomy and development?

**Q:** No, rather the difference in how their parents treated them as young kids and the lessons they learned before they came into care.

**NHS:** Absolutely, what happens over those 18 years has huge impact - we see it ourselves. We have the chance to support these families and the change is faster if we can start earlier, rather than someone who is 30 or 40. Better to start at 4 or 5, absolutely.

**Q:** This is a very important topic. How they are brought up and how much they know about their own disease is so important. If we don't do anything they will die very early from overeating. What you propose, individualised support, will require a lot of professional support. I wonder how many countries have the resources to give support in the way that you describe.

**HS:** I agree that it is important that people with PWS know as much as possible about PWS.

**Q:** Yes, and that we should start very early not only about nutrition but also things like hygiene. You can change the attitude to individualise a little in this way.

**NHS:** Absolutely and I take your point about resources over the world. The idea in this presentation was to say the principles behind this thinking and to encourage it as much as is possible, even if the goal is that this is the standard of care 15, 20 years down the line. This is why these networks are so important for sharing these things. I think it is a good point for countries to start with this.

**PC:** When we're talking about independence, we know that PWS is a spectrum disorder. So when we talk about gaining independence for one person that may be moving into their own place, a big move. For other people that might be a very small move like deciding what they're wearing that day. If there's any confusion about it, I think that it makes sense to look at it as, adding independence, or working towards independence is just a much a spectrum as the syndrome itself. It that a fair thing to say?

**NHS:** That people have different options to be independent? Some in small ways and others have the chance to live by themselves. This is very different and very individualised.

**PC:** Because their capability is different, I think that's a better word than spectrum.

**NHS:** If the staff have the idea that we will support them in all these parts to be more independent, more self-controlled, this is what we mean by this philosophy. The goal is not that each individual lives by themselves, as this is not realistic.

**HS:** Look at the resources and not the deficiencies. Start with the resources and then you have a broad range to start from.

**Q:** We have worked with people with PWS a long time and we make the way, as described in the presentation, together with them. 10 years ago we worked very differently. I like the presentation very much in that I have not heard it phrased so clear, that this can be a possible way of working. In my group home we get a lot of positive experiences in the last year because we have changed many things and I never expected that so many positive changes could be possible in people with PWS. I think it is a good idea to try and to see what you can achieve with your individual resources. There are big differences in our people, that is my experience.

My question was, do you think that it is possible for new staff who haven't worked with people with PWS, if you start with this way of open handling situations, maybe it could be difficult. Do you think it's important that staff should start in a more restricted way, as they did 10 years ago?

**NHS:** I think it is most important that they are trained before they start; this is optimal. This training programme may be practical and involve visitations, so they can determine if they are able to work in this field.

**Q:** The changes are so small and I think if you're not experienced with Prader-Willi it's very difficult to understand what the changes are, or even what the possibilities can be.

**HS:** It's necessary to give supervision on what they are doing, to give feedback not only on the theory but the practice, always combining it. That is a hard job but if we can offer this if it is helpful.

**Q:** Just an observation from your presentation where, there is a tendency to protect people and once you get a baseline where you're not creating anxiety and people feel safe and free from anxiety- that shouldn't be the place to remain. It is how you get the balance of where to push and how you enable people to then experience disappointment or frustration.

We'll all have teams of people who will go to the shop with someone, and if they don't get what they want that person will have a meltdown. Staff learn to avoid these situations. It will take time but also how do we enable our trained staff to understand that being just at a maintenance level is not enough. That is a big challenge.

**NHS:** Yes, it is not possible to start with 100% independence and individuality. We do have to make mistakes at the beginning and accept these mistakes, and to supervise and support the team. It will be peaks and valleys. 20 years ago we didn't ask the people with Prader-Willi what they feel about our actions, about their opinion of problems in the group home so this is new.

**HS:** The best step is early intervention to support parents to support their children so they can learn to handle disappointment.

## Poll Results

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1. What is your role supporting a person/people with PWS?  
Parent: 2 response  
Caregiver: 6 responses  
Provider: 3 responses
2. How long have you worked with people with PWS?  
0-1 years: 2 responses  
1-5 years: 1 response  
5-10 years: 3 responses  
10+ years: 9 responses

## Challenge presentation (Abridged)

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**PC:** Neil will be doing our Challenge Presentation today. Neil is a Special Project Manager in the Department of Health and Human Services in Melbourne, Australia. Neil opened the first group home for people with PWS in Melbourne and continues to be a very strong advocate for people with PWS. Neil sits on the PPC Board for IPWSO and has presented internationally starting last year in Cuba.

**NG:** IPWSO's Professional Providers and Caregiver's Board are starting a journey. We had hoped to bring together our Caregiver Network in person just about 4 months' time but as we can't we're starting this journey in a different way. We have exciting things we want to put to our members and people around the world so this is an opportunity to meet people online.

We'll be using the ECHO sessions to get into topics like aging, restrictive practices, housing, but because this is our first session together I wanted to start with the opportunity to ask.

1. How can we (as IPWSO's [Professional Providers and Caregivers' Board](#) (PPCB)) best support you in your community, in your home, in your workplace, with your colleagues?
2. What do you think about the Caregiver Delegate role? Are you aware of it? Do you know who your Delegate is? Do you think this is the best structure to support you in your role?

The Caregivers are the front line in what we do. Doctors will interact with people with PWS but we support them day in and day out. As a Board we really want to be able to help you discuss questions or bring topics to the table that might help you in your day to day. The Board has 10 members including Psychologists, Service Managers, Operations, people very experienced and we want to disseminate the best practice information out there.

There is a structure in IPWSO where many countries' PWS Associations are members of IPWSO and each has what is called a Caregiver Delegate. The role is to interact between the PPCB and the Country Association. The [role description](#) is on the IPWSO website.

When I started working with young men with PWS 7, 8 years ago the kind of practice Norbert has shared about in his presentation wasn't something I'd heard of. I started working with 5 young gentlemen with PWS – we were thrown into a house, our manager said, "Can you run this house?" shut the door, there you go. This was the first ever PWS specific home in Melbourne. There were others in Victoria, we had 500 group homes and people with PWS living in them but never one specifically with 5 men with PWS in their 20s, living together. I had to do my own research. I came upon a little conference in Toronto (IPWSO 2016 Conference) and met a group of people who I could work together with, collaboratively, to try and put the information we've learned together, for many years, out across the world.

We still need more help. We want to bring all our best practice information together and give you the opportunity to ask questions of us. Learning from people who understand what life is like in a group home and sharing knowledge has been a great experience and we want to be able to grow that reach.

## Discussion following Neil Gumley's presentation

**Q:** One of the questions I faced when I was starting off as a parent as well as a provider, aside from the internet, where else can you get good training? How did you find, aside from attending in person training, the answers to day to day questions we have as parents or providers? How do we get the answers out to the wider community when they have questions like that?

**NG:** I was lucky enough to find my network through IPWSO. From a wider community point of view, a lot of countries (PWS Associations) are members of IPWSO. Each association should have what's called a Caregiver Delegate. Their role is to liaise with the Caregivers Board. So if the board has best practice information they share with the delegates and this should be the starting point for sharing information to the global network. Each country will have their own challenges and we want to be here to help. We also try and support other countries and to attend and support other conferences. We'd love for more people to be involved with this.

**Q:** 2.5 years ago I was developing a residential service specifically for people with Prader Willi and in Ireland there was little information available. I was lucky that PWSA Ireland nominated me as their Caregiver Delegate and I started joining the meetings, met other Caregiver Delegates and it was a huge springboard to accessing a network of experts and information. Especially if you're in a smaller country and you don't have a network, being a Caregiver Delegate is a very useful mechanism. The Caregiver Delegate's forum should be rejuvenated to offer opportunity to new Caregiver Delegates. It would be great for people on this ECHO Programme to sign up with their Associations.

**HS:** I think as well it is important the Caregiver Delegate is supported in their own country by national Associations, by parents and by other providers. This is not always the case. How can we make projects that ensure the Caregiver Delegates are evaluated in their own country?

**NS:** When you are in a smaller country and feel like you are working on your own it's validating to find others who say you're doing the right thing and encourage you. Having that support has helped me to keep going. We want to help smaller countries to feel like they're not on their own.

**Q:** I manage a new house that was set up over a year ago. We're just starting on our journey and have been soaking up as much knowledge as we can. We've been extremely lucky to start a mentorship programme with Hubert and Norbert and Gary at PSWA Ireland has been fantastic with sharing his knowledge. We've spoken to parents and families to get their experiences. We want our team as educated as we can have them. This forum is great to help us talk to other people who understand what we're trying to achieve is just brilliant.

**Q:** PWS specific services are still quite fragmented. Example in Australia some states have PWS housing and some don't. I expect Ireland and perhaps Germany are similar where there are many more people with PWS who are not receiving services?

**Q:** Part of my role in Ireland is delivering training to service providers in Ireland. The training I deliver is based on my experience and the support I would like to get from IPWSO would be a structured, standardised training programme that I can deliver, that is IPWSO accredited and perhaps even IPWSO could deliver a train the trainer programme. It would be a great support in keeping the awareness training that I am doing up to date and relevant for the providers here.

**PS:** It's a really good point that you bring up. That is something that has been talked about over the years and not yet happened. How do other people feel about that? Having a standardised programme? It would be difficult as it would have to go from country to country. Is that something people feel we should be focussing on?

**Q:** A lot of people are training on information that was given 20, 30 years ago, or just by trial and error. To provide the highest level of care standard we could develop something and it would be hugely useful because training your staff is key to running a successful organisation and having something that was standardised, that would be just mind blowing. For people that are trying to set up group homes throughout the world it would give them a framework of where to begin, and how to operate successfully.

**HS:** I agree it would be helpful to have standards. The problem is how can they be dynamic for growth? How do we maintain these standards to be always at the best level. However if we don't start we'll never reach this so it's best to start.

**NHS:** Train the trainer – if we have a basic programme where we transfer knowledge to people in all parts of the world and they disseminate this philosophy that would be great.

**NG:** In the next few months IPWSO will do some work into updating our Caregiver Delegates for every Member Association. We know some need new people to fill the role. We encourage everyone to become involved.

## Patrice Carroll Summary

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First of all, thank you to everyone for being here. This is our first Caregivers' ECHO and we are excited to start.

We started with Norbert giving an introduction to ECHO, this being an opportunity to exchange information despite the fact that we were not able to meet in person this year at a conference we had planned in Berlin.

Norbert's presentation on the Basic philosophy of taking care of people with PWS and the history raised the question, "Were our efforts, historically, to intervene, to control

people with PWS, causing increased stress and conflict? What do we do about it now?" The need to develop training for staff for people with PWS worldwide. To allow for experiences and failures; in the States we refer to this as the *dignity of risk*, if the person has the opportunity to take chances they have the opportunity to grow. Likewise if they don't have the opportunity to take chances they don't have the opportunity to grow and learn. To allow the person with PWS to be part of planning structure and programming; this is something we would refer to as *nothing about me without me*, so don't talk about me, don't plan things about me unless I am part of that planning process.

Provide support that is unique to the person. Not a cookie-cutter approach, we need to look more at the individual's strengths and interests and create a programme based on that and consider their ability to be successful in these things. We don't ask people to do things they're not going to be able to achieve and likewise we don't ask them to do things that are much lower than what they are able to achieve. Meet the person where they are at. Discussion that came from that was around if environment plays as big a role as genetics does? Our philosophy should be around helping people do more for themselves based on strengths not on deficits.

Neil brought the Challenge question on how can the IPWSO PPC Board best support the Caregiver community? That's learning from each other, it's an opportunity to learn from other people's mistakes but also their achievements and how they got there. We discussed the role of Caregiver Delegates and finally should we have a standardised programme for training worldwide.

## Upcoming Caregivers' ECHO sessions

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| Weds 23 June | <b>Behaviour in school</b><br><i>Larry Genstil, Psychologist, Genstil Institute of Human Behaviour, Israel</i>  |
| Weds 21 July | <b>Restrictive practices</b><br><i>Damien Jones, Interaction Disability Services, Australia</i>                 |
| Weds 22 Sept | <b>Transition</b><br><i>Neil Gumley, PWS Victoria, Australia,<br/>and Laura Keane, Resilience Care, Ireland</i> |

*Thank you very much to everyone who attended the session and participated. We look forward to seeing you on Session 2 in June.*

Ends.