



IPWSO
International
Prader-Willi Syndrome
Organisation

IPWSO Caregivers' ECHO abstract summary

July 21, 2021: Restrictive practice

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 (PC)

Presenters: Damien Jones (DJ) and Lynsey Moorehouse (LM)

Video link

["Prader-Willi Syndrome \(PWS\) and Restrictive Practice" Damien Jones, Interaction Disability Services, Australia](#)

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

[Q&A Following Damien Jones' Presentation](#)

HS: Your presentation showed us the complexity of restriction, and what might be requirements we have to fulfil. The biggest requirement is how do we manage all of the things for the individual.

Comment: We've just started to look at this topic. We have 12 dedicated PWS services. So we know restricted practices goes on to some extent (in all of them). What worked as a model 10-15 years ago, i.e. kitchen was locked for everyone; everyone had their money managed in broadly the same way, and the management of people was broadly the same, even though a lot of person centric work was going on. Restrictive practice is something we are increasingly compelled to look at, not only by ourselves as a Provider but by regulators and the law. We're just beginning to get our heads round what this means.

When we look at it practically, the reality is, if we've got a 7 person service and we carry out an audit and we deem that half of the people in that service should be allowed greater access to the kitchen, for example, how will the others who we deem shouldn't have greater access respond? The model we have used has worked well for years, has had fantastic health outcomes; we don't want to undermine that either. But we accept we've got to look at these least restrictive practices and get it right and do better.

HS: Yes how can restrictive practice work well for individuals?

Comment: When somebody comes into our programme, one of the first things we do is obtain consent and educate them about the restrictive procedures. We get their buy in. We have restrictive procedures that fall into 2 different categories. Ones that are programmatic, and written into their behavioural plans, and others that are for emergency use only to keep people healthy and safe. Any restrictions in the behavioural plan, we're collecting data on those, and we have to have a fading plan in place. These get reviewed every six months by our oversight agency.

A couple things that we hang our hat on, is that people have the right to live in the least restrictive environment, but also the restrictions have to be the least restrictive AND effective. So we are always monitoring this. To provide effective treatment for people with PWS we need to be able to set some limits. That is one of the justifications we use for our restrictive practices. Last, the issue of withdrawal on consent. We go over how to withdraw consent. If we're running a time-out procedure for somebody in a behavioural outburst, we've already explained that once you're out of control, that is not the time to withdraw consent, that is the time when you need effective treatment. After the episode is over, if you want to call a meeting and withdraw your consent, that is certainly within your rights to do. We find that people know they need the restrictions, and they don't withdraw their consent except on very, very rare occasions when you're not upset.

HS: It's interesting to see a very dynamic and individual(ised) programme. It changes from time to time upon reflection but it takes a lot of resources. The resources we have in assisting people is always a limiting factor. Because human resource is a factor sometimes structures develop which are more general than individual, which is restrictive.

Comment: In France there is no general rule. Most of the families are trying restrictive practices. Caregivers are taught to push people with disability towards autonomy. What we say when doing training is that we are not looking for Autonomy with big capital letters, there are lots of ways in which people can have their freedom and exercise their freedom. In many ways this debate is too abstract, or an ethical one. We must adapt to each person which is different, and the new generation.

For me the problem of hyperphagia is very specific to PWS. I am not alone in thinking it is a food addiction, and you must protect addicted people. Very often people ask for help to control their food, to restrict access. An example is a young girl who wrote a note asking, "When I come back from my residential home please check that I don't have food in my luggage."

We all live in restricted frames. We cannot do whatever we want. In the South of France we have a hospital where people go for one month and this is very restorative. Patients comment on how free they feel in hospital, because in their head they are free of managing the addiction. I agree we must take risks and allow for errors, failures,

experiment, because there is a lot of capacities if motivated. So the key point is to find what can motivate them.

HS: We are all in restrictive frames, but we have the opportunity to make changes and move within frameworks which is not always easy for the person with PWS. The new generation will have the chance to develop different behaviours, especially around how to manage their hyperphagia. It's important at the onset to support them to regulate themselves.

Comment: For me, I don't know any adult with PWS able to control their food addiction long-term. Maybe this will change but this is clear for me.

Comment: We find one of the most important things for people with PWS is the feeling of safety. The more you can help the individual feel safe, the more they are able to go in and work with responsibility, and to make these choices of consent with the knowledge that if it fails, there is a safeguard in place around them. So, building up on each individual for whatever triggers their safety net is important as caregivers and this is how we do it. The more safe they are with you and the people around them, the more they can take responsibility themselves.

NHS: In addition, we can train them to have the competence to create this safety by themselves.

HS: Such a complex topic and in the future, we could have a conference only around this topic. What is practical and how can we use our resource for the people with PWS to make them more self-confident, safer, and to develop a better life for themselves and more responsibility for themselves. Thank you so much for the discussion.

Chat: Experienced, trained and clever staff play a vital role. a team pulling in the same direction is crucial though not always possible.

Challenge presentation (Abridged)

NHS: Lynsey Moorehouse qualified as a Registered Nurse in Intellectual Disability in 2000. In 2002 she obtained a Bachelor of Nursing Studies degree with Dublin City University. Since then, she has worked in all areas of ID from preschool age right up to the elderly. I worked in Residential, Respite and Day care. Over the years she worked with individuals who had Prader Willi Syndrome. All were living at home and attending Day Service. In November of 2019 she took on her current role as Service Manager for Lemongrove which is a PWS specific home.

LM: An overview of Lemongrove house, opened in 2019, so relatively new.

- PWS specific service and will have capacity for 6 residents (currently undergoing some renovation work).
- Each individual will have their own apartment within the house (sitting room/ kitchenette/ bedroom/ bathroom). Lends to their independence.

- 3 residents currently, male and female, all in 20s and early 30s.
- Communal dining/ living areas and gym on premises.
- Kitchen only area residents do not have access to.
- All meals are prepared. Dietician does individual meal plans daily.
- Very lucky to have huge input from a multidisciplinary team which is integral to supporting individuals.

Challenge: Supporting the individual with PWS while also being mindful of the needs of the group.

- Issues around food choices
- Issues around transport
- Refusal to engage from individuals
- Family involvement
- Personal preferences

Issues around food choices: Dietician puts together meal plans but families and individuals have huge input and things like personal preferences are taken into account. Weight management and medical needs also factor i.e. skin picking requires increased protein, extra fibre for constipation and so on. Is very personalised.

Each individual has a treat list which is specific to them. An issue we've encountered is if one person has a treat, for example one person has a Chinese takeaway meal once a week and that is his treat, but that creates an issue because another person will ask why they can't have a Chinese (takeaway meal) and we'll have to explain "That is his treat, you've picked X as your treat. You can have a Chinese but then you can't have A, B or C."

One of the ways we've overcome this is we have had the dietician make up a menu and on the nights he has Chinese takeaway we prepare Chinese-style meals for the others which still meet their nutritional needs.

Another issue with treats is that some are able to have a little bit of wiggle room in their plan, such as treat can be Friday or Saturday but then we have another person who absolutely cannot tolerate that. If her treat night is a Wednesday it needs to be Wednesday every single week. This becomes an issue on a movie night where you want to provide the treat on movie night. For the 2 residents movie night can be any night of the week, for the other resident it has to be set because movie night is treat night. This limits other people. We have discussed with the resident and given options such as attending movie night with no treat or not attending so we are trying to work around it. We worry this is a situation that could cause a behaviour.

Issues around transport/refusal to engage: 3 residents share 1 vehicle. Some activities are individual, some are shared. If it is an activity that has a time scale on it, such as horse riding or swimming that has been booked, 1 resident struggles with transition (leaving the house or from activity to activity). She will have anxiety around

leaving the house and return several times and meanwhile the other residents sit in the vehicle waiting to go. In the past we've had issues where they've missed half a timed session.

We have tried putting in place a rota for transport, spoken to the individual who struggles with transition, offered different time for her to do the activity but she wants to be with her peers and asked for another chance to try and be ready on time. Which of course we did and we hope works but we find it hard to find the balance to meet everyone's needs.

Family involvement: Some families are in a position where they can take their people home a lot more regularly than others. That is difficult because it can be upsetting to see peers going home more regularly. We try to plan a nice activity for the others while the other person is being collected by their family member. We're creating buffers because it's not something we're going to be able to fix.

Personal preference: Ability to adjust. People with PWS struggle with looking forward to an event, a birthday, a visit from somebody, etc. 2 residents need a few days to prepare. That is optimum time for them to know in advance, create plan and timing. 1 other resident, if you gave them that information that far in advance behaviour would be very different; skin picking, anxiety, crying. It almost takes the good out of the event if it's too far in advance.

This becomes a problem in a group activity, if we have a house trip planned, Zoo, for example. 2 need to prepare but if you tell them the other person will know so it is hard to strike the balance of enough but not too much time in advance.

These are things we struggle with on a daily basis, sometimes quite well, sometimes it triggers a behaviour which we then have to manage.

[Discussion following Lynsey Moorehouse's challenge](#)

Comment: About food issues. You mentioned they have individualised treats they have access to. If you've made people aware, obtained consent for this you have a procedure in place for people to change their treats, when a person becomes argumentative about the treat somebody else is receiving I think you need to be careful not to take the bait and get reeled into a PWS argument. I would recommend reminding the individual that is the treat they selected, that there is a procedure for changing their selection, and then just move on and ignore further complaining. Do not give that attention and then when the person does get back on track return to giving that attention for calming down and getting back on track.

We walk a minefield every day with people with PWS and we have to be very good at avoiding those mines and not letting them explode on us.

NHS: And what you're saying is, "We're accepting your plan which you made days or weeks ago with us before."

PC: I work with 140 people with PWS, both kids and adults so this all comes up every second of every day. I am glad you brought this up because I don't think we talk about it enough. There are some that need to know 5 minutes before an activity and some that need to know 3 days before, a week before. I've had really good luck putting it out to the group. Saying "Jane, you are most comfortable hearing about an activity right before and Sally, you really need several days to lead up. How can we do this in a way that everyone gets the information and no one gets really upset about it?" and I've been really surprised how well they've come together and agreed how far in advance they should be told.

Sometimes we forget that they have a really good understanding of what makes them anxious. So when we put it to them and say we need to find a solution and let them find that solution it often works out really well.

Comment: Agreeing ahead of time is so important but everybody needs different time. Using visuals if someone is having a lot of difficulty getting ready to go to places on time, going back to basics and having simple step by step visual of we do this, then we do this, then this, can help to get her on the bus in time. Explain to her that sometimes it's hard for her to get organised to do everything she needs to do in time, and have a think together about what can help her, what pictures to use for tasks, bring her into the problem solving as well.

HS: Everybody has his own time and it is always necessary to look at the individual and what they need and also to avoid an overload. How to avoid an overload is individual and for every person with PWS we have to look at what might cause and trigger these overloads. If we analyse this we have the chance to offer more safety and responsibility for themselves.

Comment: "The more we can control the environment the more they can run free." is an old indigenous saying in Australia. As much as we can prepare the person with PWS's environment it takes so much stress away from them.

NHS: If the structure is developed in such a way that they do not see all the things the others have (structure, building, environment) this could also be very helpful.

Comment: Visual aids, even for people with high understanding, is something that makes them very comfortable, eases stress. I have the experience of making long trips with several complex steps and visual aids, visual planning they go okay.

DJ: Privacy and talking to people separately and making plans privately is sometimes a good idea and letting them know these things are private. Encouraging privacy where there are individual differences can be a good thing, if possible.

NHS: So for example having individual refrigerators in their own apartments, they cannot want the things they do not see.

DJ: Yes, or having general rules like what you do with your family is private between you and your family and what you do in the house is governed by what we're doing in the house, so they are not the same.

LM: The individual who struggles with transition is quite new to us, she just moved in in February and we are working with visual schedules for her but it is difficult for her. We do also try to ask her what we can do to make it easier for her to be on time. So we are trying different methods and we haven't found what works for her yet but we will.

DJ: Sometimes controlling other people comes because they don't feel in control of themselves as well, so they want to control everybody else. We have people that are very anxious and the more anxious they get the more they want to control other people.

Chat: Have you tried a visual clock or watch to help with the transition Lynsey?

LM: We have and that didn't work for her. We are going through the options.

Comment: As a parent of a 17 year-old boy I still battle these things but I found rewards such as, once you get on the bus you get a sticker, or you get to sit in the special seat. I found these things worked with my son. They often respond well to rewards and we can forget at those little points along the way to reward and praise them in some small way.

Comment: Where they live, they speak together. Often they tell each other about meals on family visits and so on. So it's easy that they think about what the other has gotten. They will tell all the others and the others will also visit their rooms.

Chat: I think you have nailed the important part - the willingness and desire to keep trying things until you find out what works for the individual.

Patrice Carroll Summary

Damien gave an excellent presentation on Restrictive Practice. He spoke about the convention on the rights of persons with disabilities, the right to fully participate and self-determination, negative rights versus positive rights. Examples of restrictive practices that we use, locked kitchens, restraints, medications, both PRN (pro re nata, or "when required") and daily medications, child locks in cars.

He then spoke of the need for frameworks around restrictions. Are mental health medications given for mental health conditions or for behavioural management? Who can consent and withdraw consent?

We then spoke about informal restrictive practices; limiting types of activities, group homes rules, limits on belongings and what they can have in their possession. Lack of choice - where they live, who they live with.

Why do we use these practices with people with PWS? Because there is a diverse range in cognitive function, behaviour and health issues, lack of social awareness, hyperphagia. Restrictions can also lead to behavioural issues and dependencies so that is the other side of the issue.

The draft model of restrictive practices which we started talking about a few years ago at a Caregivers' Conference acknowledged that the person gains skills as they age and develop so you may have the need for restrictive practice in a younger person that you may not need as they age. Restrictions allow for safety but also take into account that they change over time, as long as the person is kept safe from harm. It might change with time but also back and forth so we need to be flexible in order to accommodate their needs. The model needs to have room to change and grow, and ultimately we need to acknowledge that some people require these practices but may need more or less at different time in their lives.

That led into conversation from the group about least restrictive environments and how these need to be affective. We may know that one member of the group needs less, but to keep the group safe we need to have them for the entire group. We all live with restrictions and can make choices, but that isn't always the case for people with PWS in Care Models.

Our challenge from Lyndsey was how you find the balance between meeting the needs of individuals while they are living in a group of people who all have their own needs, strengths and challenges, supporting the individual while being mindful of the needs of the group. We spoke about food choices and how we manage that, personal preference, that some people can handle flexibility in the schedule, and some definitely can't, and how do you meet the needs of each individual and the group as a whole knowing that? We talked about transportation and planned activities and how we meet the needs of each person considering their challenges and strengths while making sure the group as a whole is healthy and effective.

Upcoming Caregivers' ECHO sessions

Weds 22 Sept	Transition <i>Neil Gumley, PWS Victoria, Australia, and Laura Keane, Resilience Care, Ireland</i>
Weds 20 Oct	Young and clever: well educated people with PWS <i>Norbert Hödebeck-Stuntebeck, IPWSO PPCB Chair, Psychologist, Germany and Larry Genstil, Psychologist, Israel</i>

Thank you very much to everyone who attended the session and participated. We look forward to seeing you on Session 4 in September.