



**IPWSO**  
International  
Prader-Willi Syndrome  
Organisation

# IPWSO Caregivers' ECHO abstract summary

## June 23, 2021: Behaviour in school

*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 Lynn Garrick (LyG)

Presenter: Larry Genstil (LaG)

### [Video link](#)

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[Larry Genstil: Managing Behavioral Issues of the Child with Prader-Willi Syndrome in School](#)

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

### [Q&A Following Larry Genstil's Presentation](#)

**Q:** If we suspect that service user might be stealing food when they are out in the community, and if we know that asking them about it might cause them to become aggressive, how do we broach that with them?

**LG:** We never let our residents go out in the community without a member of staff with them.

**Q:** We would be with them. We don't know how they're getting (food). So for example we'll find empty food packets but we don't know where they're coming from. The only explanation could be when they're out with staff members they might be sneaking something in their sleeve.

**LaG:** What we have often is, if they have access to a garbage can, they'll find something, they'll put it in their pocket or something, then they'll go to the bathroom and eat, locked in. That's common.

(Another) problem with us is, a staff person will be in the kitchen, either preparing medication or the next meal, there's a behavioural issue, they rush out and don't lock the door. We all experience this, it's a problem. I would like to have doors that lock automatically but we don't have that yet in our group home. The best we can do is try and talk with them.

I have done role playing with video where you ask them "Did you get food?" And they'll say no, and you ask them a second time and they'll say yes, and they'll tell us

where and we role play it and show them. Than we ask them again, the same question (as in presentation), "Which Johnny would you choose as a friend? The Johnny that lies and steals or the Johnny that tells the truth?" The role playing is a major thing that we use a lot, with video.

The second thing is, if we know that someone is going to have a tantrum because we're asking questions, then we just wouldn't. But we would with the role playing later, just to reduce the sensitivity to the issue.

We weigh our people every morning and if there's weight gain, we'll ask them why. Of course, they'll say, "I didn't eat anything, just the diet plan." Those are things that come up all the time. There's nothing that's fool proof 100%; the best we can try and do is try and improve what is going on.

**LyG:** In the US, in our group homes we use the phrase *anticipatory planning*. So we know we're going to be taking our consumers out into the community. Sometimes we'll set the scene right before; nobody carries any money, staff will always be present. In some people we've had to, what we call, pocket check them before and after they leave.

Sometimes what we say is, "It's my job to keep you safe. I really like you, and I want you to be safe and healthy. I can't do my job if you're getting into food." Sometimes people will be forthcoming if you phrase it in such a way: "I'm really just trying to help you and you want to be healthy too. Can you tell me where I couldn't keep you safe? Did you get food from the garbage, maybe?" And sometimes they will tell you where they're getting their food. Then you say, "Ok, thanks for telling me. Now I can keep you safe and I know that I can't let you go to the bathroom by yourself, I'll come in with you." (Just to the room or the family bathroom). Sometimes in stores, make sure they're pushing the carts so you see their hands. Sometimes I've said, "I need to see your hands, so I'm going to hold your hand." That's when the pocket checks can occur too, if they let you do the pocket checks.

Then we come up with contingency plans. Reinforcing, "We had a really great outing. I really enjoyed taking you out, and we were safe, so thanks."

**HS:** I agree with you but also I think the best reinforcer is to have more self-efficacy; that must be our target. It's not possible to control the environment totally and young adults will decide by themselves. If you work with young people in school, like Larry, it's necessary to teach them how they can cope with stress symptoms. If they have tantrums, it is like something they can't control, their filters don't work anymore. How can we help them to have better filters on their own behaviour? Then when they don't need help, the reinforcement leads to self-efficacy.

**LyG:** Some of our folks, after awhile, they will say, "I don't feel safe here." They do have that self-awareness and when they can verbalise, "I don't feel safe." or "This commercial on TV is really bothering me, can you change the channel?" That's

amazing. They can move to that progression, but it is that constant reinforcement; “Thank you for telling me that.” “Way to go!” They do make those changes.

**HS:** These are the best resources we have. They feel they are involved. (In Germany, we take the advice of the [UN Convention on the Rights of Persons with Disabilities](#) (CRPD)) to get more participation. How to follow up this goal is a big challenge for us.

**LyG:** We use a lot of therapy too. Dialectical Behavioural Therapy, things like that which train their brains that they’re in control. They can pilot their own airplane, if you will, by recognising thoughts and emotions and then acting on them. Some of our folks need to get down to the basics of acting on their emotions and then through time they can learn to have that executive functioning, be more in control of their thoughts and feelings and ask for help.

**NHS:** Does anyone in the group have experience of people working alone in their city? So they learn through coping strategies or developing their competencies so that they do not need staff to go with them? In my group we do know some people like this. In what ways do you come to this situation that people are able to do things alone. Even buy food.

**LyG:** We do. It feels like PWS is on a certain spectrum. We have some people for whom we know this would not be possible, other people can. We try to afford these people the same freedoms that we have. Try it out, if it doesn’t work, dial it back. We’re going to keep trying because we want you to teach your goals of independence. We certainly do have people that are out and about unsupervised, buying food and making healthy choices.

**Q:** In Australia we allow people to exercise their rights and choices, this is part of our Disability Act. We have 4 adults living in the group home which I am handling. 1 person is pretty independent and can access the community independently. He is even taking driving lessons. So what I do is just try to educate him. He works well on a visual basis so if he should eat a can of tuna I will show him a photo of a can of tuna so he knows what he should get for lunch. I am trying to empower him on his rights and how to use and exercise his rights and choice, but moreover he is in control.

When we know he is going to access the community we plant some safety measures. “You are going out so try to make healthy choices. Is it possible you can bring back receipts?” Because I give him money, he is empowered to make his choices but we can also have a look at what he is buying. So if sometimes we notice he is buying some unhealthy stuff we’ll explain to him, “You made your choice but this may help you to gain more weight.” The next week when he has gained 500g we explain to him that the food he chose when he accessed the community contributed to this. This has been helpful and he dropped 5kg in the last few weeks. Visual learning is very helpful.

Many of our (residents) also try to get what they want from their favourite of from new members of staff. So when you establish a team you must be very, very clear and everybody should be on the same page.

**Q:** We should respect those who are unable to do things by themselves and those that are able we should encourage. My son has lived for 20 years in a group home which requires him to travel by himself six hours by two trains and 3 buses, 1-2 times per month. He never has any money, he has a lunch pack. Food security starts in childhood and he has always known when he is going to have his food. When we went to parties when he was a small child he always had his own food pack with him. So food is not a problem and he has a stable weight. I would not expect everybody to be able to do this and it is important not to demand things from those who cannot achieve these goals. We must consider them individually.

**HS:** We look after about 80 people with PWS. Most of them are very overweight when they come to our institution, now more than 80% have a normal BMI, and we had to work with each person individually to achieve this. Food is not the big problem for us anymore, it's more how to help them cope and balance their stress levels. It's important that people with PWS are able to do the things that other people are allowed to do, but in some kind they need special help.

**NHS:** About "No hope, no disappointments" in Larry's presentation. What we see is that people are able to handle and need to have disappointments because they learn from these things. As the group said, it comes down to the individual and we can't overwhelm or expect too much from them. I think it's necessary to have disappointments in order to learn and that includes around food so they learn about nutrition.

**LaG:** In my experience that is true as they get older. We have people who have been in our group home for 25 years already. As they get older they have more ability to make better decisions. School aged children, we've seen that ability in very few of them.

**NHS:** Question to the group, do you see that when young people are diagnosed early and supported early that they have more competency handling food?

**Q:** About those that are able to get their own food and be independent, I have seen teenagers, or early 20s where they can appear to be in the normal weight range, don't seem to have hyperphagia, are not always after food. If they're given freedom and maybe not monitored closely enough, by the time you realise things are out of control, things are really out of control. It's hard to reverse. I've seen a few times where people have seemed very competent and that has reversed, and it's not picked up quickly.

**NHS:** What we have to do in increase the competence of early intervention. I think in the next years what we will see is 13-15-year-olds that are much more competent in handling their food rather than 20 years before.

## Challenge presentation (Abridged)

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**HS:** As usual in our ECHO Sessions, we want to ask questions around the great challenges in everyday life when assisting people with PWS. Dr Norbert Hödebeck-Stuntebeck will briefly introduce the task we face when dealing with young smart people who are overwhelming the system. Norbert is a psychologist and psychotherapist working with children, adolescents and adults with PWS for more than 20 years.

**NHS:** We call these people *Young and clever* people. We have seen over the past 10 years a very positive change in the group of people with PWS from 10-20 years old. We call them sometimes “The second generation” because they are diagnosed early, often by 6 months old, and their families get information very early and have the chance to use the advice much more than families 20 years ago. The physical development is often much better with GH and the quality of support results in a higher rate and better level of competence than 20 years ago. They know more about their competence, have more self esteem and are better motivated to do things on their own. This is the positive part of these developments.

On the other side we have seen in the last 5-10 years more and more people from roughly 14-27 years who show the behaviour which makes it impossible for us to go on taking care of them. And we have to close the contract with them in our group homes. These were youths of 14/15 and also adults of 24/25.

One of the main problems we have is that they do not accept the rules given by the people running the group homes, they would rather decide for themselves. For example they run away from the group home. We try to reflect on problems in behaviour with them with the goal of learning new patterns, new behaviour for acceptable handling of situations next time. One of the symptoms of PWS is that people do not learn about their mistakes without help.

They know their rights, but they do not accept learning. They do not allow us to help the reflection process and learning process with them. I have seen this situation more and more. My question to the group is, do you have the same experience? Examples? Most importantly, what can we do?

### Discussion following Norbert Hödebeck-Stuntebeck’s challenge

**Q:** I’d like to share, we have a woman, 18 years old, and she sets fires. She has been doing this off and on for 4-5 years and we’ve got to the point where we have decided the danger is too great. The fact that no one has been hurt yet is just luck, and she’s going to be moving out, unfortunately. I feel really bad about it. But we haven’t been able to solve the problem. We’ve tried reinforcing and role play and talking, her parents have talked to her. We haven’t found a solution. But the danger is so great; she’s set really dangerous fires in school, in the group home, in the van that takes her

to school. She steals matches or cigarette lighters. She finds them in school, we think. That's one example of what you're talking about and we don't have a solution.

**NHS:** I think a lot of us here have been in similar situations. When we cut the contract with them there is nothing for them after this. What can we do?

**Q:** We've had some success with the systems in Australia. It's like a court/ tribunal where you can get decisions made by parents, and we can then put strict restrictions on people like this. It's like starting again, and it can take years but we have had some people that have gone from being very free and able to do a lot of things, but where they were putting themselves in a lot of danger, we've been able to make that argument and we've been able to make restrictions where they're in a locked house and only allowed out with carers. Over time that restriction can be looked at again. It takes a lot of time of them being very upset, and very strong restrictions. It's very hard.

We're going through this at the moment with one young lady who runs out into traffic, threatens suicide. She has gotten her own legal advice, as she is very smart, and brings lawyers to these meetings. It is difficult but it's something I've seen can work but it's a big battle.

**Q:** I manage a house with 4 people. Food is not our problem, it is behaviour. 1-2 times a month we get police involved. 1 young man I found 6 sharp knives under his pillow so we have to call the police to take them. I learned this young man does not want to take his medication. He hides it all in bags under his bed. When I took over I thought I will try and educate him, and I call in support from specialists. After 2 weeks his behaviour reverts to what it was. A consistent, constant and very firm approach is important. We place restrictions but as soon as there is a weak link they will find the opportunity. Behaviour will always be a problem so the question is how do we effectively manage it without risk to others? We can't eliminate it so must effectively manage it.

**Q:** We have had issues with fire as well. One was a younger person and at a time of stress. This younger generation we talk about, they want to have self-determination. They have also read that they have their rights. So they want to be the boss of their own lives and decide unsafe things for themselves. Here in Denmark the municipality often talks about the individual's rights which is really problematic in PWS.

**NHS:** It is good they know they have their rights and they should know they have rights. But we do have to handle this and in some cases we have no structure to handle certain situations. What I've heard is to lock doors, medication, these are some solutions. Are there other ideas?

**Q:** I think that they have something to do in daily life that makes them satisfied is also important.

**LaG:** With the person I spoke about, when she sets a fire, people scream, people run, she gets attention, the situation is built in to reinforce the fire setting. And we haven't

found a way not to – people can't stay inside a burning building. I would love to have found a solution.

**HS:** This is what Norbert is saying that we don't have the structures in place to deal with such a situation. It's also a matter of resources, human resource, we don't have enough resource to support them in the way that they need. Then we come to a point where nobody wants to/we are unable to support them any more. How can we get more resources, from government, for example.

**LyG:** In the US we have newer technologies that we can use in our homes, video monitoring, alarms that go off if people get out of bed, pill reminders, those types of things. Certainly with our younger folks, they know their rights, but we try to teach them, I have rights too, we all have rights, but, we need to be safe. I can't just go out and do whatever I want. It's balancing that with being safe in the community and teaching that. Use of the internet, and dating sites, and social media, teaching them safety and healthy relationships so they don't get into bad situations online.

The fire starter, seems like hopefully you could get additional staffing of a 1 to 1 for that person. But I think a lot of it is education and good behaviour planning too.

**NHS:** Yes I agree we have to include them and also what I hear from Larry is we must understand the motivation for the behaviour. These are helpful but also we need the environment for this. Up to now in Germany we have no group home for Prader-Willi which is locked. Perhaps we need this. So they can't run away and they have to reflect and discuss with us.

**Q:** The problem when you do lock doors is, it becomes a game. When you set it up like that you become the enemy and they learn. It becomes a game and they win if they get out of the house. Eventually you can turn it around but it's not simple. Also as Lynn said the ideas and the effects of the internet, even on young people without PWS, can raise expectations to higher, sometimes unrealistic levels.

**HS:** It is important to involve them and to give them the chance to reflect on their own disability and their own special needs. Often they don't accept their own special needs and often this causes aggression. How can they learn to accept their disability and how to deal with it? That needs personal contact, not only technical control. They must be able to think about why control is necessary.

**Q:** It is so important that they feel loved and heard. They are not only the problems, they have a life which is valued by the caregivers and those around them. The environment must give them what they need and 1 to 1 care is needed sometimes. We have 1 girl who is difficult and it takes a long time (10-15 years now) to make behaviour better but in very small steps it works and the relationship to the caregivers is very important, especially where the parents did not support them.

**LyG:** As caregivers it's so hard because we have a lot of staff turnover. The consistency of staff and that relationship that has built up over years is so key to helping our

individuals. When they see a lot of staff turnover, their anxiety builds up and anxiety is behaviour that comes out. They don't feel safe when they see so many new people that they have to get to know and they're scared they won't know how to take care of them.

**Q:** I find as well that if they know a member of staff well they are able to take instructions much better than from someone they do not know. In this way we can enforce restrictions but in a friendly way.

**Q:** As a parent of a 17 year old, I find that my son likes to push the boundaries. He wants to see what the outcome will be. So I think that this may be a motivator of some of the behaviours of concern. Obviously it is important to identify the purpose of their behaviour and what they are getting out of it.

**HS:** Consistency is very necessary. We also have to take care they don't develop dependency. The person with PWS must not assume ownership of the person who supports them closely. We must be careful of this from a professional side. We need really experienced staff and we have to support the staff as well.

**LyG:** It is the hardest and easiest job at the same time. You show up and model good behaviour but always keep the end goal in mind. The individual should always be goal setting and achieving just like all of us. We can't get stuck because something is going well, in the same patterns of our own behaviour; we need to constantly move them towards their goals and help them. Sometimes that is introducing new people, new situations, new stressors to deal with.

## Lynn Garrick Summary

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Today we heard from Larry about behavioural issues with children in school. 3 key things he brought out were social skills and how they learn differently than other children. Important aspects would role playing, we heard about video feedback which is helpful because then they can see that as well as hear, role modelling with behaviour rehearsals for specific situations, and reinforcing positive behaviours.

Auditory processing is often weaker than other children. While they may be very verbal they may not be understanding completely. Their visual processing is conversely above that of other children. When teaching them it's both auditory and visual. Visual components should be incorporated into all of their learning. For behaviour skills, a lot of their behaviour comes from their rigidity and their inflexibility so when this is happening use distraction and humour. Sometimes you just have to wait things out.

The ABCs of behaviour; the Antecedent, the Behavior and the Consequence. We can try to understand the antecedent, what is causing the behaviour. The behaviours themselves should be measured, kept track of so that we understand if it's a certain time of day the behaviours occur. The consequences, we try and shy away from negative reinforcers or consequences such as punishment. Using positive reinforcers when they do display good behaviour or non-maladaptive behaviour. We need to state



the expected change during the behaviours, measure them, and give frequent reinforcement. 3 times. The key to behaviour management is consistency.

As far as food security, No Hope, No Doubt, No Disappointment. No doubt helps to control some of the anxiety. There's no doubt that you're going to get into any food. It's anticipatory planning, there's no hope that you're going to get into any food, we've got this, you know exactly what times you're going to get your meals, your snacks. Therefore they can focus on other things.

## Upcoming Caregivers' ECHO sessions

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Weds 21 July	<b><i>Restrictive practices</i></b> <i>Damien Jones, Interaction Disability Services, Australia</i>
Weds 22 Sept	<b><i>Transition</i></b> <i>Neil Gumley, PWS Victoria, Australia,</i> <i>and Laura Keane, Resilience Care, Ireland</i>
Weds 20 Oct	<b><i>Young and clever: well educated people with PWS</i></b> <i>Norbert Hödebeck-Stuntebeck, IPWSO PPCB Chair, Psychologist,</i> <i>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 3 in July.*

Ends.