



**IPWSO**  
International  
Prader-Willi Syndrome  
Organisation

# IPWSO Caregivers' ECHO abstract summary

## April 20<sup>th</sup>, 2022: Education of PWS, behaviour appreciation, and positive support strategies

*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: Hubert Soyer (HS), Norbert Hödebeck-Stuntebeck (NHS), Lynn Garrick (LG)

Presenters: Patrice Carroll (PC) and Brittni Kliment (BK)

### Video link

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["Education of PWS, behaviour appreciation, and positive support strategies"](#) Patrice Carroll, Director of PWS Services, and Brittni Kliment, Director of Program Marketing and Admissions, Latham Centres, USA

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

### [Q&A Following Patrice and Brittni's Presentation](#)

**NHS:** I love to have these presentations where we talk about the basics that we have to understand, and the special things to know. I think this is the experience we all have that we understand more and as we understand background of all the things we see in people with PWS we are more able to support their development. So, thank you for this perspective, I think this is the most part we have to do in the next 10 or 20 years together with caregivers and with parents.

**HS:** The most important sentence for me was one Brittni said, "Just like us." And it's not too easy if you handle and support people with PWS to think "Just like us", but I think that's really important always to keep in mind that it should be just like us and they should learn.

I have a question to Patrice about theory of mind. Do you think it's a status from birth on, or is it something that develops in a different way?

**PC:** Well, it's a developmental stage that takes that starts in early childhood and goes throughout your lifetime. Now, that doesn't mean they can't get it. So that doesn't mean that that can't be developed later in life, it absolutely can. It's just not something

that happens automatically like it does for you and I. It's something that we have to teach, it's a skill that we need to teach. No one had to teach us that. We just came with it, they don't. So, it is definitely something that can be developed later in life.

**HS:** I agree totally with you. And I know a lot of people who don't have Prader-Willi syndrome have the same problems in theory of mind.

**LG:** We see this played out in our in the individuals that we support, but do you think that through role modelling and certain therapies like CBT (Cognitive Behaviour Therapy) or DBT (Dialectic Behaviour Therapy) that that...do we have a consensus on what is the best approach to help them gain these other people's perspectives, so they can understand how others may see or view or feel the world?

**PC:** That's a really good question. I'll give you my opinion on it and then I'd love to hear what other people think. So with theory of mind and because it does have to do with understanding, just the basic understanding that someone else has a different opinion, saying things out loud can be super helpful. So, going into a library with two people, and Mary loves horses and Sally loves chickens. So, you go into the library and you say, to Sally, "What do you think, Mary is going to want to find a book on?" And she may say chickens because she likes chickens. And if she does, you can say, "Well actually your favorite animals is a chicken. Mary's is a horse, I bet she's going to pick a book about a horse." Right? So just kind of that talking out loud, about things.

Now, you bring up a good point about CBT and DBT. I haven't seen that being successful with the PWS population and there's even some CBT that is geared towards people with intellectual disabilities, and even that I didn't find successful. But I'd love to hear if other people did, because on paper, it should work. I just haven't seen it work. So, I would love to hear others opinion about especially those two particular therapies.

**NHS:** Patrice, you said you haven't seen that people develop these competencies of changing the perspective?

**PC:** No, I haven't seen success with the particular therapies of CBT and DBT.

**LG:** We've got maybe 10 or 15 people that have graduated their program and still do after care, but the tenants, I think, of the DBT, and CBT, come from a place of breaking things down to a very base level of identifying emotion. And we work on those, there's some verbiage and skills that we use, and we constantly reinforce those DBT skills.

And we have seen success and that it is possible to kind of shape and identify others' emotions and put yourself in someone else's place. Maybe not 100% of the time.

**PC:** But even that it's a little bit effective is good news. I'm really glad to hear that.

**LG:** We have seen some success. Yes.

**HS:** I think Lynn, it doesn't depend on the special therapy. It always depends how it is adapted to the individual needs of the person, and how well it's done by the person who is the therapist. Has he a lot of experience with clients with PWS and can he use his specialist therapy for the individual person? I think that's what's successful. And even if you need behaviour therapy or psychoanalysis, it doesn't matter. I think it's always, how to use it, and to fit it to the person.

**PC:** I'm curious to see if other people have had success with the more traditional talk therapies.

**NHS:** Me too I'm really interested to hear. I'm sure that we all have these problems that people have the problem with a change of perspective, and what are your experience are you successful with different things? Maybe totally different things as we talked about now?

**Comment:** I know that speaking on behalf of some of the other people that I've worked with in the community, play therapy is something that I've heard a lot of people say they've had some good traction with, in terms of utilizing different toys and games and putting the perspective of say, "Jane and John are playing a game together. How are Jane and John going to react to a different situation" if Jane and John are dolls front of you? And I know that there's been some positivity in that area.

I did see in the chat what are CBT and DBT, so I'm not sure if Patrice you want to explain a little bit about what CBT and DBT are for those who aren't familiar with the term?

**PC:** Sure, it's Dialectical Behavioral Therapy. And what it does, is it really breaks down the skills you need to be in a relationship. It was first created for women living with borderline personality disorder, and it's been wildly successful for that population. And in fact, it really is seen as the only therapy that has been effective for that particular population. Now, a lot of people have then tried to use it in other populations, and it has been successful with them too.

I'm a certified DVD therapist, I would love to be able to use that at some point in my life because I've never been able to. I got the training and never did it, which is why I loved hearing from Lynn that it's working for some people in her population because that means that we could potentially transfer it over to Latham which would be awesome.

But what it does is it breaks down everything from how you're feeling, your perspectives, are they correct? Mindfulness tools, de-escalation tools, it hits on everything that you need to really be in a successful relationship with yourself and with another person.

**LG:** Maybe this is too high level but it is trying to rewire some of those pathways in the brain, those neural pathways. That's how I view it.

**NHS:** The experience we have here is very simple things to support these competencies, with like pictures, you see children or people at the picture, and they play to each other, or what happens with the feelings, what happens an hour before, an hour later, and all these things. And these are very simple things, and we use this here, and we saw that it supports the competence of changing the perspective, by very simple things.

**HS:** I'll add, it's necessary to use a mirror too. If you sit in front of a mirror and you see your face and another's face you can imagine. How do you feel now? That helps to change perspective. In people with autism it's common to do it. They have a lot of empathy, but in my experience, they are often not able to be sure what are the feelings behind things? If they work with pets or something with smaller children it's no problem for them. Often they come in the morning, and see you and ask you are you are you sad today? I think you all have these experiences with people with PWS, but how to use it in everyday life, and to make them able to change the perspective to the situation.

**PC:** I love the idea of using a mirror in therapy because we know that the people that we work with don't often pick up on facial cues, what they're saying doesn't always match how they're feeling so you can say in therapy like "You look pretty mad." and they say, "I'm not mad.", and you can say "Look in the mirror. You look pretty mad." So you can really use that, I love that. Thanks for bringing that up I really like that.

**Comment:** I can only tell the experience with my daughter. She had psycho therapy or something like that for years and is now 20. In Austria it is very difficult to find behaviour oriented therapy. For my daughter there was no chance to get any of those therapies so talking based therapy is better than nothing, and training some skills, always happens there also. But it's always in my mind, not the good point to only ask the PWS person. Really the biggest mistake the therapists can make is they don't involve the parents, so they never get the real condition in what the person is. So, my daughter is UPD, and the situation is changing very much. And so the therapist, they get the point maybe one month or two months later, by luck, they find out what's, what's going on. So, the new therapist we have is based on the practice on physical trauma, I don't know if you have any idea what that is, I don't have really idea of it. Many people say it helps, but I think all the therapists, have to consider the opinion of parents and of caregivers and of school teachers to understand what's really happening in the environment and why the PWS person does not understand the others, and why the others don't understand the PWS person. There's so many disappointments and so much energy wasted to do the right thing.

**HS:** I think there are two aspects to what you mentioned now. One is a systemic view in therapy, and the second, I think is special knowledge about PWS. Even what kind of therapy you use. I think it's very important aspects if you have therapy with someone

with PWS. How do you deal with these points with a systemic view, with parents with families with school? And is it really necessary to have a special knowledge about PWS if you make a psychotherapy with someone with PWS?

**Comment:** Yes, it is absolutely necessary to have PWS knowledge, and it's absolutely necessary to go to surrounding peer groups.

**Comment:** Patrice and Brittini that was excellent, absolutely excellent. It was such a simple presentation, but it gave so much information, and I probably print trees worth of *"How does a person with PWS think?"*, which is a USA publication for caregivers for professionals, for everyone, and it is so important that people do understand how they think, and how they respond, and how we need to give them time to respond to what we have asked, and say less and speak calmly, all these things. I would really love to see a small handbook come out of from the PPCB from these ECHO sessions with all this information simplified, similar to what the Famcare articles are. A 2 page article on how people think, how to speak with people, simple things, because your information is so good, and it is so important that anybody working with people with PWS understand obviously the person, but also the PWS underneath that person.

**PC:** Thank you. We actually have a [PWS mindset book](#). It's just for anyone to print and it kind of goes over this stuff.

**NHS:** So, what's been said it that it costs so much time but if experts have no information about PWS than they really go into the wrong way, and all people are frustrated, the therapist is frustrated, the ones with PWS, the parents. We talked about the environment, we have to include and have these systemic view and accept that all these things are in interaction with each other. And we cannot only work with a very specialist thing.

My only question is of these change of perspective. I thought to do a little survey and find out if there is a difference between these competence of change of emotional perspective and cognitive perspective. Do you see the same things? So, what I mean is, they are much more easier and they have more competencies to think what other people are thinking, but they have much more problems, to feel how others feel. Do you have the same experience, or do you think it is the same?

**Comment:** I think we often say they lack a sensitivity to the way other people think and feel. But I believe, as was said, that they can learn. Through role modelling, but also just sitting and talking quietly about how this person's feeling and if you tell them something they will remember. So they may not even exactly know what it is but they'll remember that that goes with that person.

**HS:** I think my experience is the same, that they are more better able to have a sense of the cognitive things. They can imagine if someone would do it in this way or that way, but they have a lot of problems in thinking about if he is angry or is he sad, or is

he happy? That's often a problem for a lot of people with PWS. For a broad range, but a lot of them have problems in finding out the feelings of other persons.

**BK:** I think so often to we try to classify or characterize what type of the CBT the DBT the ABA, you hear all these acronyms, to work with our individuals. But I think as was said, it's almost like a behavioral model for our individuals with PWS. How do we create that, because I think it is a mixture or a piece of all of those that we're combining when we talk about some of these different support strategies so I do I think it's extremely important.

**Comment:** We have clinicians that came to us with no experience with PWS and I think the ongoing training, the booklet that you talk about, that's essential to a successful clinician. One of our one of our clinicians has been with us, she's an art therapist, for 20 years, and the relationships, with both parents and students is the key to her success. We onboard people, and we train people ongoing throughout the year. That's where we find our most successful people. It doesn't necessarily mean you have to come in the gate with this extensive amount of training in PWS.

**PC:** When we're looking at what kinds of therapy, I think you're absolutely right that we how to throw a little bit of everything in. Going back to what you were saying, that your daughter is in psycho trauma therapy. We don't usually call it that in the States but we do use it, it's role playing, which is very successful and very good therapy to use. But another part of psycho trauma therapy is to over dramatize a situation so they act out in a really dramatic way, and I'm not sure that's super helpful. I would be a little bit cautious about using that only because, and this goes along with executive function disorder, part of executive functioning is knowing what's an emergency and what isn't. And the person with PWS sees every problem as an emergency. So to then add to that by having them over dramatize issues may actually be doing the opposite. So I'm curious to see how that goes with her, because I could be totally wrong, just a feeling that that may not be the best way to help her solve problems.

HS: I think if someone is really an experienced therapist, psychotherapist, I think he must have the responsibility to look at the person and not to do things that may hurt the person. Maybe, as you say, if it's done in the right way it might be helpful, but only in the right way.

**Comment:** I just have to say one thing that really irritates me is when a professional says the patient wasn't very cooperative. The patient was cooperative you didn't speak to them properly.

**NHS:** And that's the problem, if people come with their system with their theoretical or psychotherapy political system in their brain and bring it to the people, and they are not flexible and not able to understand people with PWS, and it couldn't work, and this is what we often see and this is one of the consequences. You said to write a book, but

what we should do is to instruct or to teach the therapists, so that they have the basic information and then I think they can modify their methods, and then they are successful with people with PWS to support them.

**Comment:** Not, a book, just a one page sheet so they can read something, because they won't read a book.

**Comment:** I want to mention one thing about the [book](#), in terms of what you're saying of having those short little blurbs if you will, or aspects about what can be helpful. You can only print out certain aspects of it, and we've made sure to make it really short chapters, because we always talk about the medium being the message right, the more we can identify what is going to be helpful for our caregivers, the better, and the more traction these materials are going to get. So however you guys feel necessary or see fit to give that information from the booklet, please feel free and know that we are doing continual updates on it.

**BK:** That's a great point I think sometimes you might read that booklet and there's only some aspects that might be relevant to the individual you're working with, or your son or daughter. So it's kind of pulling apart those pieces and creating your own booklet to bring to their therapist or doctors. You're trying to give a better understanding of what you're looking for, so feel free to pull it apart and make it what you want. Because I think that's what we're talking about here, it's creating that specific plan or program for the individual.

**Comment:** I have a few words related to the presentation. First of all, my son is almost five, so we don't have so much experience, but I already found some explanations about vestibular sensory situation related to his fear of rocking. And also, something about the behavior. He's working with three different psychologist, with the speech therapies, but they also approach the feelings, art, and they they are trying to work also on the development and the compartment issues. We saw something about his stubbornness and repetition. So I think some tracks, the parents or someone near him can create directions, because even though he's under the supervision of a psychologist, something in his behavior is from us. So, if we don't have the skills to treat him the right way. I mean, our patience or a correct way to keep our expectations for him and to deal with the temper phases. So I found some interesting things in your presentations, but in some level, it's a little bit both of us, because we must think for us to gain more skills, probably from information, but we do also need some new things in our conversation skills, because no one is alike who has some issues, problems. They are coping and taking from for us.

**PC:** You make a very good point that it isn't always PWS, right? Sometimes it's just, who the child is, and they get a lot of who they are from their parents. So you make a really, really good point. I just want to say one thing. You are in such a good place

because your child is young and you're doing everything that you can do right now. The more you work on these skills from a young age, the better off you're going to be. So I appreciate what you were saying.

**Comment:** And also he has moods, and sometimes the moods are I think, artificial inventing. Because I saw him, watching himself in the mirror, and he is like an actor. So, I saw he is taking what she needs also from us. And sometimes he's having a posture like when we speak to him, but it is like he doesn't hear us. And he's stating his refusal to respond or to acknowledge what we have to say. And this is also like a technique to say "I don't want to talk to you." or something like that.

**HS:** I think what you say as a father of a young boy it's so important. What do we what think for us as caregivers? It is necessary to involve parents, even more and to train them to understand their child a little bit better to do, to have better chances of modelling the behavior of their children? What is your opinion?

**Comment:** Firstly, we don't have specialized services. Here we as parents count the most. I've not heard of something like a house or system services for PWS patients. So, we are the first doctors or therapists, because we have to contract or to approach to doctors or therapists. And, so we are the management zone, and also sometimes the therapist.

**HS:** Yes of course and I think that it's not only in your country, that's in a lot of countries all over the world. And even in countries as in Germany I think to include parents and to make them more competent is not done. I wish we should have. How is it in the States? Do you do these things with parents and the environment?

**BK:** I think that's a good point. You almost need that wraparound service. You need everybody to be on the same page, to be providing the same service to the individual so you know if the student goes home we want them to be receiving the same thing that they're receiving when they're here on campus at Latham. So, almost everybody speaking the same language. We want everybody to understand that this is the approach that we're taking with the individual, and to be consistent with it. Again, that consistency is so key, so it's consistent at home, it's consistent at program it's consistent at school. It's so important for that consistency to take place.

**PC:** Do you guys do anything with parents as far as training? I think we could probably do a better job with that.

**LG:** We do. And we do do training with parents more so, when we see the need for it. I think we're more responsive, reactive. But I agree consistency of approach is key because it gets really confusing. And we see a lot of behaviors when people are coming back from areas that aren't as structured, or aren't using consistent messaging in the ways that we're talking with individuals.



**PC:** I wonder if now that we're better with Zoom if we could combine agencies and do trainings for both, that might be kind of cool.

**LG:** A PWS 101 certificate throughout the year, for age groups and for parents too.

**NHS:** What we did in the last years or over the years is we focused more and more on caregivers, but I think from the view of IPWSO I think we should be more able to offer things for parents in different countries because we have 10 or 13 or 15 countries which have professional offers for people with PWS. The focus must be more and more on this, how can we support, how can we train, how can we bring information? This is a basic to parents. So if we can support a bring it to parents I think this should be the future for the next 10 years.

**HS:** And I totally agree with Brittini, it's she talks about consistency in the whole system. This consistency always has to be based on the understanding of PWS. Otherwise, only consistency might be dangerous to come to rigidity, and that's also difficult in people with PWS. They follow a routine and it is only a certain routine and nothing needs to be thought about. So that might also arise conflict afterwards and therefore, we have to have an understanding of all these things.

**LG:** I think that's important because if you are too consistent, then they become very rigid so there's a balance of building in some flexibility into that thinking too.

**PC:** And I think there's some things that we've done all along because it's best practice but I don't know how smart it is. So that's one of them, do you keep exact routine that never ever changes and then you have people who can even take one step off of that schedule. And along with that we've always said to have low affect, don't show how you're feeling, be calm. And now we have individuals who can't read facial cues, because we don't show them. We don't show them we're mad we don't show them we're sad because we're trained not to. But are we hurting them by doing that? So just something to think about is, are our best practices actually not helping out?

**BK:** Good point. I mean, in a family situation you can't always be as consistent, if you have other children in the house or something like that, consistency might go off track.

**HS:** I think that is one kind of consistency that we have some environments which are always changing. Change is really consistent all over our life, and how they can learn to deal with it is important.

**Comment:** We as parents we learn to adapt and react to his behavior or feelings. So, we are modelling ourselves also, not him only. I mean, if he's saying or doing something, we must understand the things that he's trying to say or the underlying reasons behind what he's showing.

**NHS:** Yes, question of what is behind the behavior.

**Comment:** Yes, so we have learned to use some techniques or, like you said about, not refusing him categorically. So, we are saying, "Maybe later." Or we know that he's not knowing what is tomorrow or the day after tomorrow so we say we say to him, "Let's do that tomorrow." so we delay, but without the terms. So we can escape, or we can elude the problem. And this is shaping our relation to him, as we try to shape his relation to us.

**HS:** I think it's also necessary to distinguish between understanding and accepting. Not everything I understand I have to accept. And for parents, I think it's really one of the most important things, that not every everything you understand can be accepted as part of their development, and we have to educate our children. I think it's necessary to give them limits, to give some hope for some things they can learn, all the things. But it's necessary, not only to understand, and understanding is not accepting everything.

**NHS:** Patrice and Brittani, at the end of your presentation you said we must be a little bit flexible because you said they cannot learn or the structure should be in this way, this way, this way. And now I understand that you said, we change this, and this is what we did 20 years ago we have a rigid structure, and we make them cognitive inflexible more than they are. Then we gave them the chance to change things and that they fall down and stay up, then they have the chance to be more and more flexible and this is what parents said that life and family is sometimes chaotic. And if people with PWS do not learn to handle chaotic situation, then they always in her life are depending on us. So I'm very happy that you described it at the end.

**PC:** I think over the past 10 years or so we've gone from, every 15 minutes schedule of exactly what someone's going to be doing too much looser, so they know what the day is going to look like, but you don't have those blocks that describe exactly what's going to happen and we used to do that.

**Comment:** I think that's really important with the food as well because I find some caregivers say, "He only wants to have tuna for lunch." and I said, "Well that's fine but not every day." You need to break it up, not for nutrition, but for his own mind so he gets used to variety.

**HS:** They don't live in a separate world. Our goal is, they should live in the community and therefore, have to learn to handle a lot of problematic situations.

**Comment:** And I think that's a balance that we as caregivers and parents really have to figure out, that unique balance for your environment. So for some people it's going to be a small adult group home environment, and what is the balance for those people within that group home at that period of time. In a residential school like Latham Centers campus, what is the balance for the different suites, so that we can make sure that we keep a level of anxiety down, and that we aren't producing an environment in

which that anxiety can slowly creep up, but at the same time we are producing a situation where there are real world aspects to what we do. Sometimes we'll call them detours. So you're going on a field trip or an outing and the student or person likes everything done a specific way. They like the same route to be covered each time, the same roads, but there is roadwork. So, what do you have to do? You have to learn to go around the road work. And it's a really nice metaphor to think about that road work in life. Sometimes we hit that as adults, as children with or without cognitive functioning delays. And so what can we do as caregivers to produce an environment where our residents can be thriving and learning?

## Lynn Garrick Summary

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**LG:** Well, thank you again Patrice and Brittini that was an amazing presentation. You laid out 3 reasons for some of the behavioural challenges that our individuals can face those being and executive functioning disorders. You explained how the executive function, really where that came from is being an executive, how to plan your, throughout the day. Then you laid out the sensory processing and that starts from birth and their inner ear, those vestibular crystals and their proprioception. But how we can use an environment to support those services.

You also talked about theory of mind, and how we see the world, and how they can understand, how other people's views and thoughts come into that. So those 3 reasons can explain a lot of some of the behavioural challenges that we may encounter.

But then the second part of the talk was about positive support strategies and positive support is the key here. And so you laid out some things, so positive reinforcements that come naturally throughout the day, those compliments those, "Wow, you did a great job. Thank you." or "You look really nice today, thanks for brushing your hair." Setting clear expectations, both verbal and visual. Modeling good behavior, or appropriate behavior, using consistencies, and never giving that hard and fast No, unless it's really appropriate, like "Don't run into the street." but some alternatives to say No. Also creating some really good opportunities for some behavior programs that you can use some, some good earning that may not be food related rewards.

Thank you everyone. It was a very robust discussion and I think we could probably all talk about this for hours and hours, lots to learn, and lots to think about.

## Final ECHO session in current programme

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Weds 18 May

**Looking at different diagnostics**

Norbert Hödebeck-Stuntebeck, Psychologist, Germany

Ends.