



**IPWSO**  
International  
Prader-Willi Syndrome  
Organisation

# IPWSO Caregivers' ECHO abstract summary

## Oct 20th, 2021: Young and Clever

*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)

Presenter: Norbert Hödebeck-Stuntebeck (NHS)

### [Video link](#)

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["Young and Clever: well educated people with PWS"](#) Norbert Hödebeck-Stuntebeck, Psychologist, Germany

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

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

**HS:** Do you have any experience with this kind of behaviour, with this kind of people with Prader-Willi syndrome who are young and clever?

**Comment:** We have come across this and it can be very difficult, and under the Australian system these type of people often go through a number of providers because now part of our system is that you can choose to leave one provider if you're not happy and go to the next. So we're finding that these people might use that way of going through a number of different providers. It's not easy to find a solution especially with the rights, and they will talk about their rights. And sometimes, as Norbert said initially, you feel as though there's not hyperphagia at some times and everybody believes that this person doesn't have much of an eating problem, and then by the time you realize that there's a problem it's too late. It's very hard to draw everything back, so that's been my experience.

**NHS:** The experience that they change the companies, that they travel around the country; we have this experience in Germany, they try to find place and other companies but they often they aren't able to find another place.

**Chat:** The behaviors seem to intensify when they are young and clever. They do not respond to the typical positive behavior programs we may have had.

**Comment:** We have, what I would consider the older type generation who just accept that this is what's going on and they don't have as many behaviours, but some of the

younger folks they know, like you said, "This is my right to do this, to go here, to choose this, to have the cell phone and internet." But they don't have the mental capacity, perhaps - I don't know the better word, to handle all the situations that may arise. So when we try to help them through that they just say, "No I do not want to talk to you, goodbye." Slam the door, break, smash. And it's just harder to move them into a better spot, mentally, because they just refuse and that's their right, and they know their rights.

**HS:** Thank you. About well-being. It may be different with these people. What do you think, do they have more psychiatric symptoms, or is it more that their cognitive abilities are really too difficult for the system?

**Comment:** I think it's probably all three of those. It is partly that even though, as Norbert you've described, many of them are more able than as they move into the adult world, the gap between the skills they have or don't have becomes much greater because you need more higher order cognitive abilities when you're an adult than you do as a child, and those may be impaired in some way.

I also think that the group that you are particularly challenged by are people who also develop some mental health problem, maybe a mood disorder, maybe occasionally, a psychotic illness, so I do think a question to be asked when you're faced with someone like that is, how do you understand it? Is it the person exerting their rights, and if it is, that's at one level a good thing, or is there something else going on here that might explain why they've now become so resistant?

For me in the UK, the third problem is that once they start leaving services, and particularly if someone says, "Oh, but they're competent to make these decisions." then our social services walk away from them. So they then have nothing. And it does seem to me that even though they may be rejecting what's being offered. Somehow we have to hang in there. So when things get very bad for them we may be able to step in again and pull things back a bit. But usually what happens is services say "Well if they don't want help and they're making their own decision, that's for them to decide." and I think that's very problematic.

**HS:** That's why, as Norbert says, we lose these persons and often they die at an early stage and that's a big problem and really a pity. How can we help? What do you think about early onset in prevention and to help families for this development before they use the services? How can we intervene and help the families and the parents?

**Comment:** I suppose listening to you, Hubert, I'm wondering what the role of preparing people with Prader-Willi syndrome, for the syndrome throughout their life is. Because it seems to me there has been a generational shift and people being born now frequently get the message, "You can do anything, you don't have to worry about PWS, you have great support, the world is all yours!" And that's very nice, but that must be very difficult then if all of a sudden you realize you can't do everything. Actually, there

are challenges with the syndrome, and it is important to recognize those, I don't know what the answer is.

**PC:** We see that also with families where the families hear from an early age that same message. And sometimes they have a hard time understanding that there are competency issues and feel like, "My child should be living on their own, they should be having a full time job." and they sometimes have challenges understanding that there are limitations to that so it's the same thing as you were saying, just for the families as well.

**Comment:** Yes, I fully agree with what you said, and we are facing the same situation in France. But I would say two points. One is that even with better education and early intervention, they still have a different interaction with the world. So they live in a world which some aspect of the environment can be aggressive for them, and we don't understand that, we don't feel that because we have different vision, different interaction with the environment.

The second point, we have some cases where people spent one full year in psychiatric institution, very close, very bad depression and we put them in a different environment and everything was okay, very rapidly. To me, one of the reasons is that it's very difficult for them to be motivated for a project, which was not built by them according to what they want, what they like. I think that if we can help them to build their project and try to find a project which is their project, things would be better. Because very family say "We have a place in an institution, that's okay." But it is not a project. One young person said, "You want me to enter this institution no, and will leave when I am dead?!" That is not a project and I think we have to think about that because when they are motivated, we know that they can do fantastic things. So, to be motivated you must recognise that this is your project, and not the project of your parents.

**NHS:** That's really the situation that if they are interested, then we can, for example, reflect with them if there are negative or challenging behaviour, it is not a problem. But if we have a challenging situation with them and they do not want to work with us, this is the big question. If we are over these steps, as you described and they're motivated and it's their own project, then it's perfect and then we see 80-90% of young people who have very good chances. Not unlimited, but realistic. How can we motivate them, like try to make their own project to maybe to stay in a group home or something like this.

**HS:** I think often before they come to the services, it's used as a consequence. "If you are not able to live in the family, you have to go to this institutional service, to a group home." That's often a problem. How can young and clever people be included and integrated in in new systems for development. How can we support this development from an early stage? And that's not easy for our systems. In Germany, governmental systems are not very helpful in these things.

**Comment:** I think the problem is similar around the world. We have also seen people who have been in very good group homes but have high anxiety and have been very smart and have not wanted to stay there, so they've convinced their parents that they are quite capable and, yes, they have died six months later as well. We have another system - we have a very young, very smart man at the moment, who's just 33, he's lived with parents, all along and up until two years ago they used to be no intervention needed but there were lots of issues in the home and they gave up, and they said, "We will prove to him that he can't do it himself." So, of course, he became very sick, and was in hospital.

We approached the guardianship board for the family, and the doctors did and said, "This man will die if he is not looked after, with restrictions." so eventually it was approved, and he's now just moved into a new style of group home, which is that everybody has their own individual apartment. It's a gated environment but it's very new for our clinic as well to be involved with this so we don't really know how it's going to go, but it was the only place he would go. He would not go into a group home because he "wasn't like all the other people".

So it's a very difficult situation and we have another girl who is very similar and she's going to go to this place as well because she has never wanted anyone know she had Prader-Willi syndrome. She went to mainstream school and did very well, but of course it all fell apart when she left school. So they certainly exist, these people who are very smart, and I guess I would love to see the transition from the family home and from leaving school into a lovely residence where they're treated like adults, they leave home like other adults do, and it's a much smoother transition with positive things to look forward to. But at the moment it's not like that because our system doesn't work like that.

**HS:** It's a kind of transition to how to accept the social rules, how to learn to be responsible for your own social environment, and for your own social bonding situation. That's not easy, a lot of young people with Prader-Willi syndrome have a dysfunctional bonding situation.

**Comment:** And it's difficult I think because families don't think of their children at 16 or younger eventually moving out of home, and especially when they seem to be doing so well, they think, "Well maybe this will be good, they will be able to stay." but if the seed was sown at a younger age that when you're 16-18 you will move out of home and live with other people, and it's a very positive thought from the family as well for the person, perhaps that might help.

**Comment:** We have a Prader-Willi service and we have the individual apartments for service users and it's very much a positive thing. We definitely go from the point of view with families and with the residents moving in that, "It's your independence, you're moving out of home and you're moving into an apartment." and they very much oversee and how that apartment is decorated, and they pick their colour scheme

they pick their soft furnishings, and we've had some really good success and definitely can see the benefit and the positivity around us. If anybody visits the home, because they're self-contained apartments within a residential home, nobody will go into their apartment without permission. If somebody comes to visit they absolutely love showing off their apartments, and they're very proud of their apartments.

To be fair, while we've had some success with it and we can see the positivity and the benefits of it, it doesn't always work either. We have had a situation where we had a very young resident, again very clever, and unfortunately, it went really well for a few months, and then they stopped reflecting and working with us. I think one of the struggles that we had here in Ireland was, we could identify what some of the issues were and we could identify someone to give the help that was needed. We struggled to get other agencies to work with us in terms of mental health, and even in terms of general hospitals. So when it works, and it works well it's fantastic but when you do happen on a problem, and something that you know that you can't fix or work through by yourself as an agency, and you need to get the buy in from another agency I think that can be a problem for us. Sometimes the social care setting just isn't enough.

**NHS:** If we have the chance to offer them individual apartments it costs more money. What is your experience, does the government accept that we need these special accommodations for these people and more human resources?

**Comment:** The way that it's designed, there are six individual apartments where everybody has their own front door. You might have, for example, two staff on night duty supporting the six apartments. So, it's trying to get a balance that's affordable to the system. But what we do find is actually people with the higher support needs, who are presenting with more complexity, are the people that tend to be funded for our services. If they don't present with the same challenges in the same way, and they're seen as having a higher level of cognitive ability, the health system would say they're much more able, and seem to ignore the difficulties associated with the hyperphagia and all of the others because they see the high level of competence and say they don't need that. Yet the families are struggling at home, so that's one thing we find in the system. In terms of looking at the problems, earlier for us the biggest thing was the system isn't joined up. So when you have somebody with disability, particularly if they need mental health support the mental health services ignore it completely and say, "It's their intellectual disability it's their condition it's their behaviour." and don't recognize when it slips over to the other. We were trying to do a lot of work and influence that that if they work together as one system, and it's fluid, then maybe you can prevent the hospital admissions and actually support people more in the community.

I think made earlier is really important - if we could develop some sort of program or transition, and people are goal setting and life planning, and educated more about Prader-Willi syndrome into adulthood, so moving from home becomes something they look forward to. "This is where I'm going to live, and this is the support I get." that it's

seen as a progression, like their siblings, they're moving out of home, and that it's a positive thing and we're enabling them to do that. I know it's not easy but I think if you started at an early stage planning like that. Definitely what we found with the individual apartments and working around housing to make it their own is really important.

**Chat:** How to improve their social interaction capabilities?

**HS:** I think that's a question for us, how to improve their social skills, how to improve their social interactions. That's a big question, and often it happens in development in role playing when children and peers play together. To my experience often the child with Prader-Willi syndrome don't have this chance. How do you look at this topic?

**Comment:** I think that one of the reasons for these difficulties some of them have is the kind of interactions you have with other people they are living with. They can be very upset rapidly over things which for us seem really minor. You mentioned this role playing but we know in the autism spectrum that people have difficulty with imaginative games so how can they enter in this role playing game?

**NHS:** If they do not accept to do role play, and they refused these things it does not work. If we can connect with them, then we are able to develop and support them. You said it must be their own project. Maybe we can develop in the way that we develop training programs, if it is their idea to have a training program for themselves. Then maybe they will decide to accept and work together. Then they will say, "This is my apartment. This is my training programs. This is my wellness program. This is my work."

**HS:** I have experience of some that really like to be creative with arts, or to play theatre and are really consistent on working on theatre roles, to make plays and to produce them for others. With young adults we have to invest a lot of resources to help them feel competent to do to play roles.

**Comment:** In many institutions the person does not select the colour of the wall in his room. And this is something you know which is very important, you feel comfortable with some colours, others not. We must really be very aware of the room design and we must try to understand what they really want in terms of such details, furniture, colour and so on.

**Comment:** We definitely have some new, young adult and clever people. The problem we have at the moment with them is about when they are able to use social media and connect to other people in the outside world. Sometimes we have the problem that they finds ways to get food through social media and we have a lot of new problems, that we have no solution for. We knew we have to bring it on the next level in the interaction with the social media but we don't know how. That's really new big problem we have at the moment.

**Chat:** How are people managing things like internet use and social media?

**HS:** Yes, I think what you're telling us is, it's really necessary to find the space for them to be responsible for their behaviour. You only can offer them situations where they can experience things and how to cope with them, but it needs patience from the environment and from the people themselves. What really is a problem for us is how to find out the background, what is behind this behaviour we see. Is it someone who wants to be independent, or someone who has problems coping with stress, or someone who is very anxious and seeking food to cope with his anxiety. These are the things we have to find out to make an intervention which is helpful for this person and not for the whole community.

**Comment:** I think we must try to let them experiment. Don't say no, we must not say no, say "We will try." and then they can discover by themselves that the project is not realistic. This is totally different to saying no, that's not for you.

**Chat:** I would like to see more skills training programmes and directing towards employment or meaningful occupation.

**Comment:** Picking up on the point of social media, I think in the past, if people with PWS were given two points of view, like if they hear one thing from us and one thing from the parents, they then pick whichever view is more favourable for them, especially if it's to do with food, but on the internet, there's every view. So whatever the dream, there's always some somebody that's going to support that idea. So I think it's a very difficult thing because there's always options for more input, and we even have come across advocates for people from the church to get involved. Initially they will believe that the support staff at the house are very evil people, doing all the wrong things because of the way that the person with PWS will present that. So I think there's so many options nowadays, to get different reinforcement. So different ideas, if you're not happy with the ideas that you're getting from around you, from the people that are trying to support you.

**Comment:** That's a really good point and I think also, they tend to believe, especially if it's favourable towards what they want to do. It's really hard to get across that not everything you read on the internet is true. So that's something that that we really struggle with, is people believing things that they read that are clearly untrue but it's in writing, it's in front of them and they believe that.

**Comment:** I think part of the problem with the internet as well is the algorithms within the internet that will just promote that all the time. So when you start searching, and they've searched something like food or local shops with food, then they're going to get more and more advertising and that's just going to constantly reinforce it all the time. It is understanding what is true and that goes back to education, but it's a very difficult thing to control. The individual's got their own will and preference to be able to manage that themselves, and what they see in private, but it's a difficult thing to do. It's a difficult thing for adults. For example, the myths about vaccine. So, let alone somebody for somebody with PWS.

**NHS:** And is our answer to not allow them to use social media?

**Comment:** I don't think it can be, because that's where we are right now.

**Comment:** I think taking away that control is more disastrous and in the longer term. It's about understanding and getting the reasons behind what they're saying and what they're doing what they're searching and to be able to understand that. That's the crucial part of things, just like you were saying about the behaviour part of thing, which is very interesting. You get a behavioural instant and then you get the height of it and then you get down into the reasoning why, and it's to look back along the reflection part of things after that about what that was and the understanding and why you were looking at it. And it's complex but that's the only way that I think you can approach that.

Another example is in another situation we came across was when the person was accessing inappropriate material. The immediate action was to take that away, which was correct because it was such a high risk at that particular time. But that's just one aspect of it. The other part of the risk is going back teaching about relationships teaching about sexual content and everything and that's what you need to do, and then slowly release that back again because that just got to a crisis point. But if you could do that teaching earlier on, as you were saying all of you about childhood and the development of that, then that's much better. They all grow up with internet now , a three year old baby knows how to operate a phone, that's life.

**Comment:** We currently have a generation of adults say aged 20 to 30, who for much of their life have been shielded from internet from families who have shielded them from all the dangers of the world because of various factors, and there is a gap in how we transition children from adolescence to adulthood. As for my children we teach them about internet and how to use it and appropriate use, but I think there's a generation out there that is worried that their children don't have the capacity to access these things, in some regards they struggle with forming relationships, whereas we try to form relationships from a younger age, and they begin to develop those capacities at a younger age to help them moving forward.

So there is a gap out there at the moment because from childhood we focus a lot on medical issues. We focus on diabetes, we focus on the growth hormone we focus on even looking at could there be a cure in 10 years' time, and what we tend to neglect is that we've got a young adult who is growing into a body, and we forget about what children and adolescents go through to grow. There's a gap in literature and discussions out there about how we transition young adults into adulthood and to live in group homes or into working environments, how do we get the best results out of that. If you do a quick literature search there's nothing, there's not much out there, it is a real gap. That's where they struggle in gaining that ability to socialize with friends, to live in a group home environment because all of a sudden they've gone from a crisis



at home, and then bang they're in a group home with people they're not too sure about. I think as a group and going forward this is an area that we can focus because everyone's had the experiences of what goes wrong, let's take that a few steps back and ask how could we have changed that and going forward what are the steps we can take and then start working with young adolescents and families to realize that when they grow older these are the steps that we can take to help them instead of almost throwing them in the deep end. I think we can get some literature out there and help people.

**NHS:** I like what you have said is that we have to focus on these social competencies and that we have to work with them with social media and not, as I asked before, should we not allow them, it is not possible, but on the other end, we should more and more be very intensive in supporting in these things, we need resources for this, but this is the only way. We cannot try to not allow them.

**HS:** 11:08:25 I think about puberty in Prader-Willi syndrome, we always have problems in puberty and don't know what may be different to others. Even puberty for anyone is a difficult time. So in Prader-Willi syndrome if you think about cognitive development and emotional development there is this difference. So in puberty, is it the same, or is it different for we know our brain is immature, and will develop until the 20s. And it's often a problem in puberty.

**Comment:** Can I raise a different issue, as Norbert right at the beginning said, but it does happen, what do you do with respect to the person who refuses everything that you're offering? And I just want to raise an issue that when the consequence of that is that the person's behaviour, not so much the hyperphagia, but other behaviour, results in them, hitting people or doing things. Should we involve the criminal justice system at that moment, and should one, then use that as a means to try and bring some control back into that person's life? Our experience here is the police tend to be reluctant to do that because they say, "You tell me this person has a disability. Can they form intent? Isn't it unfair to take them through the system?" But I'm wondering whether you who are supporting people on a day-to-day basis, would see that in a positive light or a negative light.

**PC:** So, what we have found in a lot of cases is that when the police were involved and the court system was involved, because they have such a difficult time understanding consequence, they actually enjoyed the process. They love the police coming, they love the ride, in the police car they loved being important, were very friendly with the judge. And the other thing to keep in mind, at least in the States, unless you're going to a prison, if you're just being held in a cell, if you're held overnight. They don't have kitchens in jail, so they typically bring fast food for all of your meals. So, we found that involving the police was disastrous because they kept wanting to have the police come back.

**Comment:** Not only does this sometimes positively reinforce that behaviour but when I have people getting out of the group home and breaking into the neighbours' homes to get food, they don't make that connection that, "Oh this is something that I don't want to be happening. I'm getting in trouble. Therefore, I should not do it anymore." So, when I have people in court, they don't make that connection that we would, that I don't want to ever be in court again this is a bad thing for me. They just don't have that higher order cognitive ability to understand, "Because of what I did, I am here, this is bad, I don't want to do that again, I will correct my behaviour." That hasn't happened in my experience

**NHS:** Maybe I can use the examples from the beginning of the discussion and it makes me a little bit sad, because you said maybe that we gave them too much the feeling that they can do anything they want. So maybe then one of the ways is that we start very early to give them a realistic view of the world, and that there are limits, and that they cannot do what they want, and that they can't be a millionaire in 10 years or something like this. I think this is not nice in the situation to say this to them, but we also have to learn to give them limits. This should be a part of early intervention and working with children, to give them a realistic view of the world, and yes, we also include the police we also include judge, this is what we do more and more here, and I think it depends on how we reflect this with them so that they understand what happens. This is our job to transfer knowledge so they understand that live is not easy and without limits.

**HS:** Everybody has limits, and we always talk about this frame, how to live in a frame where I can develop independently, but there are always borders.

**Chat:** Is the issue here starting to talk to the families early on in that pre-crisis stage and educating them about how to handle that transition to adulthood? They've built a lot of patterns and assumptions based on their child needing a high level of care from them - how do you teach them about that transition?

**Comment:** In Australia, we do have this route that I don't know that you've got in other countries, which is a guardianship, where you can have a decision maker that can even make decisions about where somebody lives and what restrictions will be put. The only downside with that is that by the time you have enough evidence to take it to that system, things are already out of control. It's not something that can be done before there's a problem. But that's an alternate way in Australia, that it's not quite the criminal system but there's another system that's in between, that seems to be a bit more effective because we haven't had a lot of luck, when it's gone to the criminal system that hasn't really worked but the guardianship one does.

**HS:** My experience was that is we have contact with the police, either they think, "Oh he's disabled, we have to do nothing. No intervention is necessary." And others make an intervention because they see if they give them something to eat the behaviour

stops and everything is okay. Then they come back to the home and we have the same problems as before.

**Comment:** Our experience has been, across intellectual disability in general, building personal relationships with local police is often one of the key factors there. That's always going to be a little bit tricky because it depends on who's there. So we've had some police stations who've been very friendly and very open and we've been able to say, "Hey look, this is Bob. These are Bob's issues." And have them be quite receptive to that and say, "Okay, if you see something happening with Bob out in the community, these are the best ways to approach him and deal with him." and to have that happen in a productive way that's not going to cause further problems down the line. If you have a receptive police station, that works fantastic. And if you don't, then you're back to all the other problems. So it is that relationship building but there's two halves to that,

**NHS:** Some of you have said networking is one of the most important things, and to work with police, to work with the environment, and to inform and include them in the process. This is, I think, one of the answers to my own question at the beginning of what to do.

I think we do not work, enough with people with Prader-Willi. We make them not competent enough to do things, maybe, at the end, they're competent to design houses for themselves. If we talk with them very early and start the discussion with them. And the focus is not enough on this. I think the focus must be more how to handle the all-day care.

**Chat:** We need more research about puberty. They have difficulties to build a positive image of themselves. Physical differences, comparison with others, difficulties to have friends, etc.

**HS:** It's really necessary that they have the education and get the knowledge about their Prader-Willi sooner by themselves, and they can talk about this and what how to handle this. Most only say, "Oh I have Prader-Willi syndrome and I can do things, others can't do. I'm allowed to do what I want because I have Prader-Willi syndrome." Now, I think we have to educate them in this and to talk with them about their own rights and duties and about their own handicap, which may arise with Prader-Willi syndrome.

**Comment:** I agree that speaking with them directly and having these adult, maybe reciprocal conversations. They're very smart and they can be very articulate and then just building in consequences. The teaching and the training is very key and I think with the younger folks, I see that I can have more and more of these reciprocal conversations, and talk with them about "What would you do if this happens?" and allowing them to make some of those mistakes, but then accepting that there might be some consequences, and then what? And help them plan everything. It's that support to move to their goal of independence, whatever independence means for them.

**Chat:** Speaking honestly to people with PWS is so important

**Comment:** We certainly have some adults, and I have one person in particular who has gone into the universities, and talked about what it was like to have Prader-Willi syndrome. And she's very keen to be a mentor to younger people with Prader-Willi syndrome, and to go into schools and teach the schools so that they won't bully the child with Prader-Willi syndrome. So she's very competent, very intelligent, but she's also very understanding of her needs. And she lives in a group home that supplies all those needs, so she's happy.

**HS:** Yes, I also do it in a lecture in a university I take someone with me, a young lady with Prader-Willi syndrome, to explain to the students. And they are really able to, if they are educated over a long time. I think it might be helpful to have peers, not always professionals. If you have peers that might be really helpful.

**NHS:** Maybe in 10 years people with Prader-Willi will be sitting here and talking to the audience here, it will be very interesting.

## Patrice Carroll Summary

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**PC:** We started by talking about what this next generation looks like. People have more competency, but some may use this in a self-satisfying way. We have early diagnosis and early interventions and better information for our parents. The early therapies for children. The kids are informed at a very young age of their rights, the younger generation is more competent but still have hyperphagia and food seeking issues.

They can be egocentric and can struggle with recognizing their feelings and the feelings of others.

We spoke about the strive for dominance and that this is a typical developmental process but coupled with a lack of competency in some areas, such as not learning from prior mistakes, can be problematic.

The younger generation has less weight issues. They're more involved with family and community in school and the decisions in each of those places. They can be more competent than prior generations, but can refuse to reflect on past behaviours. They have a very good understanding of their rights. We looked at the crisis chart, and the reflection phase is challenging for some people with PWS. They struggle with this and even highly trained staff cannot always be successful.

We talked about some challenges for our traditional systems. So, the systems that we've been used to using all this time, now we're seeing some challenges with this new generation, and not necessarily having a good fit. We spoke about how we can intervene with families before the challenges even start. And that they get the message early on that they can do anything, and this this may be problematic and are we giving them the wrong message from an early age?

We see a difference depending on the environment. It helps if they can be motivated by owning the project. Things can go well, usually if there's buy in from them.

Services are sometimes used as a threat, and this can be problematic during that transitional phase. Residential services should be put in a positive light from a very early age.

We discussed that funding doesn't always match the need. Ideally, there are options for semi-independent living like apartments. If you can fight for the funding, you have to prove the need and to show that it's cheaper in the long run to do this.

How do we safely allow them to have experiences like social media, address the gap between childhood, adolescence and entering adult services, and things that they will have access to and the ability to do once they enter the adult services.

We need to put more emphasis during childhood on being successful adults and work on social competencies at a very young age.

We ended with the question of whether or not we should involve the police, help them understand consequence and cause and effect, and the need to educate the community, and the person with PWS from a very early age, and encourage mentorship. And I think that sums it up.

## Upcoming Caregivers' ECHO sessions

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Weds 17 Nov

### **Nutrition in Prader-Willi syndrome**

*Dr Constanze Lämmer, Senior Physician, Children's Hospital, St. Bernward Hospital, Hildesheim, Germany*

Weds 15 Dec

### **The Power of Exercise for People with PWS**

*Georgina Loughnan, Prader-Willi Syndrome Clinic, Royal Prince Alfred Hospital, Sydney, Australia*

*Thank you very much to everyone who attended the session and participated. We look forward to seeing you on Session 6 in November.*