



**IPWSO**  
International  
Prader-Willi Syndrome  
Organisation

# IPWSO Caregivers' ECHO abstract summary

## Jan 19<sup>th</sup>, 2022: Meaningful Employment for People with PWS

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

IPWSO hosts: Hubert Soyer (HS) and Patrice Carroll (PC)

Presenter: Larry Genstil (LG)

### Video link

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[“Meaningful Employment for People with PWS”](#) Larry Genstil, Psychologist, Genstil Institute of Human Behaviour, Israel

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

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

**Comment:** In France, there are sheltered workshops for people with disabilities but the specific difficulties of PWS are difficult to take into account, so, this is not a global approach. And very often they are doing jobs you don't like, not in all cases but there is no real research to adapt the work to the motivation and capabilities of the people with PWS. I think that while we focus a lot on employment but what people with PWS want, and the new generation are people with better capabilities than before, and they are asking for social recognition and social recognition can be done by employment, but it can be also a solution, and that that's something. You know we have three millions of unemployment in France now, so it's very difficult to say okay, we will (find employment). I think the most important point that people are included in a social life by employment, or as a solution. That's something we have to work on. But, of course, I agree with what was presented here. There was a big discussion in France on this, for the time being, there is no good solution, taking into account the specificities to offer PWS and they are but a few people working outside of sheltered workshop.

**HS:** Yes, you said really most important is to have a benefit from social environment, and I think that's necessary for people with PWS, and I also see a new generation wants a job like you and me, wants to be recognized like you and me and don't want to get to a sheltered workshop. If it's possible they want to go out from the home. It's a kind of independence, kind of freedom and that's necessary.

**Comment/Q:** We're working with children so we're just beginning to really settle in with our vocational program, as our population is increasingly PWS. So, it's really getting the correct placements within the community, where they can find success.

I actually had a question, are there any instances of PWS specific work sites?

**PC:** That's a really good question. The states has, over the past few decades, gone from sheltered workshops, into closing the sheltered workshops, but they didn't replace it with anything. But back in the day, they did have PWS specific sheltered workshops. I know there was some in Massachusetts, I know there was some in Wisconsin, and when they closed those, they didn't replace it with anything, but it did provide safety, a lot of socialization, a lot of camaraderie, but they closed all of those. There was a reason they closed them, and I agree with the reason, that people were doing piece work and making far below minimum wage. But then they went to working in the community which, again, I totally agree with, but they have them with job coaches and the whole idea of a job coach is that you use them until you don't need them anymore, but people with PWS will always need them. So they did a disservice to the population when they went from sheltered workshops to working in the community with nothing in between.

So that's a really good question and they did used to have them but they do not anymore, at least in the states, and I'll let the other countries speak to whether or not you have any PWS specific work.

**Comment/Q:** I am from Denmark, and it's a small country and here, most adults above the age of 25 live in some PWS home, and they have arranged themselves differently; one place they work with horses, and other place they do garden job, and another place they have a sheltered workshop. Most of the places are little out in the countryside. So, I can only say it's different, and in some places, I think there are some who are capable of more, not only sheltered workshop work.

But I have a question to you about Israel, because some of those with PWS, especially those a bit older, they have a physical limitation of what they are capable of. I think that many would be able to work with something that interests them, but perhaps not for eight hours a day, perhaps only four hours a day, and they need more rest, not only for eating but just to rest. If they are old and they have not had GH when they were young, they are perhaps a bit weak, physically, so I think it's an important point that they have reduced hours and then they can work in what interests them.

**LG:** Our people, the ones that work in the school or the nursery schools they're working five hours a day, you're absolutely right. And they are older, the women in the nursery schools are 41 and 40, and in the dental class sterilization he's I think 49. He works seven hours and he's okay with it, but most of them you're absolutely right, they don't have eight hour work days. And because they're able to handle the work day,

then they're doing a good job and they're very happy. I didn't think of that when I wrote the PowerPoint.

**PC:** I have a question about the people who work, both in the nursing home and in the dental hygienist field. Is that what they wanted to do, and then you found it for them, or did you happen to find these and say, do you guys want to give this a try?

**LG:** That's a very good question. With the nursing home, all of the people wanted to work with children, and when that was not an option, they were offered work with the elderly and they said yes they want to. And when they closed the nursing home because of Corona, then they were very upset. And now two of them are working in the nursery schools and they wanted to work with children from the beginning so they're very happy, and 2 others now are doing other things and they're not as happy, they want to work with people and they're good with people.

But this whole project that I presented, in terms of working outside of a workshop kind of setting is new, just two to three years old. And the agency fills a slot, and they can leave the person there for 20 years. And that's one of the things we're trying to fight against. So, when these girls get 2-4 years of experience, can they go and learn, taking care of younger children? I don't know what's next because it's all brand new, but things that you're doing Patrice are also cutting edge kind of things and that's why we all share this stuff.

**HS:** I think Larry what you presented is often the problem of how the workplace for people with PWS is adapted to the people, not otherwise, how the people must adapt to the workplace. Also what has been asked is how can we take care of older people and keep them in healthy condition, and what's with economics of the working place, it's a duty to think of the economics but that's often not the case.

**Comment:** We had situations similar. Many years ago, national policy was for closure of all sheltered workshops, and they're all predominantly closed now, and what they introduced then was an individualized support service called new directions. So that was aimed at people leaving school that they would have a choice of going into vocational training, which is a four-year program, very much focused around gaining skills for employment, or then day service, which was individualized programs, looking at person centered planning and people's goals in life.

There are some sheltered employment services still available but they're very limited. And that was similar to where Larry mentioned that they become assessed at their functional level, and they are paid at that level but then the state will top up the payment, because the biggest goal there was that people would have the same employment as others, equity in wages, equity in your employment rights, etc. And those initiatives are there as well. We also have then a supported employment consortium where people then can go and have opportunities to get a job coach and

individualized supports. But for many people, particularly with PWS, they also need their support person with them, because the job coach tends to focus on your CV your application your job skills and your placement, but not the actual day to day supports then on site.

And, I think over the years, one of the biggest challenges I've seen where people gain employment, or go for part time work, or work, is that then they become true employees, they become part of the workforce, and that they're not only going in to do the tasks, but that they become part of the team. And that's the difficulty again for PWS is that they go to the canteen, or that they go to the parties, or that they actually are meaningfully part of that, and that's probably one of the biggest challenges I would see in relation to employment for people.

**LG:** If the programs are individualized, how is the support regarding the food security taken care of?

**Comment:** Well, in terms of the people that we support, and now we don't have any in our group at this stage that we're supporting in employment. Generally, that would be I think with the support person with the person with PWS and they prepare and plan for everything. I imagine then that what they have to do is, you would go and you'd have your meals with you, that are all planned out, and then try managing that way. I know of other people that I have heard that were in other settings, but that the access to all the food around, even down to the condiments and everything, were causing very big stress and anxiety and then things were failing for them. So I think if we were supporting any of our own people, because we're still in the early stages of development, that would have to very carefully planned, and that either they would go somewhere else, or not be there for meal times, but it would be managed in that way. I think some people eventually do get to the stage that they can bring their lunch and they're able, with food security and the psychological security of that, then they're able to function and have lunch, and focus on that but they really do need the support person with them, to be able to help them.

**PC:** And just something that speaks to this, what happens a lot is, someone's had a job and they're doing well, and then you back off the supervision. So just a story that speaks to this, and I don't know if this happens in every country but in the United States when you go into a store, many stores have little cards that you can scan and you get reward points. Is this something that happens in other countries? Yeah. So, we had an individual, an adult who was working at a store where you got reward points every time you shopped, and he was doing great, no issues, they backed off the supervision. And then a couple months later, the store came to us and said he had a million rewards points. Every time someone came in, he would take their card but scan his own. So he was doing great, right? We didn't have to watch him, no supervision. They'll find a way. So, it just speaks to the fact that you really need to be watching

when they're there. He had a million rewards points and they found out because customers are complaining that their rewards points weren't adding up because they were all on his card. One of the hardest parts about this is that they're capable of doing so much, but we have to keep holding them back from that. That's really frustrating because, I mean if he could think to do that, think of how, if he used his power for the good how successful he could be. Very frustrating.

**LG:** That's right. One of the issues that we're always dealing with is the trade-off between need for support, and independence. We're getting better at it as they get older. In their 40s, they need much less supervision, but other than that, it's always a trade-off and we don't know how to provide enough support so they can succeed without doing too much.

**Comment:** I think it's also critical that the employer and the place of employment, get adequate training. And the planning is so crucial because sometimes people go in and then it's not quite clear, the tasks that they're going to do, and then that could be moved around and that creates pressure and they're doing so well on one and then something has changed, and it can lead to a failure, which isn't the fault of the individual. And while you have a lot of people and employers that are well meaning, unless it's so carefully planned and so worked out and continuous monitoring and review it can have a detrimental impact then as well. There's a lot of planning and in many cases, you really need an understanding employer who signed up to this and understands that yes, it might take more effort, a lot more planning, but the benefits to be gained from it usually outweighed that, but it's to get them in in the first place and to get that commitment

**HS:** To my experience I often notice that some people with PWS really always regularly need the same work and wants to do it in the same way, and they can't switch to different tasks. Even if they had done it, are prepared, a change is always difficult for some. Others are able to do it and these ones, I think, don't have the problems if they are in regular employment. And therefore, we have so different things, it's really a broad range, how to find a working place for people with PWS that fits really to the back to them. And how to instruct staff there in the working place to notice what will happen, after time was ask is it fitting anymore or should we change some things? That's always a problem that everybody is expecting this will be the same for the next three years too.

**Comment:** I'll just echo what was said, I think the key thing from my perspective is about the risk, and we do have a comprehensive risk assessment process in place but when you're looking at risk you tend to look at all those, the hazards and then trying to avoid those hazards and stuff like that so it's very much about avoidance, don't do type thing. So on the flip side of that we have a positive risk taking procedure so where you have somebody will to be able to go and do something, you're then looking at the

other, the other aspect of that the positive aspect of it. And although we don't have, you know, service users going towards employment, I think if we go down that route, that's what we will use, the positive aspect of that. Whilst on the other side of things you can look at the employer and their rights and what they have to do and all the risks associated with that so it's literally just looking at the risk associated with that but I take on board the points thing that you mentioned and how clever people are and in risk there are these unknowns that you can't foresee, but have a bit of resilience to be able to cope with that.

**HS:** Even people with PWS must have the right to make mistakes and to get an experience. In Germany we weren't prepared for this change, and therefore we have to learn how to support regular employment and how to support companies to make places of work for people with PWS or disabled people, and we are not used to doing that, in the last years we only had sheltered workshops, but now it's turning and I think it's a good way we should help them to find new ways for people with disabilities to work in in a normal, regular employment.

**Comment:** In Minnesota where I'm from many of the old type sheltered workshops now have jobs for people that is their job to go into the community and match desires of our individual. So, if one of my folks wants to go work with animals, they go and seek out employment for these people, ask the employer, "Would this be a good fit?" they do an interview and they set all this up and then they train with Prader Willi syndrome specific. Is that how it works in other countries, that there are specific jobs for people that they go out and look for employment for our folks that they want to have and train people about Prader Willi syndrome, before they go in?

**Comment:** No, I think that most people will disagree. Well, I only want to talk about PWS because if you have a person with muscular dystrophy, for example, that is quite another situation, because then they can go to university and they can have a personal assistant 24 hours if they need. But we do not see that with PWS that one person has 24 hours support, I'm sorry to say. So most people with PWS they are dependent on where they live, what possibilities there are in the group home where they are and how it's arranged there, but again it's very different. Many are very satisfied, for example, to work with animals or horses and that's part of the where they live, it's a possibility where they live. But others, I think they are capable of doing more than they do, but of course some overestimate themselves also. And then one thing I think I have to add always is that we should be aware of their physical condition, and I have seen people with PWS sitting in a sheltered workshop. They have been driven to the place by a van, they are sitting all day in a meeting or something and then they are driven back again. So, they do not move very much, and they put on weight, and they get leg ulcers, and so on. So as think is very important to be aware that they should not work more hours



than they are capable of, and they should have time in the rest of the day also for physical activity.

**Comment/Q:** I would like to ask, we have an issue, it's similar to Ireland I think, when people leave school they go through what we call the Post School Option Program and it has the two arms, the community participation or transition to work. And I have a problem with a lot of people with PWS where the families think they're not capable of working, so they'll go into community participation which gives them more hours anyway. And because of the NDIS it is all subsidized, which is our National Disability Insurance Scheme, so they go to community participation which is like day programs. And then they get used to that and then I'm always saying to them, "Wouldn't you like to work somewhere?" or you know "There are so many things you could be doing." But no, they're quite happy because they're taken out socializing and it's so hard. And the parents say no, but this is what they want to do, and I think that this they're capable of doing so much more.

And on the other hand, we have some other people whose parents have all families and even the caregivers in the group homes are always encouraging about working and I have one man who runs tours at the Maritime Museum so he has a particular ship that he takes people on, and he gives the whole tour. He knows it by rote, and he gives the whole tour of that ship. But of course Covid struck, and of course that's all closed down, but he had 24 hours support so had a caregiver with him the whole time, not interrupting just with him to make sure, you know to be with him when he walked past food places, etc. And it worked very successfully he's very good at it.

And another guy was picking up papers with their local council, working outside physically active, really enjoying it, until the other workers used to get fish and chips and he couldn't cope with that. But, I mean, some of them do very well but there is this reluctance to really try and find enough appropriate employment places for people with PWS. That's what we see anyway in Sydney, that day programs and community participation is easier so they don't have to go through all the issues. And the people with PWS so let's let them stay happy doing that, which I think is underestimating their ability, which is a shame.

**PC:** I love the idea of the tour guide though because it's so routine, and it's the same thing every time, aside from questions they may get. A great idea for a job, though.

**Comment:** And he is so proud of it because he's a good looking boy and he dresses very neatly and it's wonderful.

**HS:** I think as you say, we have a lack of appropriate jobs, but I think also it may be about money. If you find appropriate jobs do you think it will be paid by the state, or who will pay support of a full-time caregiver? It's really expensive and therefore, I think nobody will be happy if we find these jobs.

**Comment:** I think there are a lot of jobs there, but I think it takes time and effort to find the right job for the right person. Whereas other things can be much easier, which is a shame. But some of the guys do brilliantly and they have great work. I have one girl who has worked in the same industry for a long time and that's a supported industry, that is what we call sheltered workshops, and so she supported, but she's now a spokesperson for that industry, for the other people working there who all have disabilities. And she does surveys with them and she is the spokesperson if anything is wrong, so you know some can do very, very well. I think we just have to nurture the employment, and the being occupied, so much more than what we are doing, especially in Australia.

I think that you may know there is a [FamCare article](#) on the importance of being purposefully occupied, and for me, I think if we could channel many more of our clients into occupations rather than day programs they would be much happier.

**Comment/Q:** So, I work in Ireland in a PWS home there. It will be something that we will be looking at, for some of our service users to get employment, or look at it at least we have a social farm here which is kind of like a family run farm but people with disabilities can go in and they can see, do they actually like working with animals? That kind of thing.

But I do have a question, do you find that employers are resistant, or very reluctant to work with people with PWS? Do they find that there's too many restrictions around employing people with PWS?

**LG:** What we find in Israel is that a lot of the employers go on the internet and they read all the difficult stories of people with PWS, and then they don't even want to talk to us about it. It's a real problem. If they don't have internet it's easier.

**Comment:** One of the difficulties that we're having here, it's a very small island community as well. And many of these people have been in business for a long time and they're remembering back when we had come to work for them years and years ago and they've had difficulties. And there's reluctance to try again with new students.

**Comment:** Okay, well it's good. Like I said, we do have service users that maybe would benefit from being employed and that may be the next step for them, and would really like it. But there's a lot of planning has to go into it, and education to the employer obviously as well.

**HS:** I met only few people with PWS, who aren't interested in work. As Larry said, oh are they interested. That's my experience really only few people who wants not to have work for themselves and to earn money or to be in a social context in work.

**Comment:** Yeah, our guys they do want to work, they really do. It's new, they're just over two years with us and they're doing amazing with food security. And so their next



step is their adult literacy classes, which teaches them by date, say money. And so next up is that they do want to go out and get jobs. One of our lads wants to work with animals and one wants to work with children. Yeah, so it's definitely a lot to look at but definitely will be a step that we'll have to take, that we want to take.

**HS:** And I think a lot of people are very proud of the work, and they come together, everybody's working on another place they come together, if they live in a group home they tell each other about works I have. I think it's really, really important for them to have work, which they are interested in and to find purpose, which is helping them to get more independence and more social self-esteem.

**Comment:** I think a lot of times we hear about the animal care and the children care you know that's what we hear they want to work in. But then you dig a little bit deeper and you find other things that they might be interested in that we can adapt to and find areas that work. For example, they love the fire department. Are they going to be a firefighter? I don't know, are they going to need that support? But can we get them some sort of job in that realm of working at a fire station. I'm working with those individuals that they're interested in. So, I think a lot of times we hear that animal care or that child care piece of it, but then digging a little bit deeper to find is there is there something else that they're interested in and or giving them an opportunity to find something else that they might be interested in.

**HS:** Is there really different kinds of work for people with PWS, or is it more the same work or in the same direction as animal work or farm work or something like that.

**Comment:** We have a student that works in an airport, and the planes come in, he tracks down the numbers for TSA so he has a really important job at one of our smaller local airports, which I think is kind of a creative and different type of job that I've heard of. But other than that, we do we do see a lot of animal care, a lot of child care, those types of things.

**Comment:** We have people working in museums as tour guides. We also have people working in clothing centers and shops, hair salons and things like that, so we have somewhat of a wide variety of employment opportunities for folks, but it's the supervision again, and the training that has to go along with it that kind of complicates things for our individuals.

**Comment/Q:** With animals and childcare do you think that they tend to go for those kinds of jobs because there's food involved? When you're minding young children obviously they have to be fed. Is that why they're doing it? I know one of our young lads, he really enjoys bees, but he also likes the honey. So, are they thinking of the jobs that they really want, or for what they can gain from us food wise?

**Comment:** Yes, I was wondering why people with PWS would like specific jobs, and I don't see any reason why they should not be interested, as a any other person would.

The problem that they have themselves is, they very rapidly understand that some jobs will not be possible for a lot of reasons, which we should think about it.

**HS:** I agree totally with you, I think it's often the lack of a possibility to find out what's interesting, and they are all directed in one direction so often the problem, is they couldn't try out a lot of things which other people often can do.

Larry, what do you think is the reason that you experience that people over 40 are more able to do it, to be integrated in in the community about their behaviour, what do you think?

**LG:** I don't know what the reason is I just know that it works. Not 100% there's still food issues, but in essence, it's not bad enough to make them get fired from their jobs, it's working. But all of these people have low normal intelligence, so I think they can reason with themselves, if it's worth it to steal some food, and maybe lose the job. So sometimes they can't control it, but most of the time they do, but they weren't able to do it when they were in their 20s.

**Comment/Q:** Do you think part of it is just life experience and having the coaching and the support throughout life that as they get older, they're used to the structure and they've developed more skills over time so the behaviors somewhat do decrease?

**LG:** I think that's part of it. I think part of it must be neurological. For some reason, even when they have access to food they eat less than they did 10-15 years ago.

**HS:** I think that would be interesting to compare this with people in different living settings, if they live at home, or in a group home, or if they have enough support, and special support. It would be interesting to find out if the setting in which they live is really important. If there are trained staff or not trained in which environment, they are living. For me, we have the same experience. It lasts a long time till people with PWS adapt to their environment and can manage their environment, and often it's five or six years and then it could get better and better. So if they come with to us at 20 years it is only is another 20 years to 40. They have to learn and to adapt and even behavior problems, go down. It would be interesting if there is some, some research on it. If it's neurological. And what kind is the environment and, but always we learn only , in a good environment. It will also change our brain. I think that's the problem.

**LG:** In Israel, we don't have that many people in their 40s, maybe 12 or 15 altogether in the whole country. So, we can't really do a study on it, but maybe countries like Germany where there's a lot, maybe you can.

**HS:** Yes, I think that would be really interesting it when I read your sentence about people over 40 hour, how it's easier for them to be integrated in a work process and the behavior problems go down. That's really interesting. Maybe IPWSO can make some research into this, a worldwide questionnaire would be helpful at the beginning.

**PC:** I think we find the same, absolutely in the US. The 16-year-old with PWS is a completely different person than the 46 year old, completely different. You can't even compare them. We definitely see it that way.

**HS:** But we don't know really little about and that would be interesting. Especially if you think it's caregivers who have another insight, and to get more experience about how to handle it over time.

**LG:** I talk with our staff about the fact that when they work with these people that are really difficult behaviourally, there's hope that later on, they're going to become much easier to handle and also because of this kind of programme they'll be alive, where 30 years ago they wouldn't be alive with those ages. So, I hope that reduces some kind of burnout.

**HS:** Yes, I think it's necessary for caregivers to see the results, and we learn from each other, from the people with PWS, and vice versa.

**Comment:** I just say that we have rather many above the age of 40 in Denmark, and those who are functioning the best are those who are not overweight, and those who are treated for their hormonal deficiency. And I mean, especially men, that they are not too low in testosterone, because that makes the muscle function less good. So I think that those who are in the best physical shape also function the best. But it does not tell anything about what they are capable of in work, I know that, but I think that it helps if their physical status is optimized.

**LG:** Are you saying that testosterone can improve behaviour too?

**Comment:** No, I'm not saying it would improve behaviour. Not at all. But if you, if you are very low in testosterone - and you have to check that with a blood test, if you need to treat, and you should not give too high doses either. Most often we use a gel applied to the skin. But, I see some older, also in other countries that have not been treated for their hypogonadism, and they are very weak, and if you are low in testosterone and you are a man, then your blood concentration will go down and your muscle function will go down. So, I just think it's important that their health is as good as possible and that you go to regular checks and have blood test for your hormones and so on. And then you can discuss, and it's not in all countries that you can get growth hormone, but some adults will benefit from it, but not all adults will need GH, but you also have to consider. So just that you optimize their physical status, I think that helps their function. But then about behaviour, I think there's so many things and here food comes in, if there's not food security, then you have all this.

**LG:** I wanted to ask, one of my bullet points was, in every country are there agencies that place somebody in a vocational setting, and that's it, leave them there and they don't check if they could advance and move up to something better? In Israel, it's a constant battle. They get paid, so it's easier for them to leave the person where they

are and not worry about advancing them helping them attain more independence, or functioning. is it the same in every country? Or maybe there are countries we can learn from.

**HS:** In Germany I can tell you if parents and caregivers do not work together and look for a place, that you will never find a place. Even though we have official people who are paid for that. It's a pity we have to look for them and we have to help them, that's our task. I don't know if in Ireland or in the states it's different. I don't think so, it often depends on the people, on the parents and the caregivers and on the staff, to find a good place to work for people with PWS.

**Comment:** Absolutely we're the same as well (in Ireland). The staff and the parents, the family unit, that's all up to us to meet their needs or to find their employment, if that's what they want to do.

**Comment:** In Australia we have organizations that do do it, but usually it's the parents and caregivers that find the better jobs.

**HS:** I think maybe it's the same in France?

**Comment:** Yes, but I also agree with what was said about social media and the internet. PWS is not well represented generally speaking, so people are reluctant to employ them, and we have work to do to change this image.

**HS:** I agree but I think it will take a long time to change an image. But if we don't start and work hard on it I think we don't succeed.

**Comment:** Yes, I just want to add that we know a lot of positive stories, and we must promote those positive stories. For example, the [YouTube channel of IPWSO](#) could be a good way to promote that.

**HS:** Thank you. First of all I want to thank all of you for your discussion, all you who participated today. It was a really interesting discussion. And I also saw that we have a lot of work before us. And thank you Larry for your presentation.

## Patrice Carroll Summary

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**PC:** Larry you started the presentation talking about factors determining employment - age, level of cognition, is it food secure, are they motivated to work, and what training is available? You talked about the types of opportunities, every from sheltered workshop to independent work. You shared some really cool examples of programs in Israel, that was really nice to see those.

We spoke about age in relation to behaviours, and supervision in relation to cognitive ability. How much staff supervision is directly related to the person's level of anxiety, environment, and physical need. Supervision regarding food, and options for

transportation and training. Does the person want to work? What's their reasonable expectation and does he or she have the skills to do that job?

We talked about ADD and its effect on jobs, also ASD, epilepsy, etc. The need to train either in groups or individually, finding the best fit. The motivation of the worker, do they want to work, and can they do the job that they want? The behaviors affecting job placements, is the staff support there to manage or deal with behaviors effectively? The need for staff to be trained in PWS and the need for a plan B.

We then went on to our discussion which in my opinion I think is the best discussion we've had so far in these ECHOs, it's great, we talked about sheltered workshops, vocational opportunities across the world. The physical limitations and the fact that people fatigue easily. The need the need for a shorter workday, to try to adapt the workplace to the person as opposed to adapting the person to the workplace. The need to train employers and other employees. The difficulty for people to switch from tasks, and the need for sameness for a lot of people with PWS. The need to be willing to take well-thought-out risks.

We again spoke more about the physical limitation. The lack of appropriate jobs, changing perspectives when the employer has had a negative experience in the past. Age plays a factor and we know that when you're trying to place someone in a job and they're over 40 you're going to have less behavioural issues. And finally the need for vocational workers to not only find jobs for individuals with PWS but to stay with them and help them grow in their employment careers.

## Upcoming Caregivers' ECHO sessions

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Weds 16 Feb	<b>How to attract and retain PWS Caregivers</b> Lynn Garrick, IPWSO PPCB Chair, Programme Director for AME Community Services, Minnesota, USA
Weds 23 Mar	<b>Managing routine medical checks and other regular requirements</b> Susanne Blichfeldt M.D, Denmark
Weds 20 Apr	<b>Education of PWS, behaviour appreciation, and positive support strategies</b> Patrice Carroll, Director of PWS Services, Latham Centres, USA
Weds 18 May	<b>Looking at different diagnostics</b> Norbert Hödebeck-Stuntebeck, Psychologist, Diakonische Stiftung Wittekindshof, Germany

*Thank you very much to everyone who attended the session and participated. We look forward to seeing you on Session 9 in February.*