



IPWSO
International
Prader-Willi Syndrome
Organisation

IPWSO Caregivers' ECHO abstract summary

Feb16th, 2022: How to Attract and Retain PWS Caregivers

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) and Patrice Carroll (PC)

Presenters: Lynn Garrick (LG) and Claire Poor-Harmon (CPH)

Video link

["How to Attract and Retain PWS Caregivers"](#) Lynn Garrick, Programme Director, and Claire Poor-Harmon, Recruiting and Hiring Manager for AME Community Services, Minnesota, USA

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

Q&A Following Lynn and Claire's Presentation

Comment: In Australia, it's a little bit different. We probably don't have as many homes. I remember when I first attended a conference in Toronto many years ago, I sat next to someone and they said oh how many group homes do you look after, and I said just the one, and she said I look after 9 or 10 just in my area so I was quite shocked. But I think this is one of the hardest areas to progress in, the retention of staff because it can be such a difficult area to work in, but at the same time, I find it the most rewarding area to work in because I never used to be able to interact with other residents like I have with the people I work with, with PWS so it is it is such a niche area. And one thing that we try to do when we look at recruitment is, I look for people with human skills, the ability just to talk to people, just to have that ability to have conversation with people because especially in the group home I work with, the gentlemen there, they really focus on just wanting to be normal. One of the guys. And that's what they really do enjoy. So I'm very lucky because the company I work for, we're a large company, we have one home out of 280, and we have a group that work in our recruitment area but they leave the recruitment up to my house supervisor and myself to look after that area. So we really focus on people who have worldly experience or people who are into sports who can who can actually get down and

relate to the gentlemen in a way that other staff might not in other group homes. We've tried to say that we're a little bit different and that's what we found works for us the best.

LG: Thanks for that. I think every one of us have been at the local gas station or the supermarket and we see a very friendly attendant. And we say, Hey, if you're ever looking for a job, give me a call and hand out some business cards that's another strategy for attracting people.

Q: Can I ask what I hope isn't a rather negative question but it is, to what extent are you constrained by money in terms of what you want to do? The challenge in the UK is that something like 98% of the funds to support people with PWS or people with intellectual disability, come from social services. So, if they say we've only got this amount of money and we're only paying this amount, you can't really argue because there's no one else you can go to and say well we'll support these people because they're being funded by someone else. And I would imagine the state supports most of the people that you're supporting financially. So it is that a constraint, you may have this wonderful vision, but if it costs, that vision. Is it a constraint?

LG: Absolutely it's a constraint, so in the states were funded by the state funding, like you said, the fortunate thing for us, in Minnesota at least, is we do have some wiggle room with our legislator, we can go back to the state and say we need more money to care for individuals with Prader Willi syndrome, and here's why. Here are the cost drivers and there's a formula that's broken down. I need additional money because I need to pay staff, I need to have additional workers compensation insurance because my workers are getting injured because I have high behavioral needs. I have people that break windows, I have people that rip apart our vans that we drive. I need to cover those costs. I have more sick time, because people need to take off, because this is a high stress job. So, there are certain cost drivers that I can present in a numerical fashion to the case managers for the state and say I need more money. So we do have a little bit more wiggle room, which in turn, we can pay our individuals more, but it is presenting the case that I need a higher rate of pay because of the complexity of this syndrome. And so that's what works for us.

CPH: That was the case when I first became manager of a home for the first time, Lynn was my direct supervisor, and we had funding in day one for one individual teenage boy with PWS, and we had no idea the extent of the behavior, but unsearchable by other area organizations, and it took a while, but Lynn did the work, and if you are looking into it and really taking the time to figure out that formula to approach the social workers in the state. She got us a rate exception, and that home, the staff there were paid at a higher rate than at another home because of the increased level of behaviors. Now at other homes I can tell people, you can go to this home. Are you

ready for a challenge, it pays more? And then attract people to that home, where they know they're getting paid a little bit more for their services.

HS: May I ask you a question? You tell us your homes are established since 25 years now. I'm wondering, how long do your staff stay in the average in your homes? And if there are some requirement, if you will have a one, to hire staff, what is a requirement, basic education or something like that?

LG: The basic requirement is to have a pulse, right, to be alive, and unfortunately, I think where we're at with staffing globally, is if you can fog the mirror, if you're alive, and you can relatively communicate will take you and train you.

CPH: I always say if you come in and you go through the bad day and you just keep coming back. I feel like it really is our responsibility as an organization to support the staff to learn the job and do better. Because when there is no statute or law that requires CNAs or nursing certificates or licenses. When those don't exist, and we don't have those education certifications and programs, it's our responsibility. We can't expect people just coming in to know anything. So, we're so focused on just supporting staff and teaching them everything they need to know. I have 60 year old women who thought they could do laundry but they can't, but if you didn't show them how you can expect people just to know everything? So, focusing on the training and developing them.

LG: There is no education requirement. And we've had staff with us, we've been in business for 30 years. We've had people here from the beginning. I've been there for 15 years, Claire for 8. I think, on average, we retain our employees for about 5 or more years. But no education requirements coming in, not even a high school diploma.

HS: I think that's a that's a big difference between Germany or Switzerland for here, we have a requirement of a basic education. You can only work in group homes if they have a basic pedagogic education. Therefore, I understand as you say DSP must be a certificate and a professional degree. I think that's really, really important for good support and to enhance quality of life. And one other question is, what you spoke about, increased communication. How does it work, this communication, do you have a certain method or a certain system?

CPH: So, I'm finding that I have a high population area in one city of Liberian immigrant workers, and where I'm somebody who might have a communication barrier because language and just our culture is so different, I've learned about their culture, and they're coming from, where they have never seen a stop light, they don't understand navigating, they're nervous about driving in the Minnesota winter. But when you have a referral, I have a staff who was at one house, it didn't work out they went to another and walked in, she's like, Oh my gosh, there's my best friend from back in Liberia from when we were little girls our parents grew up together.

So just having that familiarity with those external social communities and networks, it allows our staff to be more open with each other as a team to communicate important things, whereas if you don't know the people you come in to work with at your home, you might be hesitant to speak up when it's very important. But if you're around that culture, that work environment that you relate to more, they communicate on their own, they set up the group chat to help each other and that kind of thing, instead of calling the supervisor all the time, they'll call each other.

LG: And then as far as day to day communication. We have a computer system. We debrief after every shift, the oncoming shift comes and the earlier shift says this was a day, here's what happened or everything's good, x y and z is done. So it's both, we document, much like everywhere else, on a computer, either via a computer program like fair app or just a free text, also just handing off shift to shift for communication, and then regular staff meetings, regular company wide meetings, just to keep everybody on the same page.

CPH: Our preceptors are really acting as mentors. I tell the new hires in the first six months that they're there, that's their new hire orientation period, and your mentor is this person, I write their phone number on their training checklist and so questions like, where's the schedule when is my time sheet due, little questions that when Lynn, or myself are getting them from 200 staff, teaching our preceptors to take responsibility of those management questions is really helpful, and they feel like they have a co-worker colleague to go to.

PC: Do you have issues with finding staff and keeping staff with the requirement for basic education? Is it harder to find staff because you have that requirement?

NHS: Maybe you can answer this, because this is what is in my mind when I saw the number of money you get in the US. Maybe the first thought is, oh it's understandable that people search for other jobs but we have the same situation here in Europe, they get more money, they are educated, but we do not find staff in these days. In your presentation I thought that the aspects of qualifying, and making well being for the staff, that's the important aspects to find to find staff and to hold them and to give them the chance to stay 10, or 5 or 15 years. I think it depends not on the money at the end, I think it depends more and more on the quality of the trainings and the support we give them as they stay longer or not.

HS: But as was said it's really expensive to have the money for the stuff. Fortunately, it's possible in Germany and in Switzerland to get it from the state. It's not only for one institution, all institutions know how much money they get for paying staff.

NHS: In addition to what you describe, what they do here in in Switzerland is they have these meetings, so you see here people from 3 different organizations all over Switzerland, and they come together. I think this motivating to see how it works in

other group homes and what others experience. They come together they work together and I think it helps them to stay longer in the group homes working with people with PWS.

CPH: We always say you can't give what you don't get. So, if we're an organization who isn't going to let you be offered two weeks when your mom overseas dies, how can I ask you to stay through a traumatic event that I'm in and help me out if we're not going to stick it out and give you the support you need when crisis happens.

Q: In any country do the caregivers, receive training on PWS, before they actually go into a house?

CPH: Part of our onboarding is, say you're a direct support professional, but you're specializing in the best, most current practices for supporting individuals with Prader Willi syndrome. So I actually utilize a lot of the Prader Willi syndrome USA conference videos, I utilize IPWSO videos, and before I even meet you on site I want you to know what PWS is, I want you to watch the quick food security behavior video or the 10 minute intro to the developmental disability, to give you a good idea. And I find that all the different staff from different cultures and backgrounds, they do really well with the videos and the talking presentations that are now available on demand, all the time versus relying on myself to be consistent have no distractions and do a good training in a house where life is going on. So I can send people that before they come into the house.

And then the College of direct support online training, that is something that is free, and the content is provided by national alliance for direct support professionals, and it's also provided by University of Minnesota's center of cultural inclusion. So, those trainings, with the baseline for maltreatment, neglect, Community Inclusion, medication administration, and then we add the PWS specific stuff on top of it. I'm requiring that that is done at home on your computer. If you don't have a computer, I'll set you up with one at a house, but I want that background knowledge to be there, and then we will pay you for the 30 hours of the credited training, and doing it on the online module to introduce you to it. A lot of this, because there's no formal education and professionalising it, people don't know what a direct support professional is. I have a lot of CNAs come in and say, I've been doing this for 20 years, but it's really about interviewing and educating them about what the job is before they even get there.

NHS: What we do normally is to invite them to stay for two days in a group home for people with PWS and work with them and see what happens. And in some cases, we have the chance to hire the whole staff four weeks before we start with a group home, and we can train them before, but in not in all cases, when we open a new group homes. So, one of the group here, one of them is three weeks starting his job in a PWS

group home, and then he starts the training, but some others are more than 10 years or five or six years working with people with PWS and then start the special training.

HS: I can tell you, he had a lot of experience, or other fields with psychiatry with children and his basic knowledge is a big knowledge with all of his children with autism, and he worked with trisomy 21, and he has a lot of knowledge, before he starts in the PWS group home. So what we do when they stay for 2 days, we ask their future colleagues, then we also ask the people with PWS what their experience with them was like, and they decide together if the colleague will come or not. It's so necessary to ask people themselves, people with PWS to have a choice for their staff. It's not easy but they have an impression and have an emotion if they can work with someone. Otherwise, often when someone new comes in a group home conflicts arise, and we don't know why, maybe it's the change, and it's a new person.

Comment: Unfortunately, we have a lot of emergency staff coming in at the moment, and they know nothing about PWS and they're thrown into a shift, hopefully with somebody shadowing them but not always.

LG: It's interesting that you're using those emergency staff during the time of the pandemic. We've had the state of Minnesota come and ask us to provide staff with extremely minimal training, and I can't imagine how that would look if I had to bring somebody off the street with no prior knowledge into a really high behavioral house, or any house, it would create extreme chaos and a lot of mental health problems, complications for our individuals. So, yeah, it's scary.

Comment: In Australia each one of our participants - in Melbourne, we call them participants - who live in a group home, each have a pool of money, their own money, which is spread out for their rent, their day to day living and other services like psychologists. So when we have training for new staff or if we were starting a new home for people with PWS, we would we would have your specific training for disability support workers like Claire mentioned before, medication, or that which everyone goes through. Because each one of the participants have their own pool of money part of that money is attached to maybe a psychologist who works with them throughout the year, and we would use them to have specific training on each of the participants. The house that I work with, we have one psychologist who works with the six residents. So when we bring staff in, periodically every, every three or four months we'll do a day's training session. So it's individualized training. So, it's training on the actual specific person, not just PWS. I've done, specific PWS training and general PWS training, and a lot of the times the two don't marry up because the spectrum of people who live with PWS is so different. In Australia it's called it's a National Disability Insurance scheme. And what it does is it allows each person to have a specific funding level, and then you can utilize psychologists, occupational therapists, speech therapists who come into that. And then we can actually engage them specifically to train staff and work with

staff. So I think that really makes it a bit more personalized for the staff, and instead of walking into a home going ok, I have to make sure the fridge is locked and I have to make sure of all these things, we actually walked into a group home where we know Mr B over there and well we can actually take him out. He does do some cooking classes because he's at a different level to Mr C over here in the corner. So we try and individualize it, so that seems to be working at the moment for us.

LG: I'm interested in how do other countries attract employees. Because I know in certain areas there's small villages, so you don't have a huge pool of people to draw from to attract employees so how does that look in other countries as far as onboarding or just finding people to work?

Comment: I'm not an expert on this in the, in the UK but I think one of the difficulties is that in finding people, there's a tendency to try and pinch people from other services. And so there are people that are moving from one care provider to another care provider. The other thing is that of course, the biggest population that requires support and care is the older population, and so there are people going into care for the elderly. So there's movement within the care service both towards the elderly population, as well as across different organizations.

Comment: Really everything that has been said echoes, all the problems and issues that we have here in the UK with recruitment and retention. I think we all agree that pay is probably the biggest concern for a group of people that we expect to be professionally trained, but we can't afford to pay our staff for that level of expertise, and our turnover is particularly high. We do similar recruitment exercises, like we've heard, cash incentives, we have everybody has an app on their phone with an employee assistance program that gives them benefit discounts in supermarkets and various High Street shops, but again, we still get that turnover. And again, trying to recruit staff with experience in PWS is an impossibility. We're not able to recruit really anybody from a similar background. Some people come to us who worked in services with a learning disability, or with the elderly but that's not always a good thing because they can also bring along some poor practice. So, we always find recruiting people with probably no experience is the best, and give them the training and the support to hopefully stay but, yeah, it's an ongoing problem pattern.

We have what is called eCademy so, we have our own training department so we were able to write our own programs. It's a system that everybody can look in to so all our staff have to have that module that we've written, and we're looking at introducing a certification. So again, we're in the process of writing lots of different modules, and we will expect all our staff to complete those modules. And again, we have what's called a career ladder. So, the more qualifications, and the more experience that our staff get, they go up in increments of pay. So, again, a bit of an incentive really to get people motivated to take on board that training. We also have our own in-house trainers that

go around the services and deliver face to face training. So it's just PWS awareness and PWS nutrition and they're just programs that we've all written ourselves.

CPH: Something interesting about getting staff from other industries like elderly caregivers. I found ever since the covid pandemic that more than ever I get CNA certified nursing assistants who are making, for example one individual came from a company that he said he was making \$17 an hour as a CNA, and then overnight they raised it to \$24 an hour, because our nursing homes are that short staffed in the wake of covid. I'm hearing stories from people that are National Guard, they're sending in to help be nursing assistants for the elderly. However, us as an agency, we still get those staff to come to us, they try us out, and then they want full time, and they leave the nursing home because of our culture of support. They are coming off overnight shifts where they're the only person, a 65-year-old man on a floor with 20 people, as a CNA, and he's just exhausted, they're treated like a number. No one's coming to help you, if, your help doesn't show up. It's so near and dear to me that every single person at our agency that has come from direct support will still show up and do direct support at any time if called. That is huge in our industry to know you're not stranded there, and if you're done and need to go, you can get relieved. So culture of support.

LG: I think for retention. What I'm hearing too and even from Hubert and Norbert, maybe initially the pay will attract people but what keeps people is the culture of support from your organization. That's why people leave because they don't like their co-workers, they don't like their company, but if you can build it in a manner and support your employees like you support your individuals that live with you, people want to stay with you. That word of mouth really does help but it is investing in a good solid helpful, good communication team, and that's what can sustain the organization, especially during times like this in the pandemic when everybody's quitting everywhere. So, and so many organizations that support people with disabilities are filing for bankruptcy here in the States, so it's all about building that culture internally too.

CPH: I'm wondering about how you schedule staff, because I go back and forth between, am I being too flexible by piecing schedules together around an individual's personal life because say they quit in three months, I've now created a schedule, you know, continuously around somebody who is no longer here. But, I hear more than ever that if that if I'm able to add another layer of an hour cushion like, I can't be here at two I gotta pick my son up off the bus and dropped him off here, and then I can get here by 2:30-3:00. When I have hospitals and nursing homes, they all do 6am-2pm, 2pm-10pm. For everyone I hire I say we individualize the shifts for the residents needs, if their plans change, ours do, we do dynamic scheduling, but it is it's difficult. Do you all do that or do you have set shifts like, same for everybody work it or don't.

Comment: Like you, we try and be flexible, and we didn't use to be. It used to be a very set shift pattern. But over the years, it's much more flexible. Some people just pick up 10 hours a week, some will pick up 30 hours a week. And, being able to work around family commitments, and children, we just found over time. that's the only way to recruit and retain.

CPH: Especially when School's out this week, and they were virtual that week, we lost a lot of staff when schools shut down completely, in the spring of 2020, and then we actually had a lot come back once school was back in.

Q: Have you thought of providing childcare facilities through your organization? Nursery facilities for very young children, or anything like that?

PC: We're in the process of trying to figure out how to do that, that's been one of the number one things we've been asked to do by staff.

Comment: Yeah, that's something that we've suggested to our HR departments on a few occasions.

LG: Does anybody do that right now. any organizations present on this call, provide childcare? No?

PC: Do you know of anyone, Lynn, in the states that does?

LG: I do not, I have not heard of that. I mean, what a great way to have a benefit but also, well an additional expense, that will greatly affect your budget, overall.

Comment: But you could get together with another care provider organization if you're not big enough and presumably, it would be reasonable to charge the family for the cost of that care albeit at a relatively low, low rate, but it does mean that in a sense, they would be more even more committed to your organization and less likely to leave. I mean I hate to say this, but I suspect most of the people who support people with PWS are women rather than men, and who also take on a greater responsibility with young children. Although hopefully is changing a bit but I suspect that's the case.

LG: Well, and you also wonder, could that tie into employment for those that are able to with PWS, in a day care. I mean that's a great opportunity to provide meaningful employment to the individuals that want to work with kids, which are a majority of them, or bring your dog to work and there's a free dog walker.

PC: One other thing, if money wasn't so, so much of an issue. What other things, could we put in place to retain staff to keep them? What else could we do, aside from raising the hourly. What could we do to keep staff in our agencies, happy not wanting to leave because we know it's not the money that's going to do it? What could we do if money wasn't an issue?

CPH: My, biggest thing when I was a DSP was, I started at a different organization in a really rural area, and my biggest thing was when I work a 16-hour shift from 7am to 11pm, and I'm waiting for my awake overnight to come. And I have to be back in six hours for that 6am shift to do a 16-hour day again. and I call the overnight, no answer. I call my supervisor, no answer. I call the next one. You're stuck, you cannot leave. And that was the biggest thing about this job. I'm single, my family lives out of state, and I knew that I could take on that on-call responsibility, because that is why I left the other organization, because you can't leave me hanging as an organization, and just not care that I've been up for 36 hours, and I've had a supervisor look at me and be like, you're driving the van to the hospital for the appointment. So more casual staff is what we've done, more options to call people. You're paying you have to have two people, or three people at each site at all times. It doesn't matter so much if we have a lot of casual staff. I have some staff who maybe pick up one shift a month. However, another person to call and increase the homes and viability training and flow between. We offer if I call you and it's a tough shift, within four hours would give you \$100 gift card.

LG: I think this is just an ongoing issue that we all need to be mindful of and be creative, and I really think creating the internal culture, but providing a career path and making this a destination. This is what I want to do for the rest of my life is provide care. And I want to be recognized for that with certification or something that I can transfer is what I would like.

Patrice Carroll Summary

PC: Thank you Lynn and Claire, a really important topic that I think everybody is feeling right now, more than ever. So we went over some statistics of staff turnover which is extremely high and salaries which are extremely low. We have positions that are low wages, high stress, a lack of training, and it's a really hard job. Everyone's job is harder and our individuals with PWS suffer when staff turnover is high.

And why is this such a high rate of turnover? It's a demanding field. We need more effective supervisors recruiting and hiring, or a recruiting and hiring manager, and the mission is to support staff in the same way that we support our individuals. It's really, really important - how can we expect our staff to be compassionate when we're not compassionate towards them?

Attracting new employees, having existing connections to other staff in their social networks is important. We need to train the staff to work in multiple locations. Community outings with multiple homes creates a tighter community throughout the agency. Supporting and respecting staff creates a safe and fun work environment, and having a mentor is also important.

Training, we need to be sure that people are trained in behavior, nutrition, the history of PWS, goal setting, health, and communication strategy. We've got some really good

resources for online training services, and talked about the importance of sending people to leadership trainings to have the opportunity to then move up in the agency.

Retention strategies, flexible benefits, casual positions, for people to fill in for longer vacations, especially if people have a home based out of the country. And we need to be flexible with people because they have multiple jobs because of the low pay that we're paying people are not able to have one job.

Creating a pathway to leadership. Love the DSP to DSP-Preceptor to then Supervisor, really liked the way that you have that set up. Having career goals incorporated into the annual evaluation, not just for your information, but so staff know that we think this matters and this is important to us. The longer staff, say, the stronger support to the individual.

We spoke about the vision for the future and how we need certification and accreditation for direct support professionals that needs to be a career that people want. There's a definite need for PWS specific curriculum as well.

We need to pay staff a liveable wage and spoke a little bit about what we look for in staff, and the fact that our vision doesn't always match our funding, so what we want to do doesn't always match what we are able to do. Some people have increased pay for homes with people with PWS, made it a more special position.

And then we spoke about the importance of the culture of support. Usually I would say that's more important than the money that they're making. We then spoke about some incentive for staff to stay, some ideas, supportive culture and day care. And that sums up what we spoke. Really nice having everybody on.

Upcoming Caregivers' ECHO sessions

Weds 23 Mar	Managing routine medical checks and other regular requirements Susanne Blichfeldt M.D, Denmark
Weds 20 Apr	Education of PWS, behaviour appreciation, and positive support strategies Patrice Carroll, Director of PWS Services, Latham Centres, USA
Weds 18 May	Looking at different diagnostics Norbert Hödebeck-Stuntebeck, Psychologist, Germany

Thank you very much to everyone who attended the session and participated. We look forward to seeing you on Session 10 in March.