

6th International Prader-Willi Syndrome Caregivers' Conference

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Staff Retention: and what happens when there is a breakdown?

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Workshop Summary

Staff Retention: and what happens when there is a breakdown?

Workshop Leaders:

Lynn Garrick, Programme Director, AME Community Services, USA
and Claire Poor-Harmon, Staffing Director, AME Community Services, USA

Workshop description:

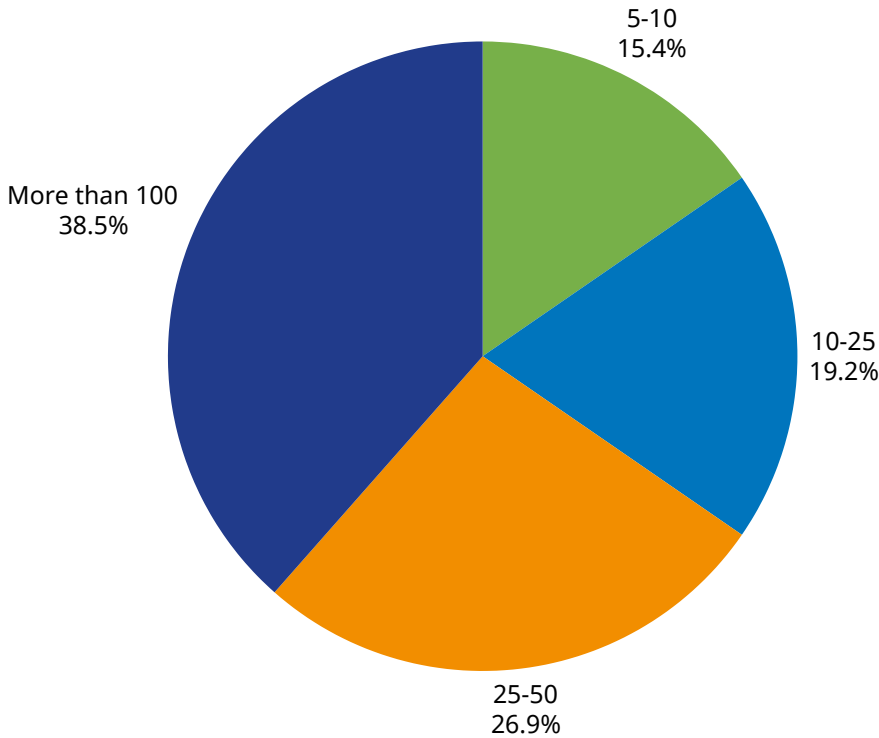
Individuals with Prader-Willi syndrome do best when there is structure and consistency. Maintaining stable staffing is critical to the success of individuals with PWS individuals (I think should use person-first language consistently – i.e. individuals with PWS) and organisations. When retention rates fall or key people within the organisation leave, it brings about organisational instability that negatively effects the employees and the individuals they support. An employee retention strategy should be a fundamental part of any organisation.

Staff retention poll:

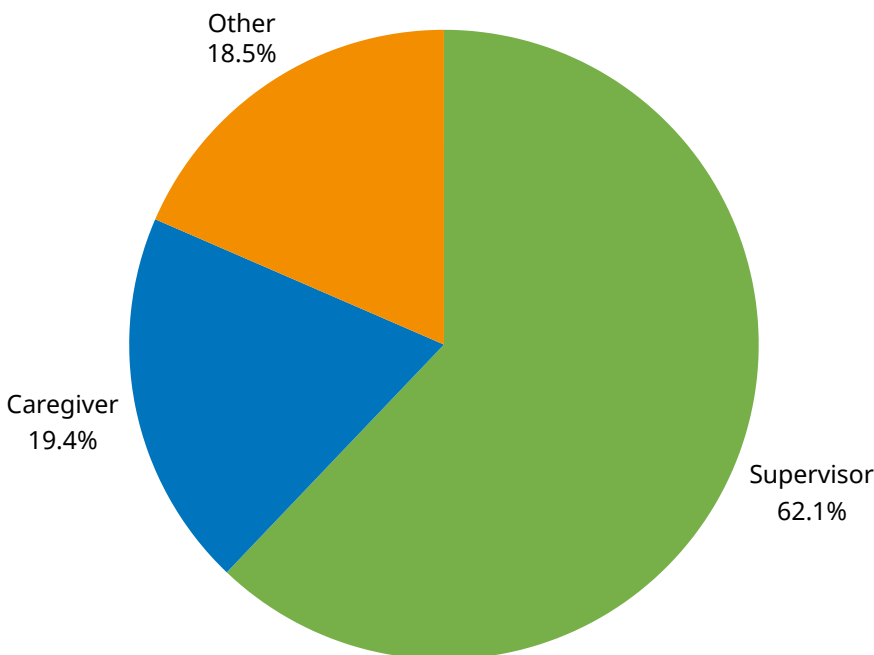
The workshop leaders began by asking participants to scan a QR code in order to respond to a short poll about staff retention in their own organisations. The poll had 26 responses.

The key takeaway from this poll was that **work/life balance was the greatest staffing challenge.**

How many caregivers does your organisation employ?

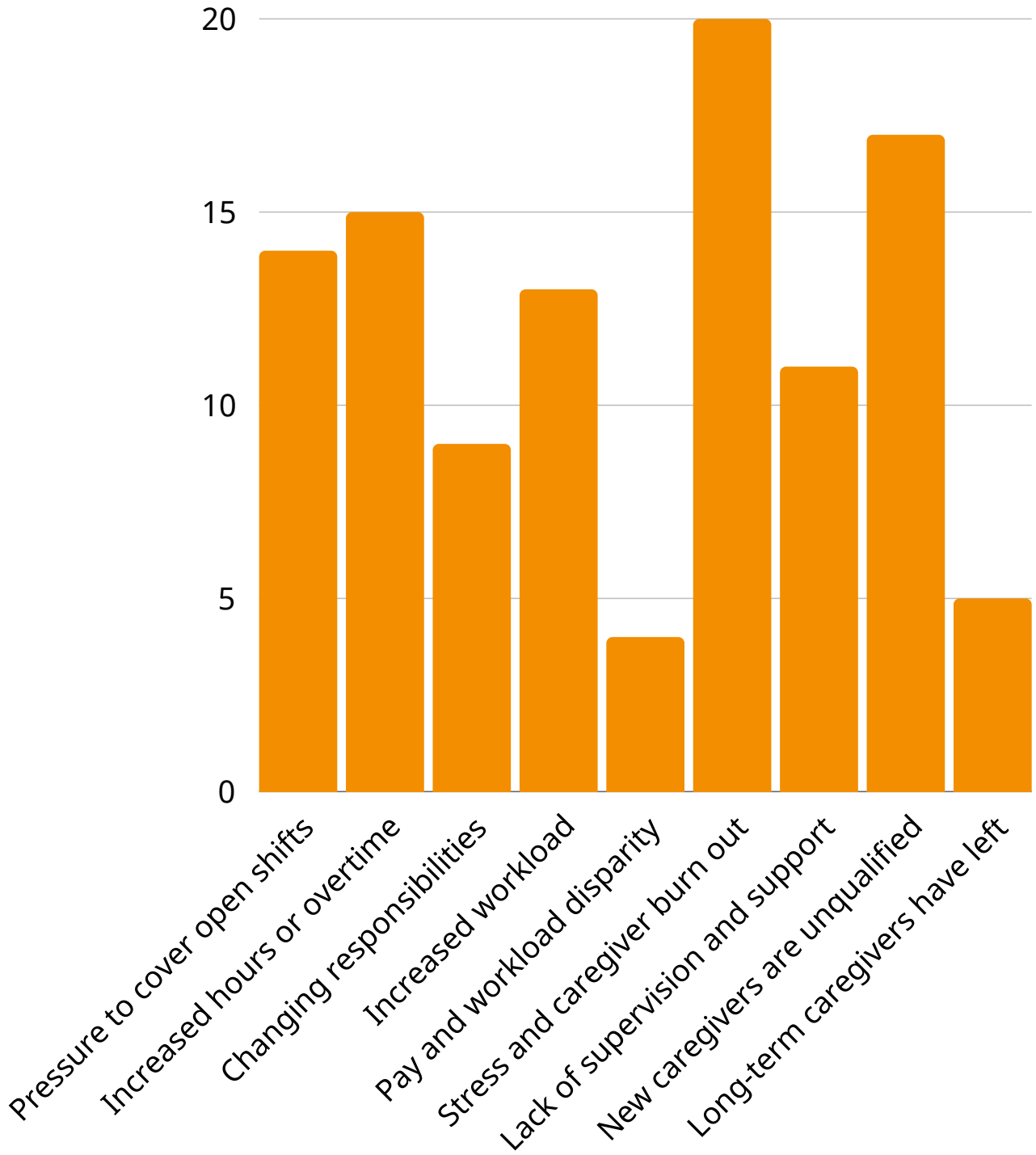


What is your role in direct support of someone with PWS?

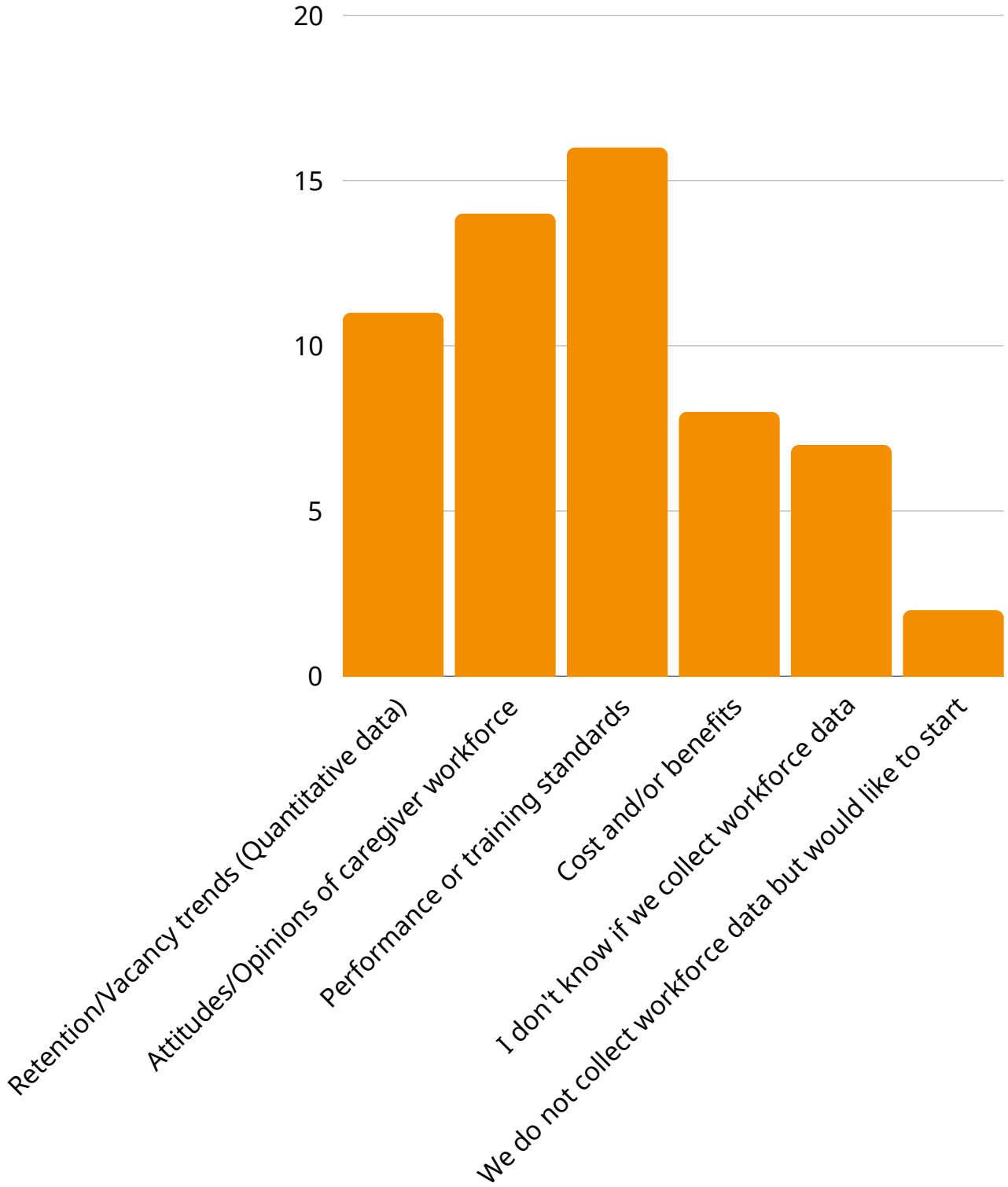


7 people responded "other". These responses included family or people with PWS, psychologists, or those that work in care but not yet directly with people with PWS.

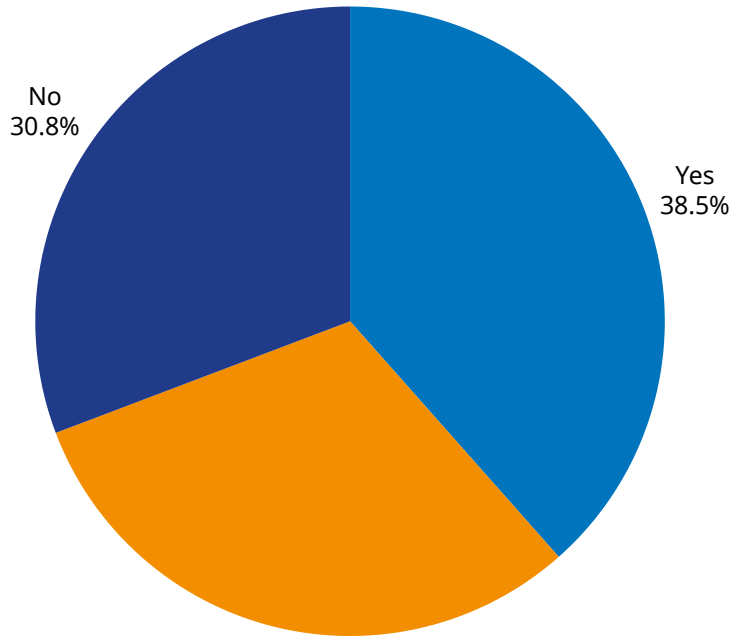
How is staff retention/turnover effecting your organisation?



What kind of workplace data do you/your organisation collect?

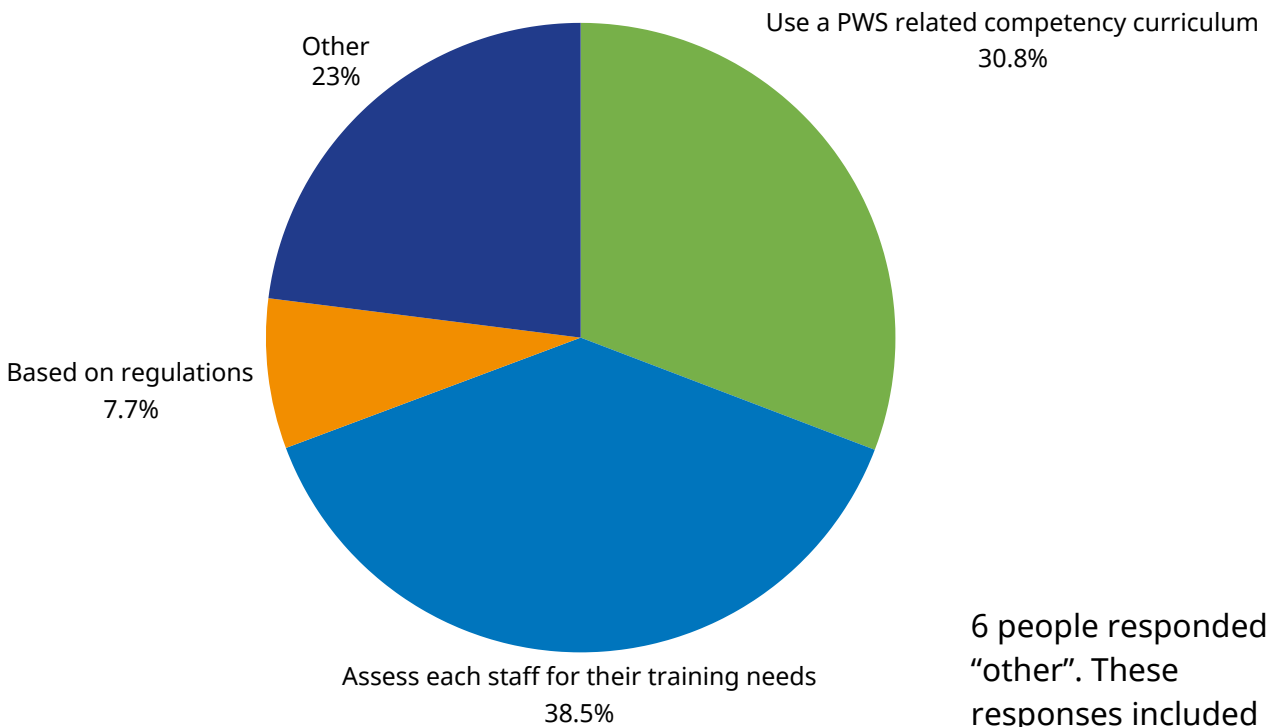


Does your organisation currently use a career pathway program?



I don't know what a career pathway program is
30.8%

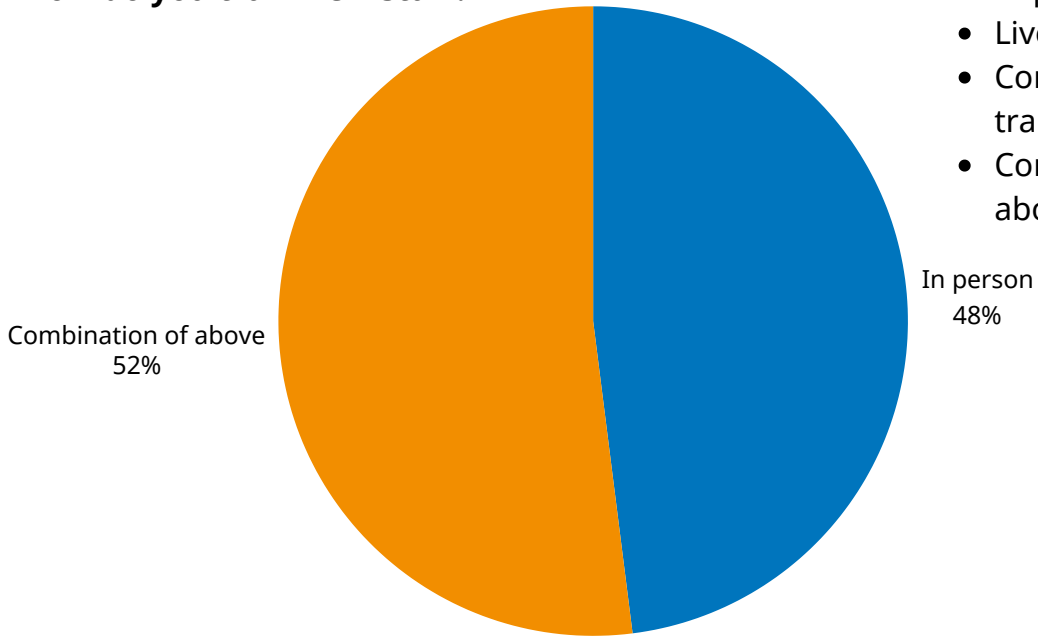
How do you decide what topics to train staff on?



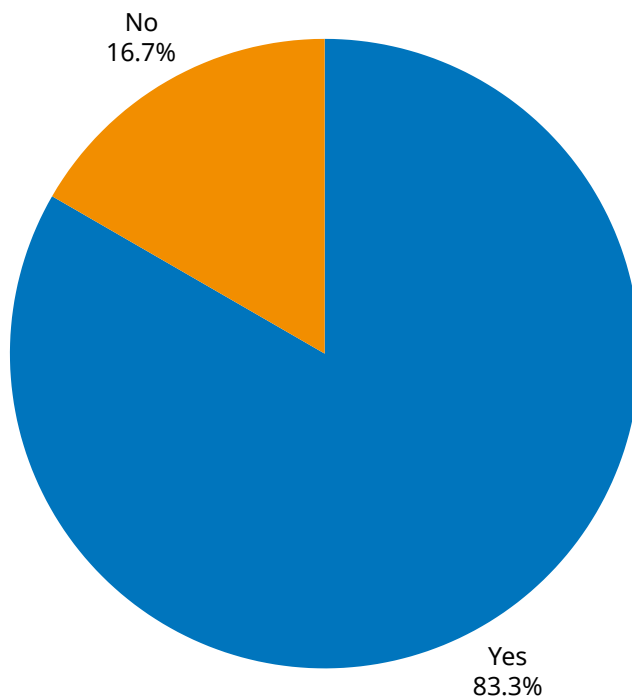
6 people responded "other". These responses included asking staff members , external training services, a combination of the above or they were unsure of the answer.

How do you train new staff?

- In person
- Live online
- Computer based training program
- Combination fo the above



Do you have different training products for leadership/management roles?



Personal experience of staff turnover in PWS organisations (group homes)

Presentation by a parent of a woman with PWS.

This presentation focussed on the personal story of a 34 year old woman with PWS, who has lived and worked for more than 10 years in a residence in Germany. Her mother attended the conference and presented on her family's personal experience of staff turnover, highlighting how turnover in PWS organisations is a big challenge for all persons involved.

In 2011: BMI 44 / age 24 years

The daughter with PWS was living at home. She participated in activities designed for groups of people with varied disabilities. Her declining physical and mental health condition led the family to make the joint decision to move the daughter to the closest PWS group home in the area, 400 km away.

In 2015: BMI 30 / age 27 years

The young woman was thriving in the PWS group home.

"I am healthier. I have new friends who have the same condition, I have employment which I like very much, and I can choose, I am an adult person with my own experiences outside of home, I have 2 homes now!"

In 2019:

She moved into new assisted PWS shared living accommodation. This allowed her greater self-determination. She had an apartment to herself.

But...

In 2020: The pandemic hit.

The home then required a restricted structure; no visitors, no travel. Work units were limited only to people from the same house. This was surprisingly well managed by both the people with PWS and the staff. All showed wonderful resilience!

The care home provider also had a sudden change of staff in the director role, this led to further staff turnover and the recruitment of new caregivers not as familiar with PWS specific care.

The presentation went on to describe the consequences that staff turnover can have for all those involved...

Personal experience of staff turnover in PWS organisations (group homes) (continued...)

For caregivers this could include insecurity in their roles or duties, an imbalance in the quality of care in PWS-specific daily life, conflicts at work, stress, illness, burn-out, resignations, etc.

An example was of **tension among caregivers, colleagues and their group leader** where some staff were well educated and experienced in PWS and others were engaged with good intentions but had less experiences with people with PWS.

For parents this could lead to a loss of trust.

In this case the parents had a lot of trust after many years of working with the provider as the primary caregiver. When no solutions were offered they felt they had to intervene to become much more involved with the care of their daughter again.

For people with PWS they could also have a loss of trust in staff and could lose an important person they are attached to. Not enough staff to maintain care standards means fewer leisure time offers, less time for personal contact, and an imbalance in the quality of care in specific PWS daily life situations.

In this case it was observed that people with PWS felt overburdened. Stress levels increased, alongside behaviours of concern such as running away, and increased temper tantrums. Some gained weight. Their sense of independence was compromised due to parents needing to intervene.

The presentation concluded by asking what could have been done to prevent this difficult situation in the care home. Examples included:

- Prepare an alternative plan in advance
- Professional and consistent management and training of team members
- Crisis management by PWS experts
- Additional support for the staff
- Adequate information for individuals with PWS
- Involve and inform parents – be transparent
- Decrease stress wherever possible.

This was a topic of open discussion for the workshop participants. Other open discussion questions are also included in the Questions and Answers section of this report.

Workshop presentation

The workshop continued with an interactive presentation wherein participants discussed caregiver retention and organisational sustainability using a data driven, employee centered systematic approach.

Key topics included:

- The four pillars of retention (see [Workshop Presentation](#) for more details)
- How breakdowns happen and how to pro-actively approach issues
- Strategies to get back on track
- Developing a personalised retention strategy
- Data metrics to identify workforce shortages and track for improvement
- Creating a robust new hire onboarding program
- Leadership styles & manager roles in staff retention
- Investing in & empowering employees

The presentation used to facilitate the workshop is available [here](#).

Questions and Answers

Throughout the workshop, leaders and participants posed questions and offered answers examples or solutions. While not every question had a definite answer, this section captures the topics discussed in chronological order.

Claire Poor-Harmon (CPH), Lynn Garrick (LG), Workshop Participant (WP)

Experience (WP):

Staff retention is a struggle when staff are directly working with people with PWS. They may wish to learn about PWS more, but time is limited. Psychological trauma and not setting enough boundaries are big issues reported by staff. Staff are manipulated and traumatised by PWS individuals.

Q:

How do we build knowledge of PWS before a Direct Support Professional (DSP) begins work with people with PWS? Time to train takes away from staff, any ideas to fix this?

No answer to this question was recorded.

Q (LG):

How to build sustainability when a leader leaves? Is your organisation planning for this?

WP:

Retention after Covid was not happening. Planning has helped for backup when we are short staffed.

Q:

What do shifts lengths look like?

LG/CPH:

For our organisation, between 5-10 hours. We try to make the hours work based on what the individual staff can manage.

WP:

We have been trying to shorten shifts to help fill them because people do not want to work for long with our person with PWS.

CPH:

Being creative and making it work for staff. We want to be staffing centered. We focused on calling someone else than the site supervisor when a staff calls to say they are unable to work.

At this point in discussion LG presented on Maslow's Theory, Human Capital Theory, Social Exchange Theory and The Four Pillars of Retention. See [presentation](#).

CPH:

Staff should learn to train more staff. Staff should be recognised and empowered in this way.

Q:
Do you tend to over recruit in case someone leaves or is a "no-show"?

CPH:
Yes, we over hire.

Claire then talked about the hiring director role in the company.

LG:
Do you involve the individual(s) with PWS with the hiring process?

WP:
Ours does the same.

WP:
Our organisation does one interview and then they meet the individual before the end of the hiring process.

CPH:
I don't have an office to do the basic interview. The interview is at the home. It helps to initially understand how the individual interacts with residents.

WP:
We ask other staff on the team already if they want to work with the individual.

LG/CPH:
An observational interview is very important.

WP:
We do not involve our people because a person cannot go into the home before they are approved to be hired. A resident can come with staff to the office. The hiring process takes 6-8 weeks. It helps to have a person interested in providing care.

CPH:
Robust onboarding can be a big investment, but worth the time.

WP:
We cross-orient staff (for a home with mixed disabilities). Staff will choose to not work with the resident with PWS.

CPH:
It could just not be a good fit. We want to keep people in the organisation.

LG:
Do you involve the resident when the person chooses to leave?

WP:
We have in cases where the staff want to leave or the person with PWS wants the staff member to leave.

CPH:
It's important to find the preferred staff to keep above everyone else. Try to be flexible with those people.

After the break, CPH presented on Pillar I Recruitment and Retention. There was a worksheet activity.

WP:
We use a reward system for someone who stays for 3 months.

CPH:
AME offers a referral bonus payment.

Q:
Are there any conferences in your area for caregivers?

WP:
Denmark has a conference to work on issues within group homes for caregivers to attend.

WP:
How to introduce someone into the mix as needed without causing disruption?

CPH:
Bringing in casual staff who have had a relationship from before can be a pleasant surprise for the residents in their home.

On the 2nd day of the workshop CPH presented on Pillar II Work Environment and LG presented on Pillar III Growth Opportunities, and CPH then presented on Pillar IV Retention Data. See [presentation](#).

Statement:

"Work/life balance is hard to manage."

WP:

We provide student counselors for staff to visit. Staff are recommended to visit the counselor before a traumatic event happens which staff are ill-equipped to handle themselves.

CPH/LG:

It's important to separate the person from the syndrome.

WP:

We do visa work and bring people here. We also use a temp agency, but they need to work a minimum amount for us in order to stay on the team.

CPH:

How do you do scheduling?

WP:

We have both google docs and a roster managed by managers.

CPH:

Do you share staff schedule with residents?

WP:

We post the person on shift without the times. Weekly schedules are known because of patterns but they want to know. Having a visible roster helps create less anxiety and keep consistencies. Daily schedules are posted so they know what is going on.

WP:

We encourage staff to check in with staff before the residents to create a united front when coming on to shift.

On the 2nd day of the workshop CPH presented on Pillar II Work Environment and LG presented on Pillar III Growth Opportunities, and CPH then presented on Pillar IV Retention Data. See [presentation](#).

CPH:
It is important to do check ins without residents being near to speak candidly and decide what to do when certain situations come up.

WP:
Issues that come up need to be talked about with the team.

CPH:
Staff like to be included in everything like residents do. Keeping them involved is very important. I don't ask yes or no questions. I ask about what they do in their free time or if they are a parent.

WP:
What about education skills?

CPH/LG:
AME does not focus on education.

WP:
Do you offer cooking classes for staff who do not cook well?

CPH:
We have a nutritionist that teaches and helps staff by putting on classes and displaying photos of food.

WP:

Who sets the goals for the person with PWS?

LG/CPH:

We are always working to find and help set goals for the residents. Everyone is on the team to formulate plans and create informal and formal goals.

WP:

How do staff work on the goals with the people with PWS?

LG:

We have charts posted and information on their profile on our documenting system that tells us everything.

WP:

We are always being so careful about data security. How do you manage this?

LG/CPH:

Our documenting system is password protected. Our schedules are not private and everyone in our company can see who is on the schedule.

WP:

We cannot give out that information. It is not for the team except leadership. I can only schedule out 4 weeks in advance. Government mandates the level of education allowed and training before people can work for us. Expectations are high; we can pay more, but education levels need to be met for us.

CPH:

It does present a challenge if you can only hire people who have a minimum education level. How many applicants do you receive for one job?

WP:

We have a small pool. It is highly competitive because of other jobs offering better pay and a better work/life balance.

WP:

Do you have a schedule when you hire people?

CPH/LG:

I can change a schedule, but I show a specific 2-week pattern for people to look at. This schedule can be changed by me so I can be flexible with people. After hiring is when the firm schedule is set.

Further discussion was around privacy laws and employee regulations regarding length of shift times allowed. These can make it difficult to build a collaborative platform for staff schedules.

Conclusion:

Through creating positive and engaging work environments, supporting caregiver needs, providing employees with growth opportunities, and focusing on recruitment and retention of caregivers, an organisation can make great strides towards workforce development improvements. Understanding the components of staff retention and formulating an individualised plan can help with organisational sustainability and overall consumer satisfaction. This involves person-centered approaches for both employees and consumers as an integral part of an organisation's mission, vision, and values to support overall job satisfaction and longevity.



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