IPWSO Summit Meeting 2026

Learning from Bereavement: Improving Care in PWS

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Why was this study done

- Families' reports to PWSA UK raised concerns
- PWSA UK was informed about **129** deaths between 2006 and 2026
- Absence of comprehensive UK data or studies on PWS deaths and any learning
- LeDeR (Learning from Lives and Deaths) was established in 2015 in England

Aims & Methods

Aim:

To hear families' experiences following the death of a relative with PWS, exploring:

- The person's age, year and certified cause of death
- Families' perspectives and any questions about the events surrounding the death
- Whether families were offered a review of why their relative died the causes, including LeDeR

Methods:

Ethical approval was obtained from the University of Kent

- PWSA UK invited participants through its communication channels and social media
- Participants received study information and provided informed consent
- Fourteen family members were interviewed by telephone or online video call in 2025/6

The individuals and the causes of death

- The interviews concerned 14 people with PWS: 12 males and 2 females.
- The mean age at death was 34.9 years, median 33.5, range 13 to 57 years.
- Death certificate wording was provided for a small number of individuals
- Some parents found it difficult to recall the cause of death, potentially due to emotional distress and the time elapsed since their child's death.
- Pneumonia or bronchopneumonia was reported in 6 accounts.
- Respiratory factors were involved in 9 of the 14 deaths.

Reflexive Thematic Analysis

Our analysis generated three interconnected themes:

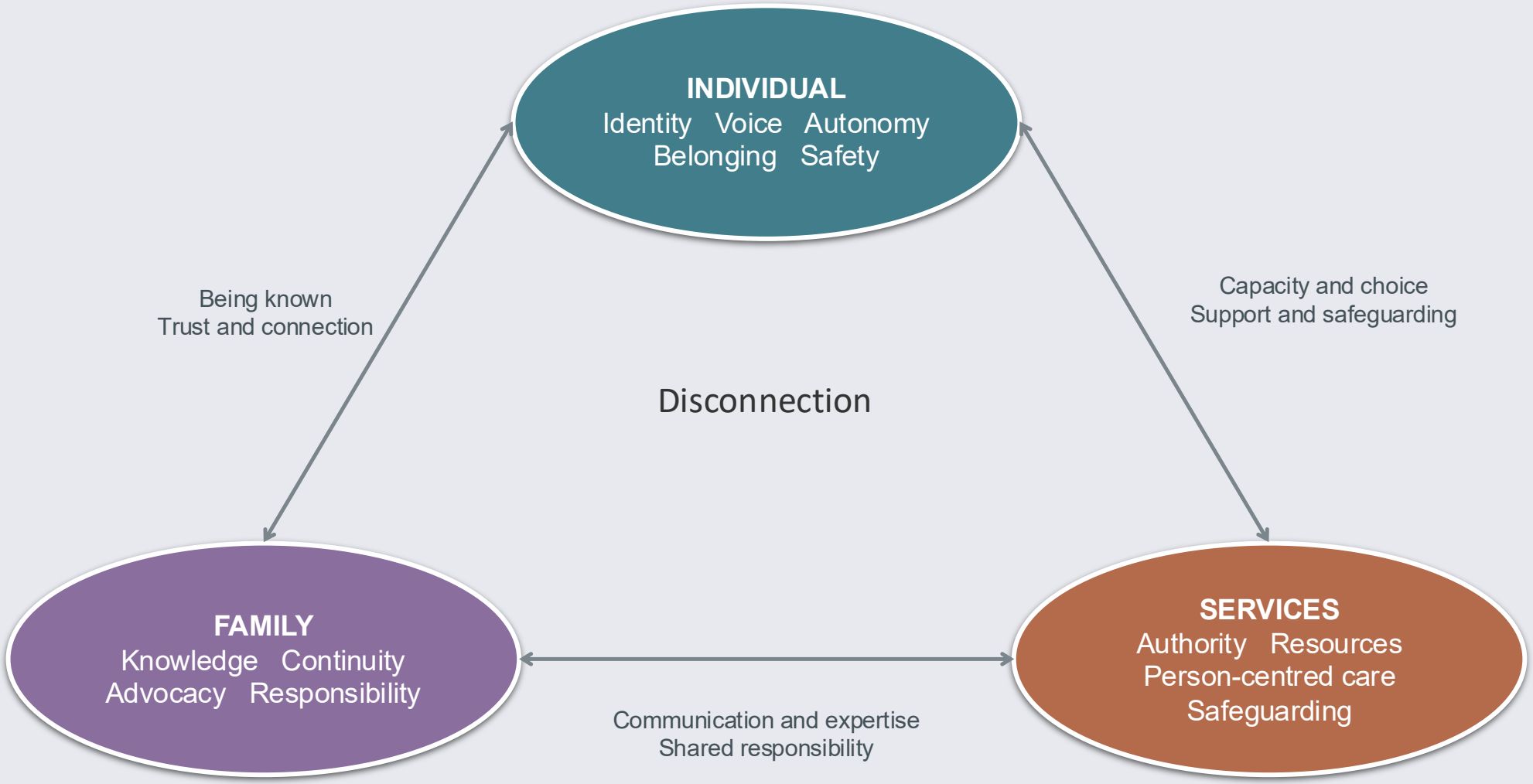
The individual, the family and the services.

The relationships between these —and what happened when knowledge, communication and responsibility became disconnected— run through all three themes stated above

Theme	Central concept
The individual	Being known as a person whose life, preferences, strengths and vulnerabilities and medical condition must be understood together
The family	Hold longitudinal knowledge - and responsibilities
Services	Responsibilities across settings and transitions

Subthemes are currently being finalised in preparation for publication

Individual, family and services



PWSA UK

Michael, 14yo

"He thrived at school. He had these challenges and these difficulties and if anything changed in his routine, then it was just nightmare meltdown. But he loved school. It was his focus … his happy place. He just loved school. He loved routine, he loved learning. He loved his teachers, his friends. He was a popular boy. Very popular."

Stephen, 27yo

"He's capable of making decisions, but whether those decisions are beneficial and correct for him is another matter … I didn't want to take away his decision making, but there always had to be someone who was responsible to say, 'Well now, come on … think about what you've decided. Is that going to be right?'"

PWSA UK

Noticing the change, advocacy & co-ordination

Michael, 14yo
'I've lost count of the amount of referrals. We had social worker doing referrals. We had his school doing referrals, his respite team doing a referral. The GP done a referral … and he was the only one that would listen to us."

"Nobody coordinated it. Nobody knew about all these separate incidents except me."

James, 35yo
"They never asked how he got there. We were always, one of us, either me or his keyworker the support worker, would take him and remind him, organise everything. Without that, he wouldn't have gone."

"It was all confidentiality, secrecy. 'He's got capacity.' We weren't to know anything."

PWSA UK

Alex, 45 yo

“They think they know everything about PW and, I’m sorry, they don’t. They’ve not lived it … I thought, ‘You’re not listening. He does.’ And in the end it proved he did it … I thought, thank you. Why don’t you listen?’”

Hospital

Chris, 38yo
"They gave him what he wanted and then he was running around the ward chasing the tea trolley … he found out where they kept the biscuits … When they discharged him, they discharged him with no discharge notes."

Alex, 45yo
"He says, 'We can fix it now.' I said, 'What do you mean, fix it? Fix him? Make him better?' 'No, no. Put him like you would an animal, put him down.'"

In a nutshell

- **Positive experiences:** When services understood the individual, PWS & collaborated with families and provided consistent, predictable care.
- **PWS expertise:** Many families reported limited professional understanding of PWS or that specialist PWS input was not sought.
- **Mental capacity and certain decisions :** Families reported Capacity Assessments did not always consider the cognitive and biological complexities of PWS, especially hyperphagia.
- **Family expertise:** Families' knowledge was not consistently recognised or incorporated into decision-making.
- **Fragmented care was reported:** gaps in coordination, continuity and accountability across services and transitions.
- **Learning from deaths:** Few, inconsistent, reviews involving family especially during/after COVID. Limited evidence of LeDeR involvement in this group.

PWSA UK

Where do we go from here?

- **Professional awareness:** Strengthen PWS-specific knowledge through training, advocacy, prompts, research dissemination and other opportunities
- **Family voices:** Ensure families' experiences and expertise actively inform care and decision-making.
- **Mental Capacity and decision making surrounding Capacity :** Improve understanding of PWS in assessments of mental capacity .
- **Study limitations:** Small qualitative study reflecting individual family experiences over a wide age span.
- **Further research** with families and need to link family & professional information in case reviews

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EDUCATE professionals and communities
SPEAK UP for change

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Thank you

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