



BEING HEARD

Exploring Parents’ and Carers’ Experiences of the Diagnostic Journey and Psychosocial Impact of Caring for a Child with PANS/PANDAS in the UK

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WHAT WE ARE HEARING

Being heard matters alongside the search for a diagnosis.

Data collection is complete. Thematic analysis is ongoing. The patterns below are provisional.

The study

To explore UK diagnostic journeys and the impact of caring on parents’ and carers’ wellbeing, family life and experiences of care.

12

individual interviews
11 mothers and 1 father

Semi-structured interviews via Microsoft Teams.

Eligibility: parents/carers aged 18+, caring for a child or young person up to age 21 with a formal PANS/PANDAS diagnosis and UK diagnostic experience.

Theoretical lenses

Epistemic injustice [1]
Exploring whose knowledge is recognised, and how parents’ accounts are received.

Transactional model [2]
Exploring appraisals of demands and the resources available for coping.

Emerging patterns

01 Being disbelieved and unheard

“But then everybody was telling us there was nothing wrong. So you have nowhere to go at all.”

“I've had basically my oldest friends say, you're making it up, basically. There's nothing wrong with him.”

Feeling dismissed and not listened to brings the recognition of parents’ knowledge into focus.

02 Daily strain, uncertainty and loss

“every day is surviving”

Uncertainty, anxiety and grief feature in the developing analysis, including a sense of loss around changes in the child and family life. Experiences of trauma remain an area of exploration.

03 Finding validation and connection

Diagnosis brought validation and relief, alongside guilt. Facebook support groups and speaking with other parents were described as helpful.

These working groupings may change as analysis develops. Quotes are anonymised interview extracts reproduced with consent.

Provisional conclusion

Early accounts suggest a need to recognise parents’ knowledge and attend to the emotional impact of caring. These possible implications require further analysis.

Scope and next steps: The sample mainly represents mothers of children with a formal diagnosis. Refine themes across the full dataset and explore differences between accounts. Planned completion: 30 September 2027.

[1] Fricker, M. (2007). *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford University Press.
[2] Lazarus, R. S., & Folkman, S. (1984). *Stress, Appraisal, and Coping*. Springer Publishing Company.