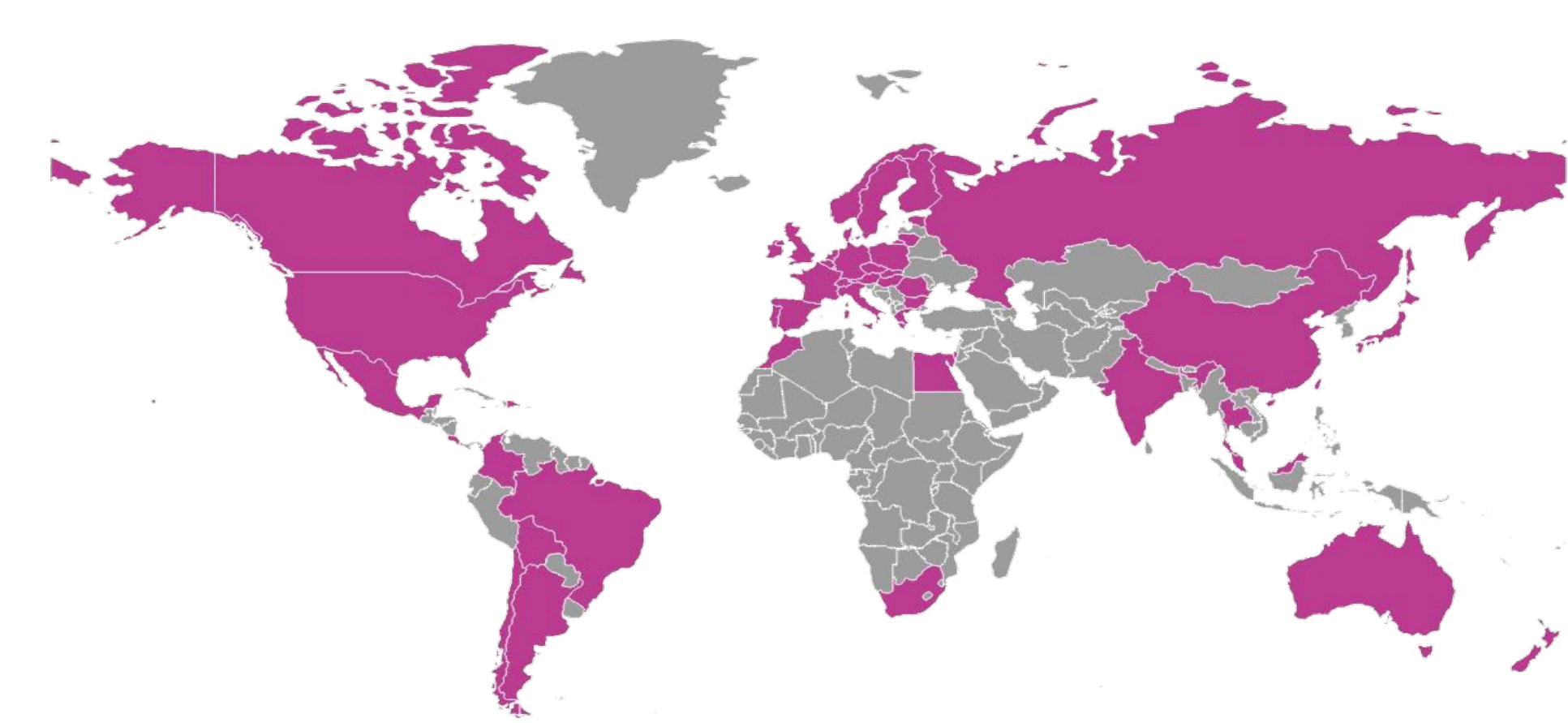


INTRODUCTION

- Prader-Willi syndrome (PWS) is a rare neuro-developmental condition associated with a complex behavioural and psychiatric phenotype.
- PWS is associated with an increased vulnerability to emotional dysregulation, anxiety, and behaviours of concern.
- Specialist mental health provision remains inconsistent worldwide, and there is no internationally agreed guidance for assessment or management.
- The International Prader-Willi Syndrome Organisation (IPWSO) established a Mental Health Network, producing a 2025 report to inform practice.



IPWSO has members in 47 countries



- The aims of the report were to:**
- Understand PWS neuropsychiatric phenotypes.
 - Inform evidence-supported mental health interventions.
 - Stimulate international discussion on service design and multidisciplinary care.

METHODS

- The report was developed through an iterative international consultation process coordinated by the IPWSO Mental Health Network (**Fig 1**).

Figure 1: Evidence and collaboration informing the IPWSO Mental Health Report



RESULTS

Models of mental health and well-being in PWS

- Feedback indicated that assessing mental health solely through behavioural or psychiatric symptoms is insufficient.
- Mental health was reframed as the interaction of emotional, cognitive and social functioning, with operational definitions outlined (**Table 1**).

Table 1: Operational definitions

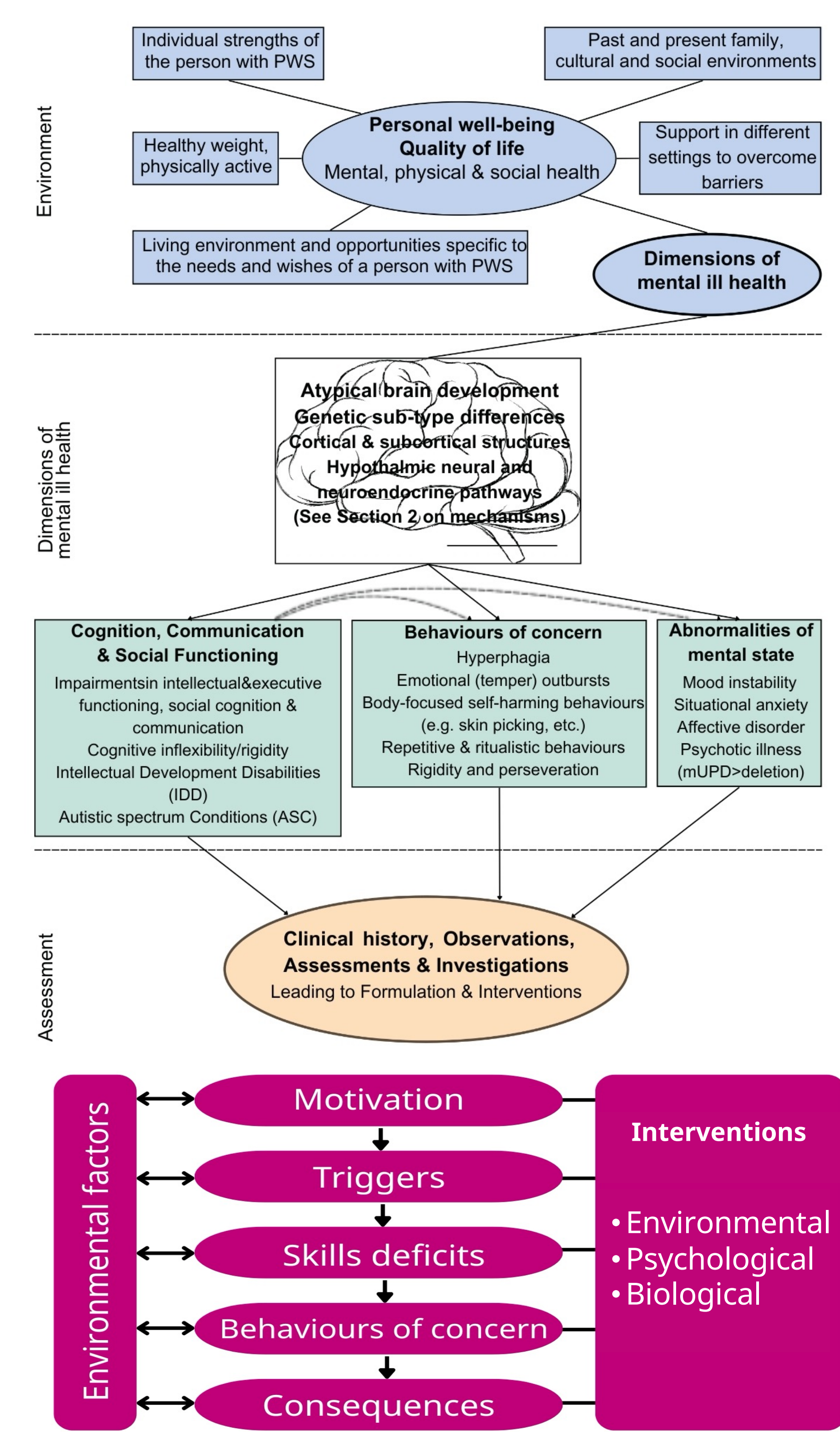
Mental ill health	Emotional, behavioural or cognitive difficulties, regardless of diagnosis
Wellbeing	Emotional, psychological, physical, environmental, and personal domains
Quality of life	Autonomy, social inclusion, human rights, and meaningful participation

Behavioural and mental health dimensions

- PWS was characterised as a neurodevelopmental condition with a distinct behavioural and neuropsychiatric phenotype shaped by genetic and environmental influences.

- These features were conceptualised as dimensions of mental ill health varying in severity across individuals and over time (**Fig 2**).

Figure 2: Key PWS dimensions and interactions between biology and environment



Practical evidence-based solutions

- Effective PWS support requires integrated, evidence-informed approaches addressing shared and condition-specific needs (**Fig 3**).

Figure 3: Key practical evidence-based solutions

Promoting wellbeing and quality of life
Address shared and PWS-specific needs
Inclusive policies and coordinated care
Reduce caregiver stress and systemic barriers

Behaviour management
Detailed behaviour assessment
Environmental and psychological strategies
Structured monitoring and evaluation

Mental health treatment
Careful psychiatric assessment
Individualised medication when indicated

Service design and transition planning
Multidisciplinary PWS- informed services
Crisis support, respite, telehealth access
Person-centred transition to adulthood

CONCLUSION

- PWS is associated with significant neuropsychiatric vulnerability requiring multidisciplinary, lifelong care.
- Mental health outcomes reflect the interaction of genetic, developmental and environmental factors, supporting holistic, person-centred intervention
- Coordinated and accessible psychiatric services will be critical to improving long-term outcomes and quality of life, underscoring the need for international dialogue on service design.

Contribute to service mapping in PWS!

Scan the QR code to help inform future international guidance.

