

POSITIVE BEHAVIOUR SUPPORT IN PRADER-WILLI SYNDROME, INCLUDING RESTRICTIVE PRACTICES. AN AUSTRALIAN EXPERIENCE.

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Balancing the foundations of Positive Behaviour Support within the necessary limits that keep people with PWS safe, healthy, and secure.

Aims

Under the National Disability Insurance Scheme (NDIS; an Australian government program that funds support services for people with disabilities), Positive Behaviour Support (PBS) plays a critical role in supporting people with Prader-Willi Syndrome (PWS) by promoting quality of life, reducing behaviours of concern, and ensuring the safe use of any restrictive practices. But what does this look like in practice for behaviour support practitioners?

Materials and Method

Behaviour Support Practitioners at Interaction Services completed a questionnaire via Microsoft forms about their current practices with people with PWS (17 in total, 15 with a Behaviour Support Plan) and reflections on their experiences. Follow-up questions were asked as needed.

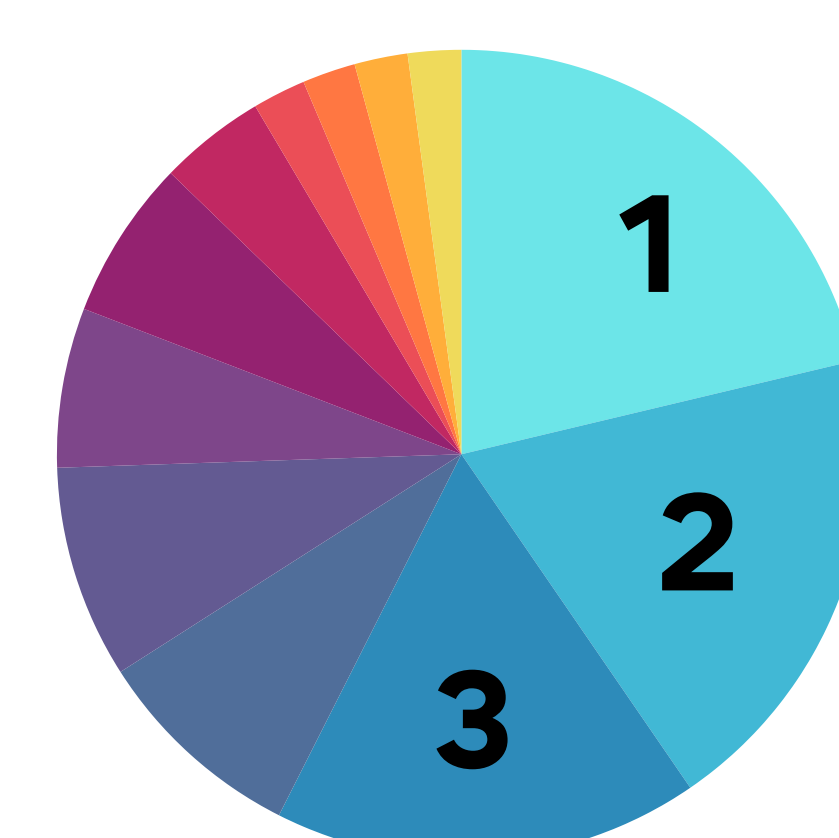


Results (Current Practices)

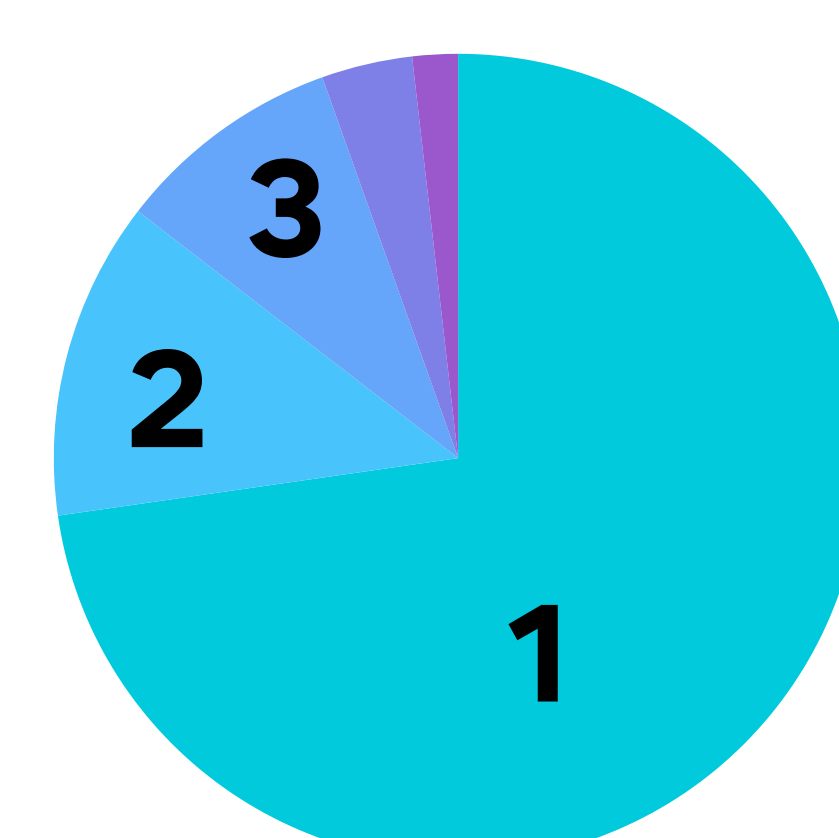
Key themes were identified from the responses; the top three are outlined below.



Positive Practices



Skill Building Tasks



Restrictive Practices

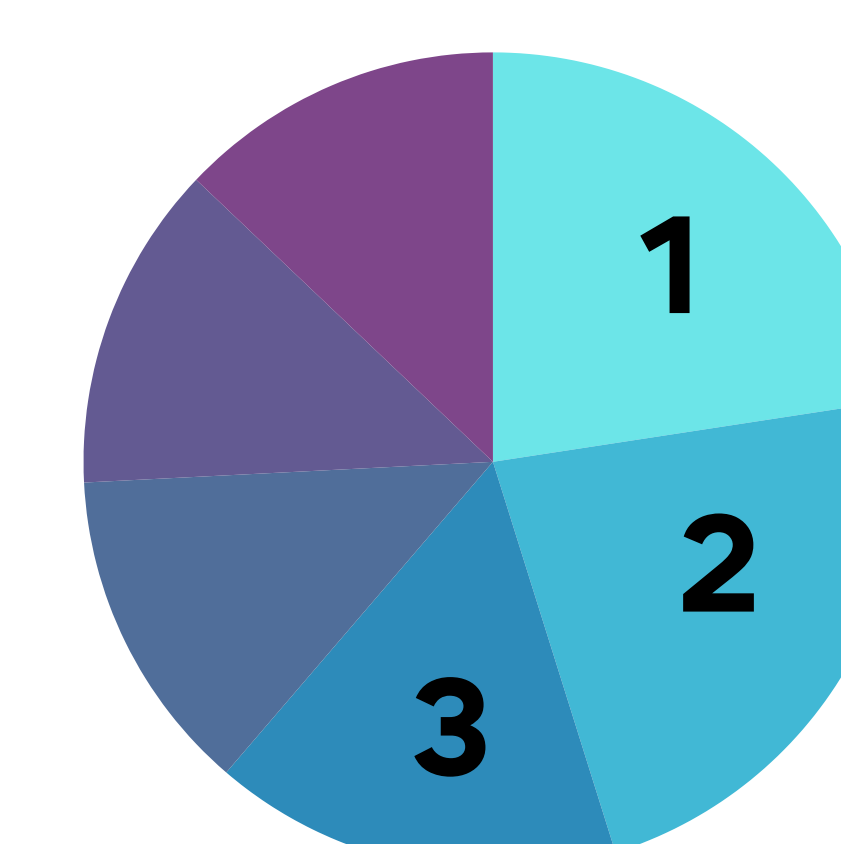
1. Communication and interaction guidelines
2. Proactive 1:1 time
3. Routine and structure

1. Emotional Regulation Training
2. Problem Solving
3. Exercise

1. Environmental Restraint
2. Chemical Restraint
3. Mechanical Restraint

Results (Reflections)

Key themes were identified from the responses; the top three are outlined below.



Barriers Experienced



Key Considerations

1. Lack of consistency
2. Knowledge of PWS
3. Interpersonal challenges

1. Ensuring choice and control where able
2. Psychoeducation
3. Food Security

Conclusion

PBS in PWS should focus on varied, proactive strategies that build skills and quality of life. While restrictive practices remain a necessary component in most cases, the main barriers of inconsistent support and a lack of PWS-specific knowledge highlights the need for cohesive support teams, specialised training and consistent implementation. What's next? An implementers' perspective.

Further Information



Collated responses of the factors reported on



References and resources the BAHS team use



Got a question? Let us know!

With sincere thanks to the BAHS team for generously sharing their time and insights, and to Prader-Willi Syndrome Australia for their ongoing encouragement and guidance.