

TRANSITION FOR PEOPLE WITH PRADER WILLI SYNDROME

SEPTEMBER 22 2021



IPWSO Caregivers' ECHO®
International
Prader-Willi Syndrome
Organisation



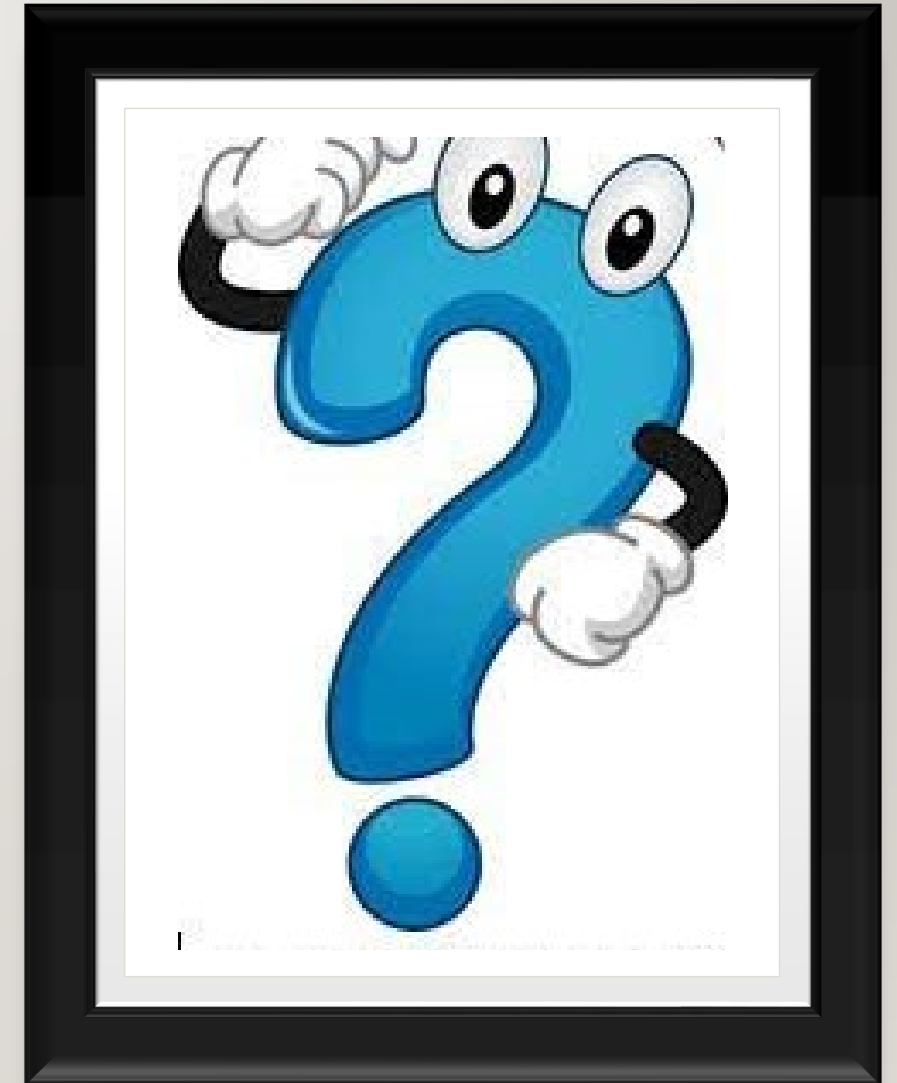
THE TRANSITION FROM ADOLESCENCE TO ADULT IN PWS

- Navigating the Health System
- Building Relationships
- Moving from Schooling to Day Programs
- New Accommodation
- Newly Found Independence



WHO AM I?

- Currently employed by Home@Scope In Melbourne Victoria
- Managing supported accommodation since 2007
- In 2014 Set up the first and still only PWS Specific Supported Accommodation In Melbourne, Victoria
- Attended 2016 PWS International Conference
- 2017 studied with Hubert and Norbert in Sydney
- 2018 Australian Rep on the PPCB
- 2019 attended Cuba Conference
- 2019 elected to the PPCB



DISCLAIMER ALERT

- I don't have the Answers
- I will not claim to have the answers
- What's out there?
Research?



DEVELOP OUR OWN STRATEGIES

- Use of the ECHO Programme
- Discussion and Discourse
- Tap into the vast knowledges from other countries
- Present findings and developed strategies at the Ireland Conference

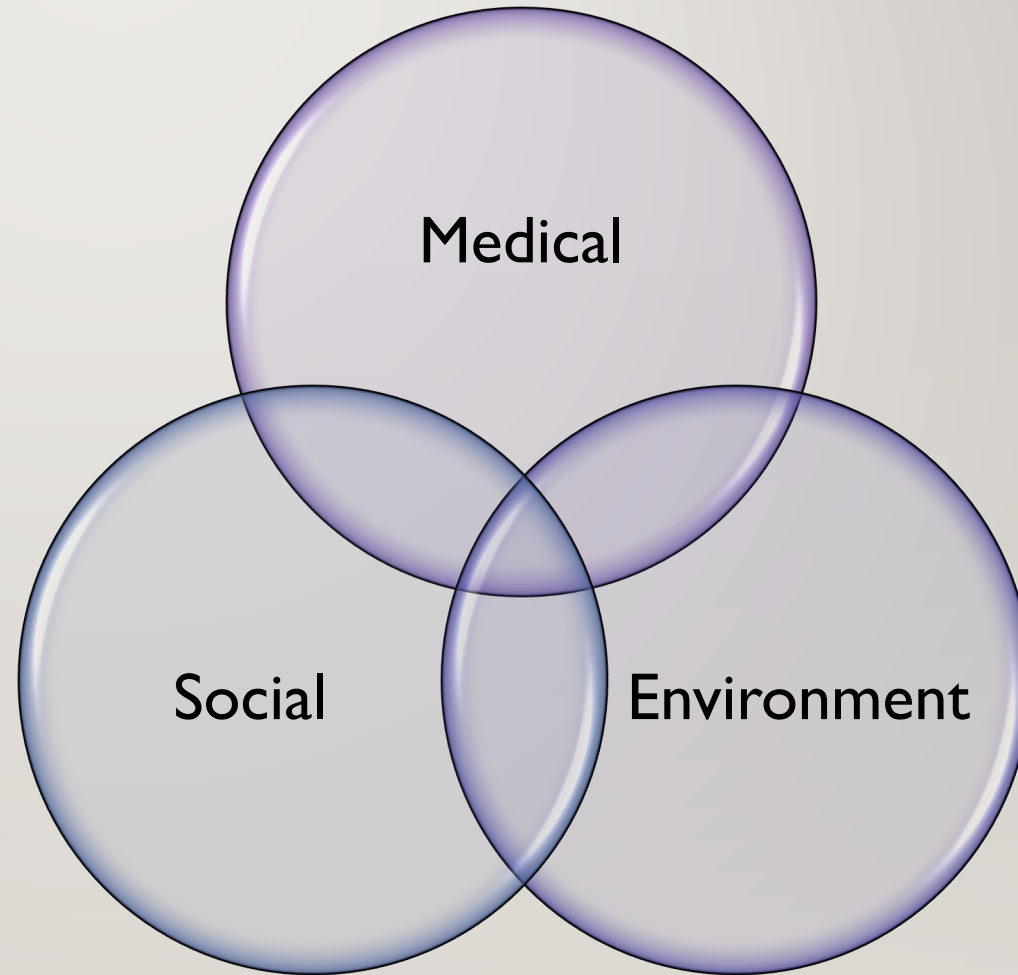


FOCUS AREAS OF TRANSITION

Medical

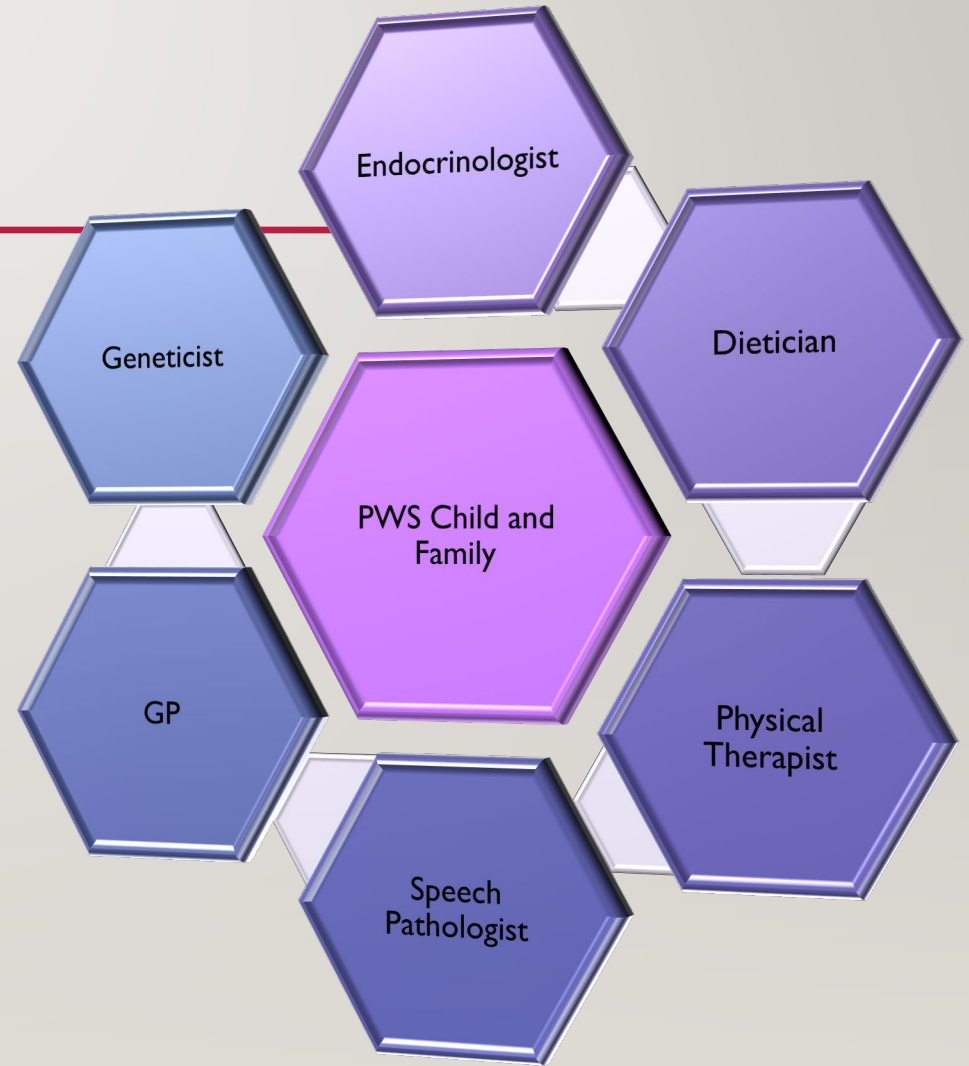
Social

Environment



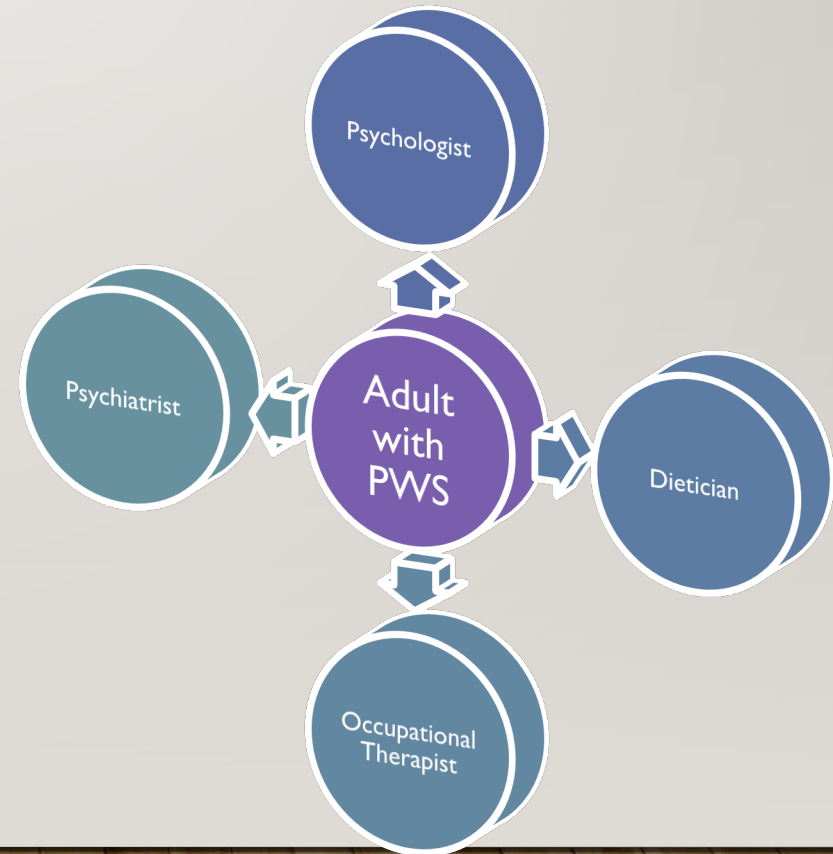
MEDICAL TRANSITION

- When we look at a Health Related Transition we are mainly Focusing on:
 - A Paediatric Team to Mainstream Adult Service
- The Paediatric team is normally Multidisciplinary
- These Teams Work Closely Together
- Have Been with the Family Since Birth
- A Well-Oiled Machine
- Family are Happy and Comfortable



MEDICAL TRANSITION

- The move to Adult services can be daunting
- In many circumstances there is no “Team”
- Starting all over again
- Less expertise for Adults
- Specialised Services Reduced



BARRIERS TO MEDICAL TRANSITION

Emotional attachments
built between Families
and the paediatric teams

Adult PWS patients with
cognitive impairments
and delayed growth.
Adult services struggle
with paediatric issues

Psychological and
Psychiatric problems
become more prevalent
in adults

Service in many places
are not under the one
roof

Autonomy/Consent

OVERCOMING BARRIERS

- Start early with overlapping Communities of practice
- Engage in specialist “Case Manager’s”
- Utilising localised Support Networks
- Services working together



ENVIRONMENTAL TRANSITION

- The Physical Environment that Person a with PWS transitions to:
 - From the family home to group or individual housing
 - School to adult Day Program's or further study
 - Transitioning to Employment

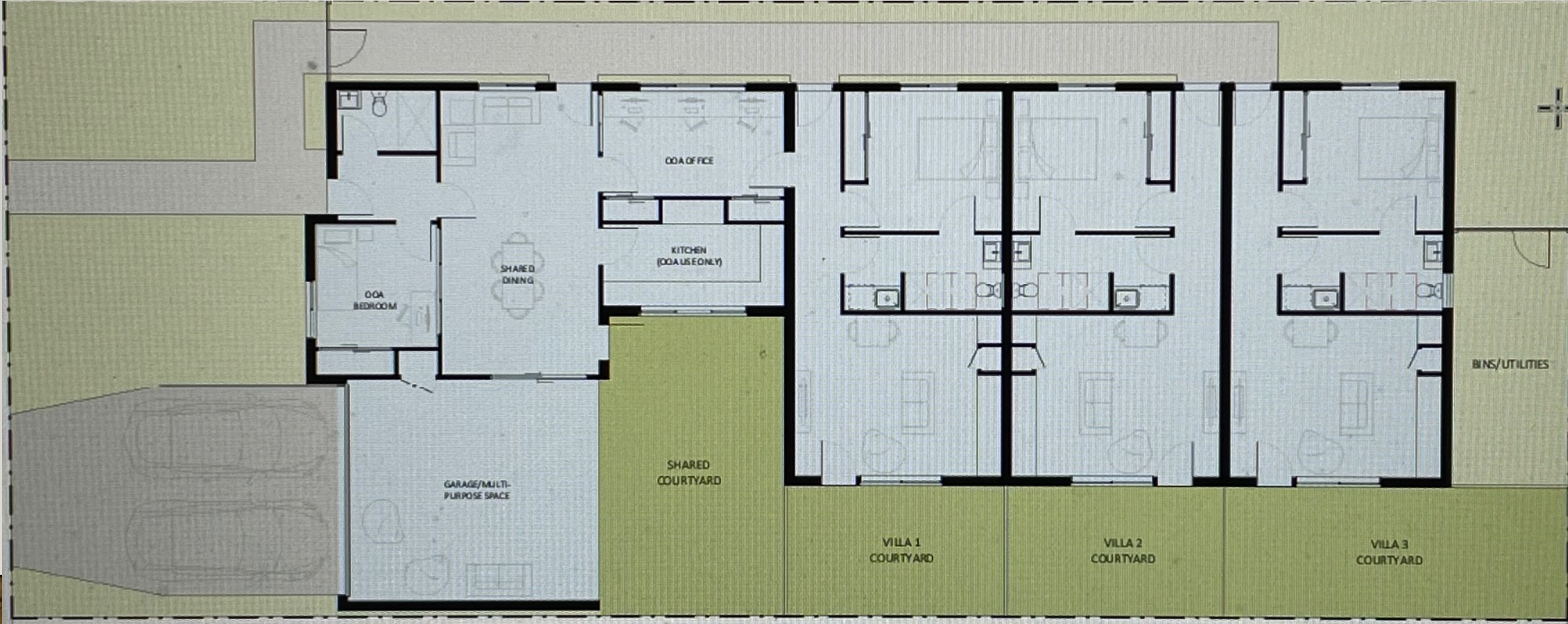


SUPPORTING ENVIRONMENTAL TRANSITION

- Day Program's or Employment
 - Training for Support networks
 - Transport
 - Case Manager or Support Coordinator
- Housing
 - Location
 - Staffing and support networks with in the facility
 - Gradual move in
 - Physical layout
 - Routine from the start
 - Right mix
 - Family's expectation



POTENTIAL HOUSE LAYOUT



SOCIAL TRANSITION

- Friendships
- Shared Accommodation
- Independence and Autonomy
- Egocentrism
- Relationships
- Families



SUPPORTING SOCIAL TRANSITION

- Early socialisation with peers
- Role models
- Managed independence
 - Finances
 - independence
 - Autonomy
- Understanding communication needs of the individual
- All support networks to understand PWS
- Continued Learning
- Working with Families

IN SUMMARY

- Transition is **HARD** work!
- Communities of Practice
- Networking
- Early Interventions and Early

OVER TO YOU!

- Question?
- What about your experiences?
- What do you find works for you?
- Let's start the conversation!
- I will collate your ideas and we will present in Ireland!

