TRANSITION FOR PEOPLE WITH PRADER WILLI SYNDROME

SEPTEMBER 22 2021
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
ENVIROMENTAL 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 within 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!