‘WELL-BEING’ AND PRADER-WILLI SYNDROME

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MENTAL HEALTH IN PRADER-WILLI SYNDROME
“Happiness... is over-rated!”
CHALLENGE: MANY CONCEPTS INTERTWINED WITH ‘WELL-BEING’

‘Happiness’ (Wallander et al., 2016)
- Positive affect
- Life satisfaction
- Meaning and purpose

‘Quality of life’ (inc. HQoL)
- Biological/physiological factors
- Symptom status
- Functional status
- Subjective perception of own state

‘Mental health’

‘Positive emotion’

‘Life satisfaction’

‘Subjective well-being’ (SWB)
TRADITIONAL APPROACHES TO THE CONCEPT OF ‘WELL-BEING’

● ‘Wanting’ theories
Rational desire fulfilment, where desires are defined non-subjectively
Well-being defined in terms of observed choices (e.g., spending of money)

● ‘Liking’ theories
‘Feeling good’
Well-being defined in terms of feelings (emotions, moods) and thoughts (evaluations)

● ‘Needing’ theories
Autonomy, meaning, personal growth – may not involve immediate happiness or satisfaction
Well-being defined in terms of objective lists of ‘goods’ required for wellness
'Well-being' requires positive alignment of four domains:

- **Subjective Domain**
  - Personal experience of happiness or life satisfaction

- **Health and Functioning Domain**
  - Good biological and psychological health as assessed externally

- **Environmental Domain**
  - Access to high quality material and social environment

- **Values and Ideology Domain**
  - Ethics, morals, engaging in life in a ‘good’ way

Source: Henriques et al. (2014). *Rev Gen Psychol*
CHALLENGES TO ‘WELL-BEING’ IN PWS

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- **Autonomy, self-care, ‘hedonic’ pleasure**
  - Hyperphagia
  - Emotional outbursts, self-harm
  - Perserveration, rigidity, ritualistic behaviours, OCD

- **Secondary stresses arising from physical function**
  - Hunger
  - Scoliosis, hypotonia, restricted mobility
  - Sensitivity leading to skin-picking

- **Compromised ability to leverage social support**
  - Impaired social cognition
  - Oppositional behaviour
  - *Ableism in society

- **Challenges to self-reflection**
  - Executive function deficits
  - Egocentrism
  - Ongoing anxiety and mood disruption
CONCLUSION: ISSUES TO CONSIDER WHEN DISCUSSING ‘WELL-BEING’ IN PWS

- Definition(s)
- Measurement
- Interpretation
- Intervention
WELL-BEING: More than ‘the absence of mental ill-health’
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Project ECHO