

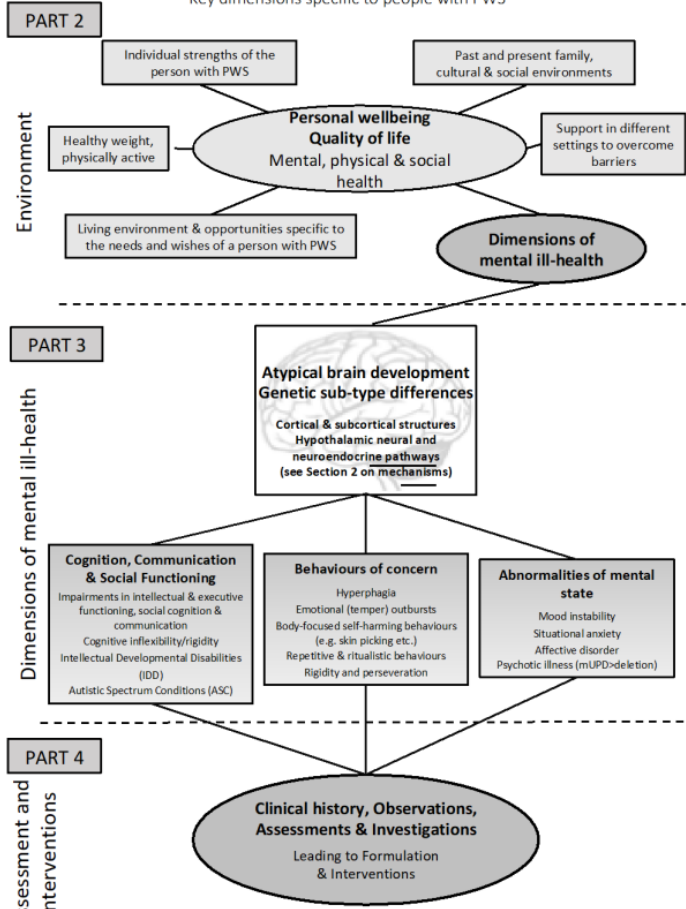
# 'WELL-BEING' AND PRADER-WILLI SYNDROME

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MENTAL HEALTH IN  
PRADER-WILLI  
SYNDROME

PERSONAL WELLBEING, QUALITY OF LIFE AND MENTAL HEALTH  
Key dimensions specific to people with PWS



“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:

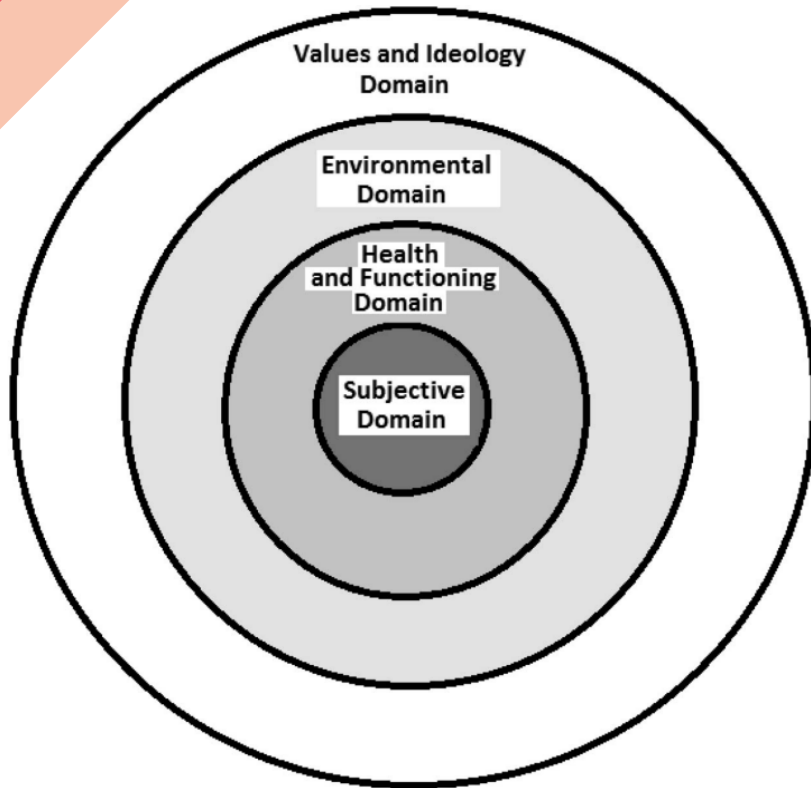


Figure 1. The Nested Model of Well-Being.

- **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*

# CHALLENGES TO 'WELL-BEING' IN PWS

- **Subjective Domain**

- *Personal experience of happiness or life satisfaction*



***Autonomy, self-care, 'hedonic' pleasure***

- Hyperphagia
- Emotional outbursts, self-harm
- Perversion, rigidity, ritualistic behaviours, OCD

- **Health and Functioning Domain**

- *Good biological and psychological health as assessed externally*



***Secondary stresses arising from physical function***

- Hunger
- Scoliosis, hypotonia, restricted mobility
- Sensitivity leading to skin-picking

- **Environmental Domain**

- *Access to high quality material and social environment*



***Compromised ability to leverage social support***

- Impaired social cognition
- Oppositional behaviour
- \*Ableism in society

- **Values and Ideology Domain**

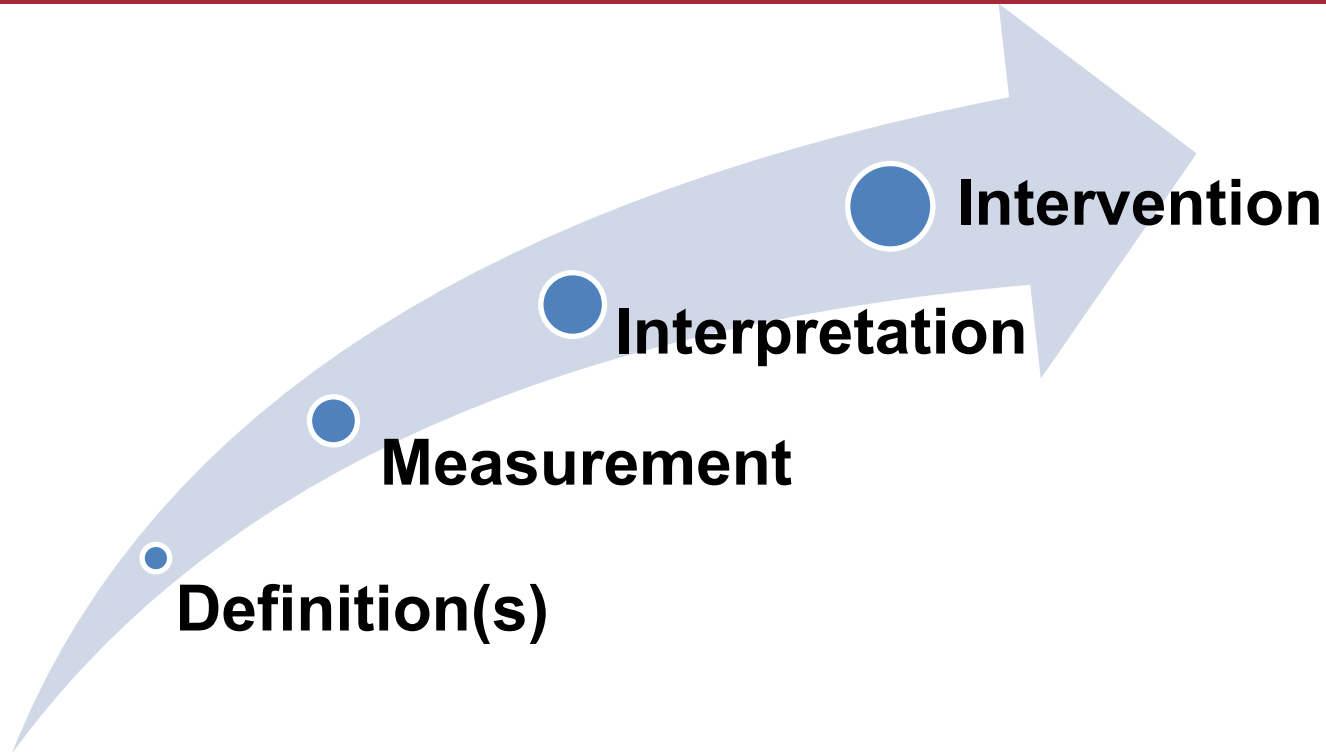
- *Ethics, morals, engaging in life in a 'good' way*



***Challenges to self-reflection***

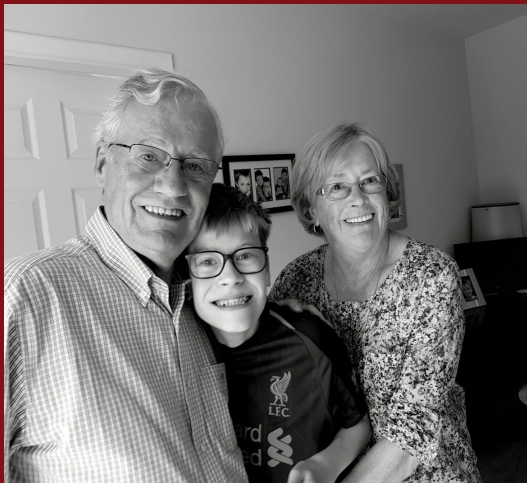
- Executive function deficits
- Egocentrism
- Ongoing anxiety and mood disruption

# CONCLUSION: ISSUES TO CONSIDER WHEN DISCUSSING 'WELL-BEING' IN PWS





# WELL-BEING: More than 'the absence of mental ill-health'



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