

# PBS and Quality of Life

-an introduction

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“if we know the quality of  
life a person has, we can  
think of ways of making it  
better”

-Zac Taylor, director of quality and practice, Mencap

# Aim of session

- ▶ Setting the scene for PBS
  - ▶ Defining **what** quality of life means
  - ▶ **Why** it is important
  - ▶ **How** we can use quality of life to help
- 
- ▶ Remember Self Care if any of the content is upsetting
  - ▶ None of the content is about your child

# PBS a definition

- ▶ “A multi-component framework for developing an understanding of behaviour that challenges...used to construct socially valid interventions which enhance quality of life outcomes for both the person themselves and their carers”
  - ▶ -Gore et al (2013)

“Illumination not elimination”

-Weiss and Knoster (2008)

“An extraordinary blend of Vision, Values and Science...the focus of PBS is to create effective environments and a better quality of life”

- Horner (2009)

# PBS Framework

- Considers the **person** and his or her life circumstances **as a whole**
- Reduces the likelihood of behaviours that challenge occurring by creating **supportive and capable** physical and social **environments**
- Is **proactive and preventative** and aims to teach people new skills to replace behaviours that challenge
- Involves input from different professionals and include **multiple evidence based approaches** that come from a shared value base, provided in a coordinated and person centred manner.

-PBS Academy (2017)

# The Twelve Key Components of PBS

## Rights and Values

Person-centred foundation

Constructional approaches and self-determination

Partnership working and support for key people

Elimination of restrictive practice

## Theory and Evidence Base

Biopsychosocial model of behaviours of concern

Behavioural approaches to learning, experience and interaction

Multi-professional and cross-disciplinary approaches

## Process and strategy

Evidence informed decisions

High quality care and support environments

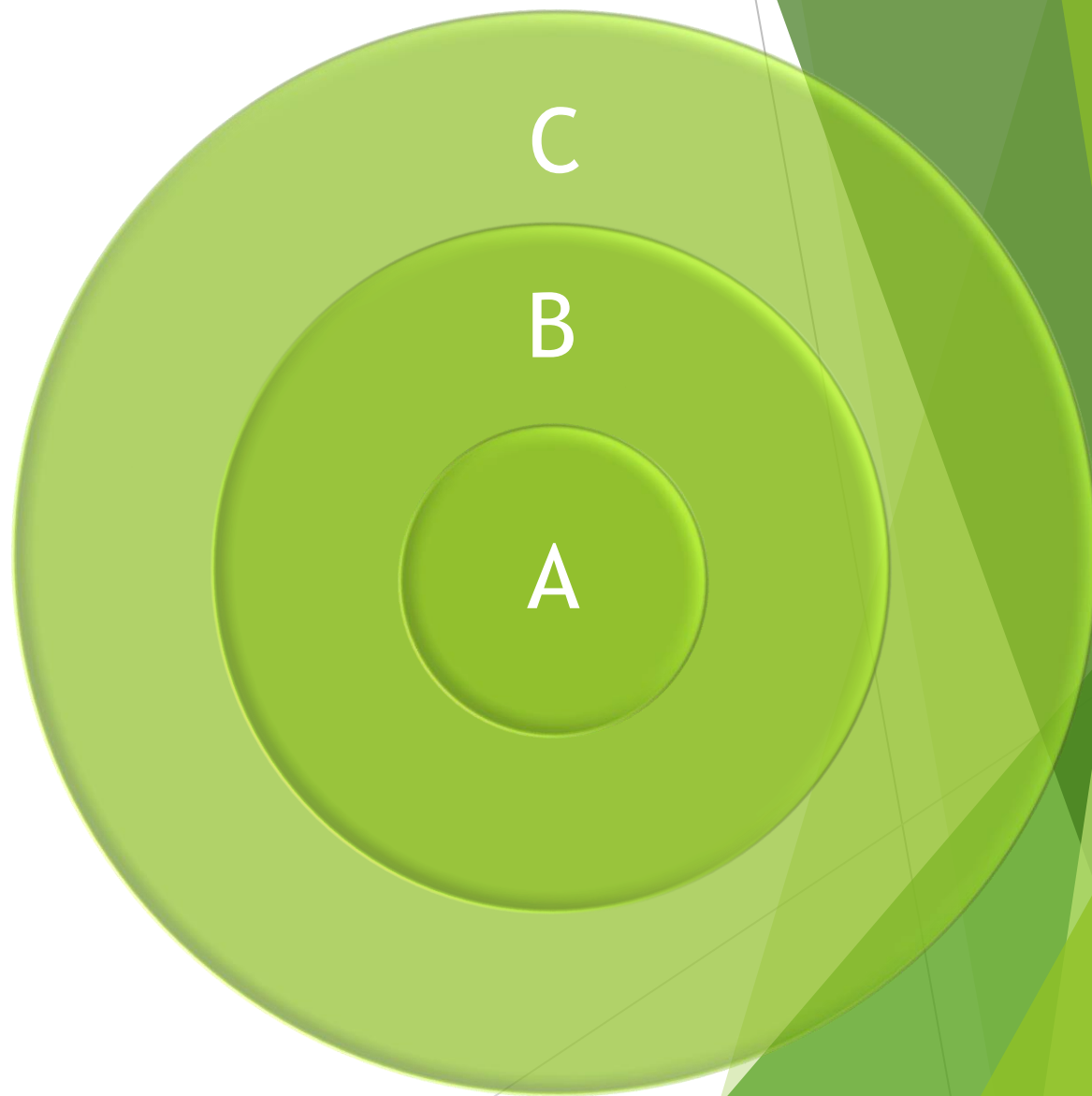
Bespoke assessment

Multi-component, personalised support plans

Implementation, monitoring and evaluation

# Capable Environments

- A. Creating high quality care and support environments
- B. Functional, contextual and skills based assessment
- C. Behaviour support plan, evaluation and monitoring



# Quality of life- a definition (Teolie & Bhardwaj, 2023)

- ▶ A concept that aims to capture well-being
- ▶ Regarding both positive and negative elements within the entirety of existence
- ▶ At a specific point in time. Includes:
  - ▶ physical health, mental health, spiritual health
  - ▶ Relationships, education status, work environment, social status
  - ▶ Wealth, sense of security and safety
  - ▶ Freedom, autonomy in decision making
  - ▶ Social belonging and physical surroundings



# Quality of life domains and some indicators (Shalock *et al*, 2002, Bigby *et al*, 2014)

| Domain                  | Indicator/example   |
|-------------------------|---|
| Emotional well-being    | Contentment, satisfaction, freedom from stress, self-esteem   |
| Physical well-being     | Health, being able to do activities of daily living, physical activity  |
| Material well-being     | Housing situation, work status and environment and financial status, possessions  |
| Personal development    | Education, personal competence, achieving, having success, being productive   |
| Self-determination      | Personal control and autonomy, having goals and expectations for your own life, having some choices and preferences             |
| Interpersonal relations | Positive interactions with others, relationships with family and friends, support, doing things with other people               |
| Social inclusion        | Being in and part of the local community, having a role in the community  |
| Rights                  | Human rights: respect, dignity, equality, right to family, etc. legal rights such as citizenship, accessibility and due process |

# Happiness and quality of life

- ▶ First of the key components of PBS document (PBS Coalition 2015):  
“Prevention and reduction of challenging behaviour occurs within the context of increased quality of life”
- ▶ People with a LD whose behaviour challenges services are consistently denied opportunities to experience quality of life equal to non-disabled people (Townsend-White *et al*, 2012)
- ▶ O’Brien and O’Brien (1987)- Critical Boundary- the gulf between the domain of community life and the experience of disabled people

# PERMA model (1)- McDonnell and Gayson (2014)



Positive emotions



Engagement



Positive Relationships



Meaning



Accomplishment

# Why is quality of life so important?

- ▶ Increase in meaningful activity= occupation, engagement, happiness
- ▶ Increase in skills building= learning, self-determination, achievement, communication
- ▶ Increase in community participation= relationships, inclusion, choice, belonging
- ▶ *“the reductions in challenging behaviour alone are perhaps necessary but certainly not sufficient for PBS”- Hastings et al, 2013*

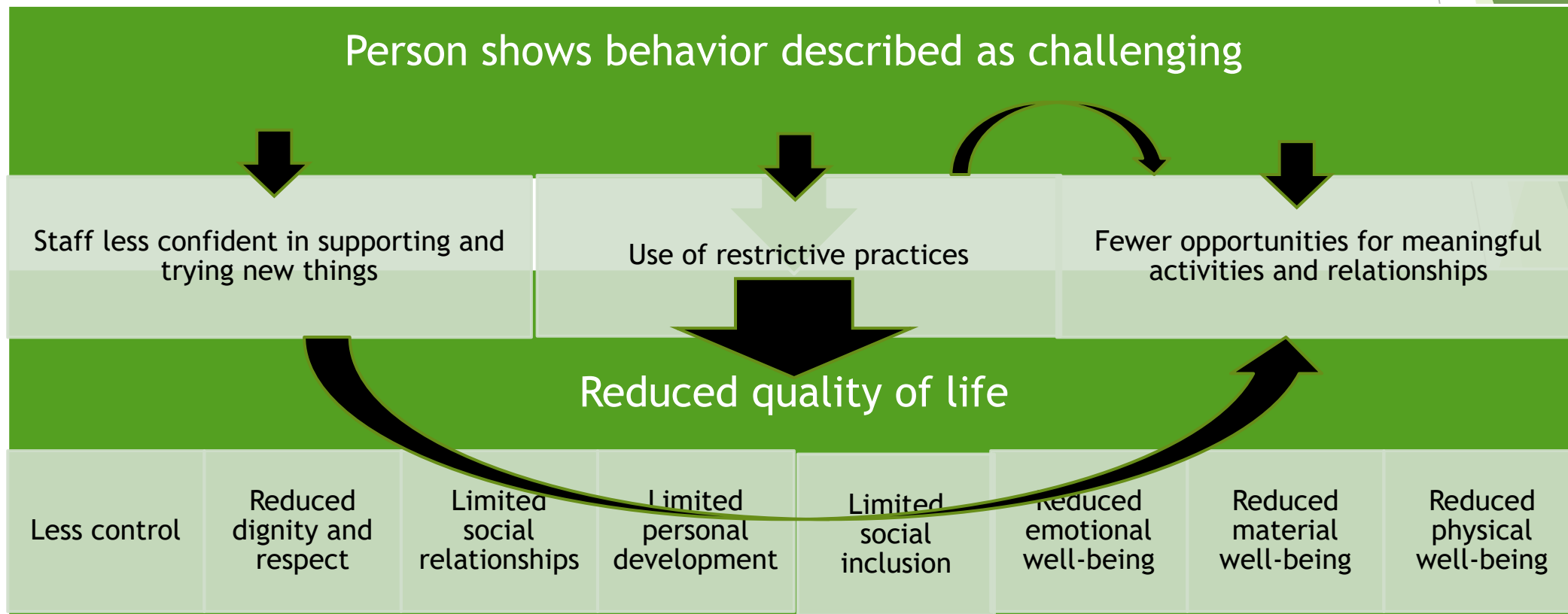
# QoL relationship with BoC



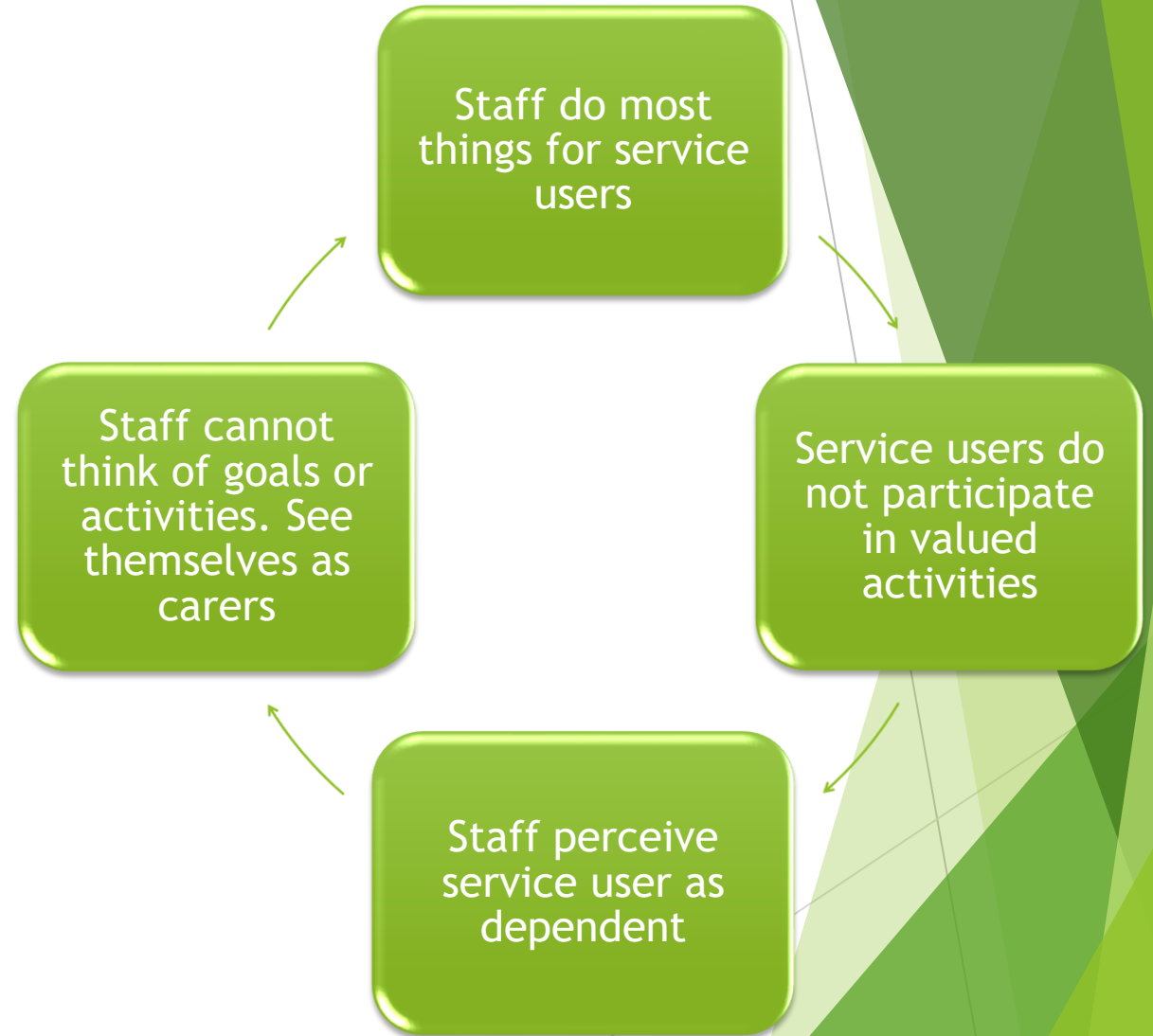
Quality of  
life

Behaviours  
of concern

# The vicious cycle of behaviour that challenges quality of life



# Disempowerment : the hotel model



# Assessing and monitoring quality of life

- ▶ Guernsey Community Participation and Leisure Assessment
- ▶ Wheel of life exercise
- ▶ Family Quality of Life Scale (FQOL)
- ▶ Active Support and PBS



NAME:.....  
 DATE:.....  
 AGE:.....SEX:.....

## The Guernsey Community Participation and Leisure Assessment – Revised Baker, Taylor-Roberts & Jones (2016)

Please indicate, by a tick in the appropriate box, the frequency with which the client does the following activities. See overleaf for definitions.

| ACTIVITY                             | Frequency |                          |                         |                            |                           |                          | ACTIVITY                           | Frequency |                          |                         |                            |                           |                          |
|--------------------------------------|-----------|--------------------------|-------------------------|----------------------------|---------------------------|--------------------------|------------------------------------|-----------|--------------------------|-------------------------|----------------------------|---------------------------|--------------------------|
|                                      | Never     | Less than every 3 months | At least every 3 months | Monthly or more frequently | Weekly or more frequently | Daily or more frequently |                                    | Never     | Less than every 3 months | At least every 3 months | Monthly or more frequently | Weekly or more frequently | Daily or more frequently |
|                                      | 0         | 1                        | 2                       | 3                          | 4                         | 5                        |                                    | 0         | 1                        | 2                       | 3                          | 4                         | 5                        |
| <b>Services</b>                      |           |                          |                         |                            |                           |                          | <b>Outdoor pursuits</b>            |           |                          |                         |                            |                           |                          |
| Doctor (GP)                          |           |                          |                         |                            |                           |                          | Holiday or daytrip                 |           |                          |                         |                            |                           |                          |
| Dentist                              |           |                          |                         |                            |                           |                          | Swimming                           |           |                          |                         |                            |                           |                          |
| Hospital                             |           |                          |                         |                            |                           |                          | DIY                                |           |                          |                         |                            |                           |                          |
| <b>Public Transport</b>              |           |                          |                         |                            |                           |                          | Gardening                          |           |                          |                         |                            |                           |                          |
| Bus                                  |           |                          |                         |                            |                           |                          | <b>Social</b>                      |           |                          |                         |                            |                           |                          |
| Train                                |           |                          |                         |                            |                           |                          | Disco/Nightclub                    |           |                          |                         |                            |                           |                          |
| Taxi                                 |           |                          |                         |                            |                           |                          | Pub                                |           |                          |                         |                            |                           |                          |
| Ferry                                |           |                          |                         |                            |                           |                          | Restaurant/ Café                   |           |                          |                         |                            |                           |                          |
| Flight                               |           |                          |                         |                            |                           |                          | Go to a friend's house             |           |                          |                         |                            |                           |                          |
| <b>Leisure</b>                       |           |                          |                         |                            |                           |                          | Spend time with family             |           |                          |                         |                            |                           |                          |
| Look at books/magazines etc          |           |                          |                         |                            |                           |                          | Social club/Society                |           |                          |                         |                            |                           |                          |
| Play games/computer games            |           |                          |                         |                            |                           |                          | Social networking via the internet |           |                          |                         |                            |                           |                          |
| Watch TV                             |           |                          |                         |                            |                           |                          | Help others                        |           |                          |                         |                            |                           |                          |
| Watch DVD                            |           |                          |                         |                            |                           |                          | Citizenship/Political activity     |           |                          |                         |                            |                           |                          |
| Browse internet                      |           |                          |                         |                            |                           |                          | <b>Facilities/Amenities</b>        |           |                          |                         |                            |                           |                          |
| Interact with pets/animals           |           |                          |                         |                            |                           |                          | Work (paid or voluntary)           |           |                          |                         |                            |                           |                          |
| Participate in sport                 |           |                          |                         |                            |                           |                          | Adult education/College            |           |                          |                         |                            |                           |                          |
| Spectator sports                     |           |                          |                         |                            |                           |                          | Local shop/Post office             |           |                          |                         |                            |                           |                          |
| Exercise/aerobics class              |           |                          |                         |                            |                           |                          | High street store                  |           |                          |                         |                            |                           |                          |
| Cycling                              |           |                          |                         |                            |                           |                          | Supermarket/Large retail outlet    |           |                          |                         |                            |                           |                          |
| Listen to music                      |           |                          |                         |                            |                           |                          | Car boot sale/Jumble sale          |           |                          |                         |                            |                           |                          |
| Participate in performing arts/music |           |                          |                         |                            |                           |                          | Hairdresser/Beauty salon           |           |                          |                         |                            |                           |                          |
| Create art                           |           |                          |                         |                            |                           |                          | Bank/Building society              |           |                          |                         |                            |                           |                          |
| Attend museum/art gallery            |           |                          |                         |                            |                           |                          | Place of worship                   |           |                          |                         |                            |                           |                          |
| Attend live performing arts          |           |                          |                         |                            |                           |                          | Library                            |           |                          |                         |                            |                           |                          |
| Attend cinema                        |           |                          |                         |                            |                           |                          |                                    |           |                          |                         |                            |                           |                          |
| Go for a walk (local)                |           |                          |                         |                            |                           |                          |                                    |           |                          |                         |                            |                           |                          |

| Sub-Scale             | Score |
|-----------------------|-------|
| Services              |       |
| Vocational Activities |       |
| Leisure               |       |
| Social                |       |
| Facilities/Amenities  |       |
| <b>Total</b>          |       |

Scores for each item are totaled – yielding subscales scores and a total score.

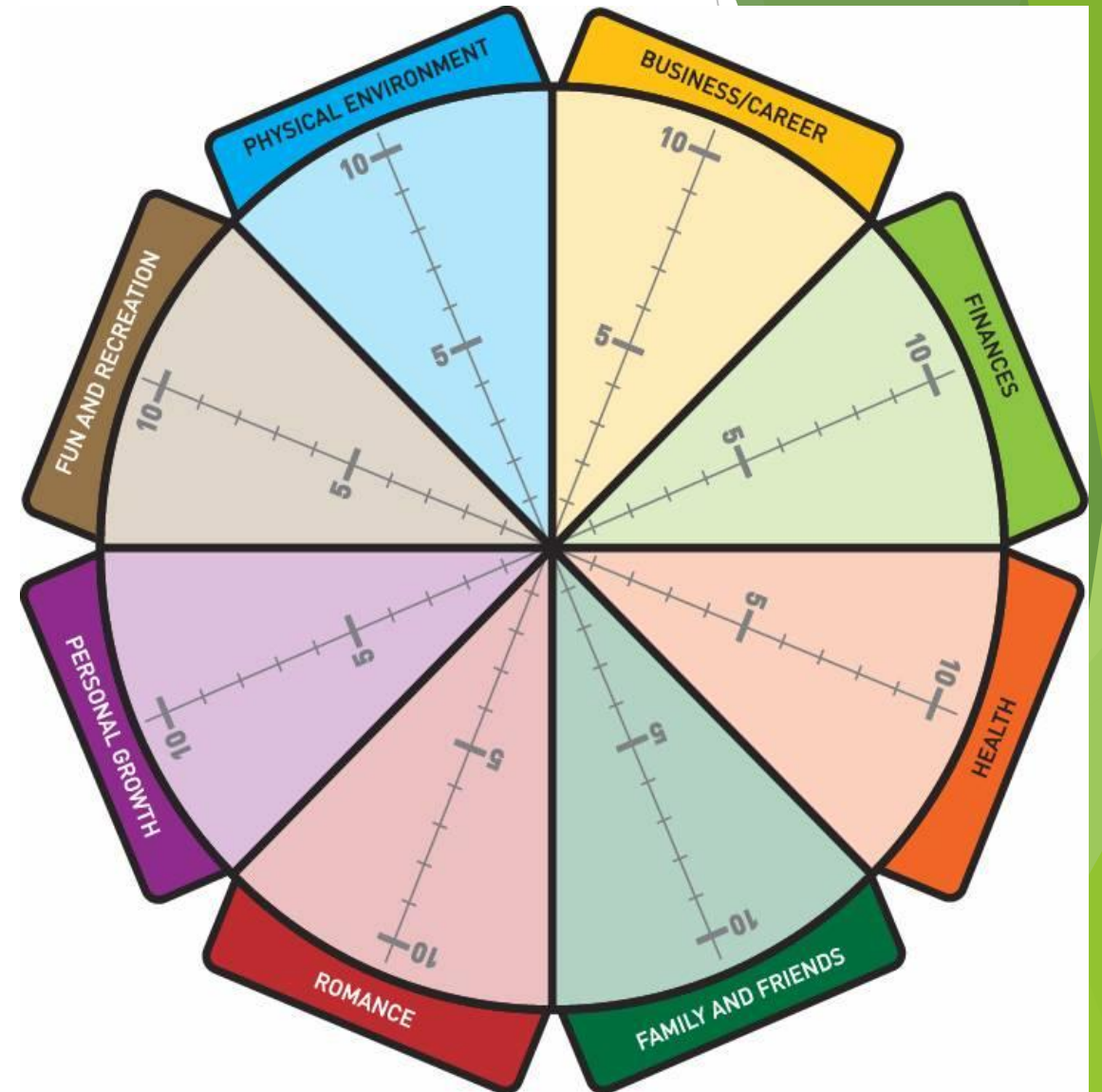
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# Guernsey- continued

- ▶ Record the frequency of certain activities
- ▶ Most of these are typical activities many of us will engage in and often take for granted
- ▶ Scores are achieved for different headings (services, vocational, leisure, etc.)
- ▶ Aim is to use this as a baseline measure and seek out tiny incremental increases over time by increasing frequency of activity
- ▶ Other measures such as the Subjective Quality of Life tool (Evans, 2016) also look at value of activities

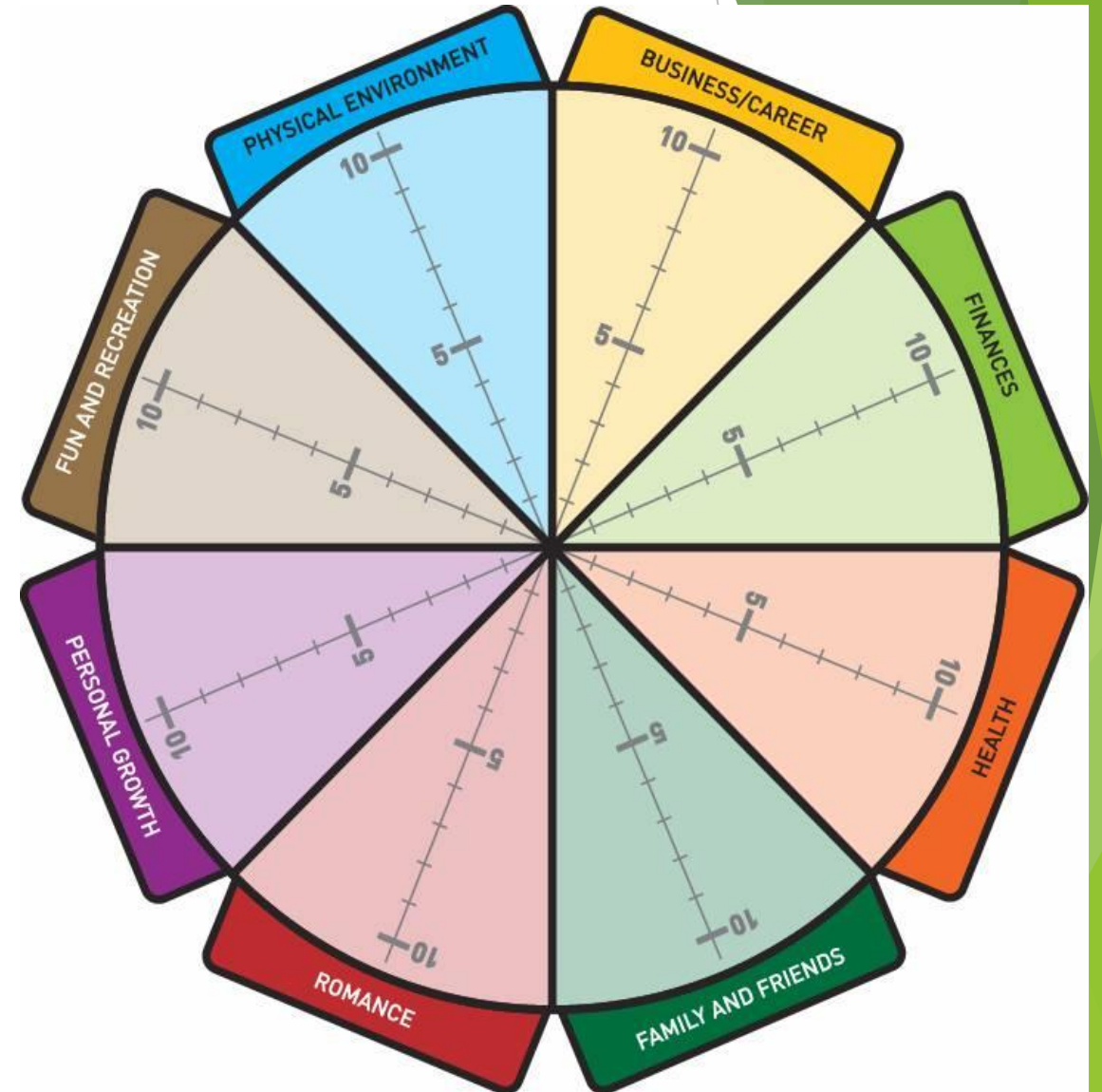
# Wheel of life exercise (1)

- ▶ Each spoke is one aspect of your life
- ▶ Think about another neuro-typical young person and try to complete each aspect of the wheel
- ▶ Rate from 0-10 (10 is best)
- ▶ Add all the numbers for a total QoL score



# Wheel of life exercise (2)

- ▶ Now think about your child/young person you work with
- ▶ Do the same for them
- ▶ Compare the scores
- ▶ Any interesting discoveries?



# Family Quality of Life Scale (FQOL)

- ▶ Looks at a whole family approach
- ▶ Scores via 25 items on 5 domains:
  - ▶ Family interaction
  - ▶ Parenting
  - ▶ Emotional well-being
  - ▶ Physical/material well-being
  - ▶ Disability-related support
- ▶ Can use as pre and post intervention measure as well as clear indicators of where need lies

# What is needed to improve quality of life

- ▶ 40 years of research found two things
  1. Severity of the disability
  2. The nature of the support they receive (enabling and empowering)

# Active Support, United Response, 2017

(1)

- ▶ A range of approaches which aim to enable people to participate successfully in meaningful activities and relationships so that they gain more control over their lives
- ▶ Shown to be important in:
  - ▶ Determining Quality of Life
  - ▶ Increasing participation in daily life
  - ▶ Increasing skills, adaptive behaviour and choice
- ▶ Primary outcome is engagement, but is person-centred in its implementation

# Active Support and PBS (2)

1

- Every moment has potential

2

- Little and often

3

- Graded assistance

4

- Maximising choice and control



# Empowerment: circles of positive interaction



# Using quality of life measures (2)

## Advantages

- ▶ In line with primary goal of PBS
- ▶ Removes focus on child as ‘the problem’
- ▶ Can indicate clearly critical boundary
- ▶ More sustainable
- ▶ **Shift in carer thinking**
- ▶ **Can indicate the limits of CYPLD involvement**

## Disadvantages

- ▶ Families can be reluctant to engage
- ▶ Can be a very emotional experience for them
- ▶ Can lead to potential conflict with other services
- ▶ **Shift in carer thinking**
- ▶ **Can indicate the limits of CYPLD involvement**

A better Quality of Life is  
both an intervention and  
an outcome of successful  
PBS

-Beadle Brown (2019)

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# Thank You

Any Questions?