

Prader-Willi-Syndrom InterNational



Qualität ist die Basis

# Prader-Willi-Syndrom Well-being

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# Well-being

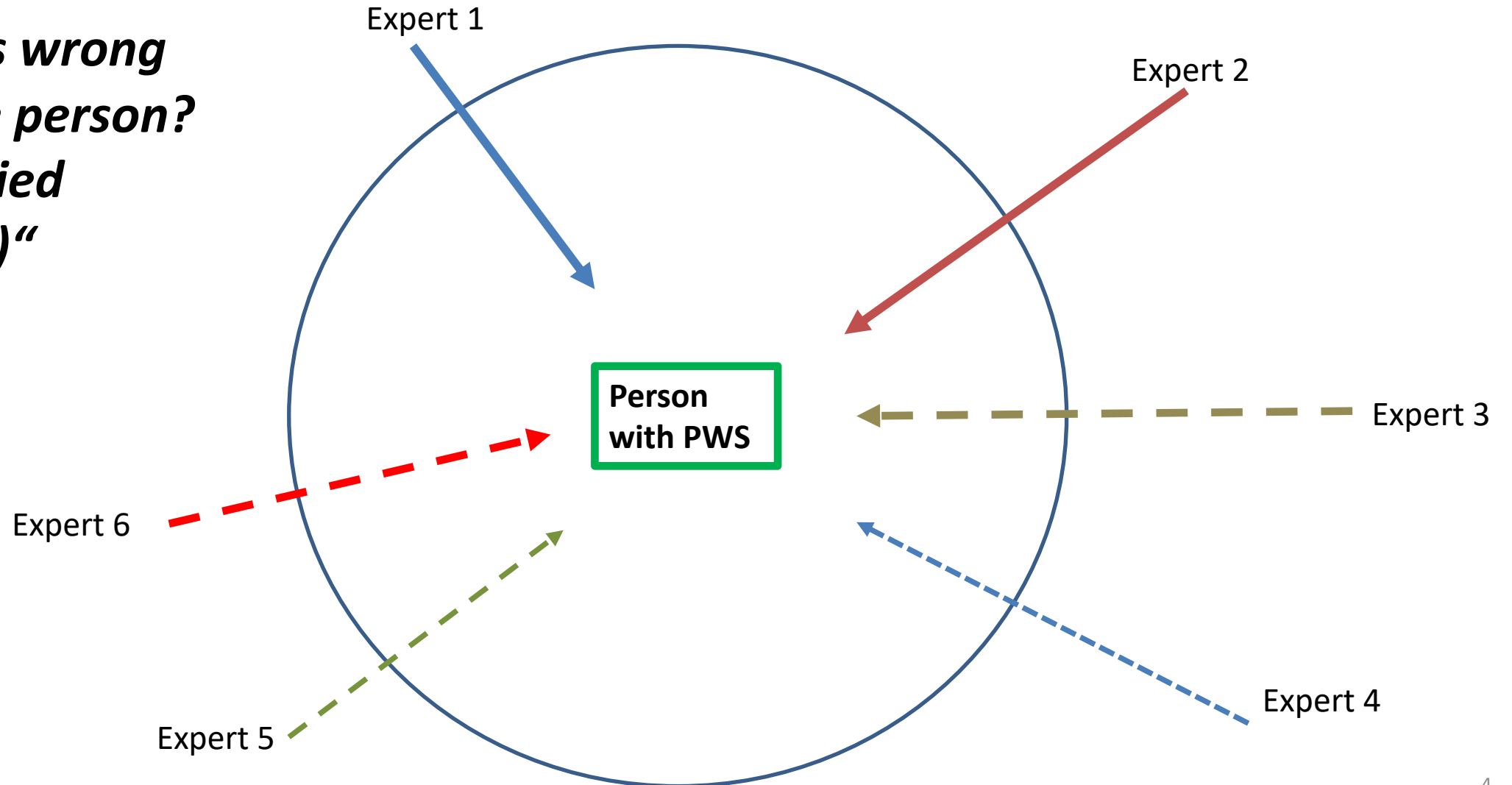
## The criteria of the quality of care in PWS

What are the basic needs to reach wellbeing?

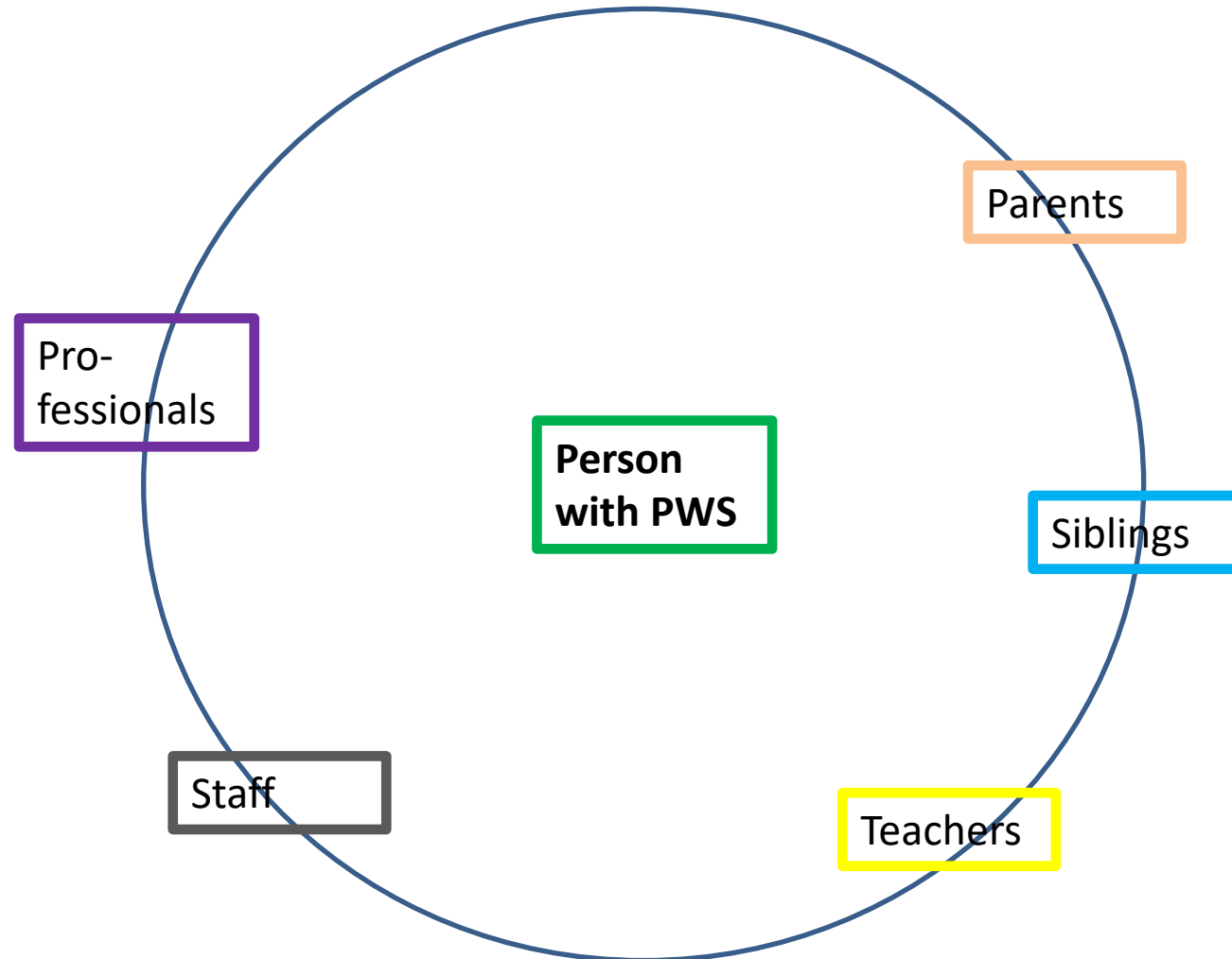
What does wellbeing mean concrete in all day work?

# Changing from the old and traditional approach...

***„What is wrong with the person? (‘Identified patient’)“***

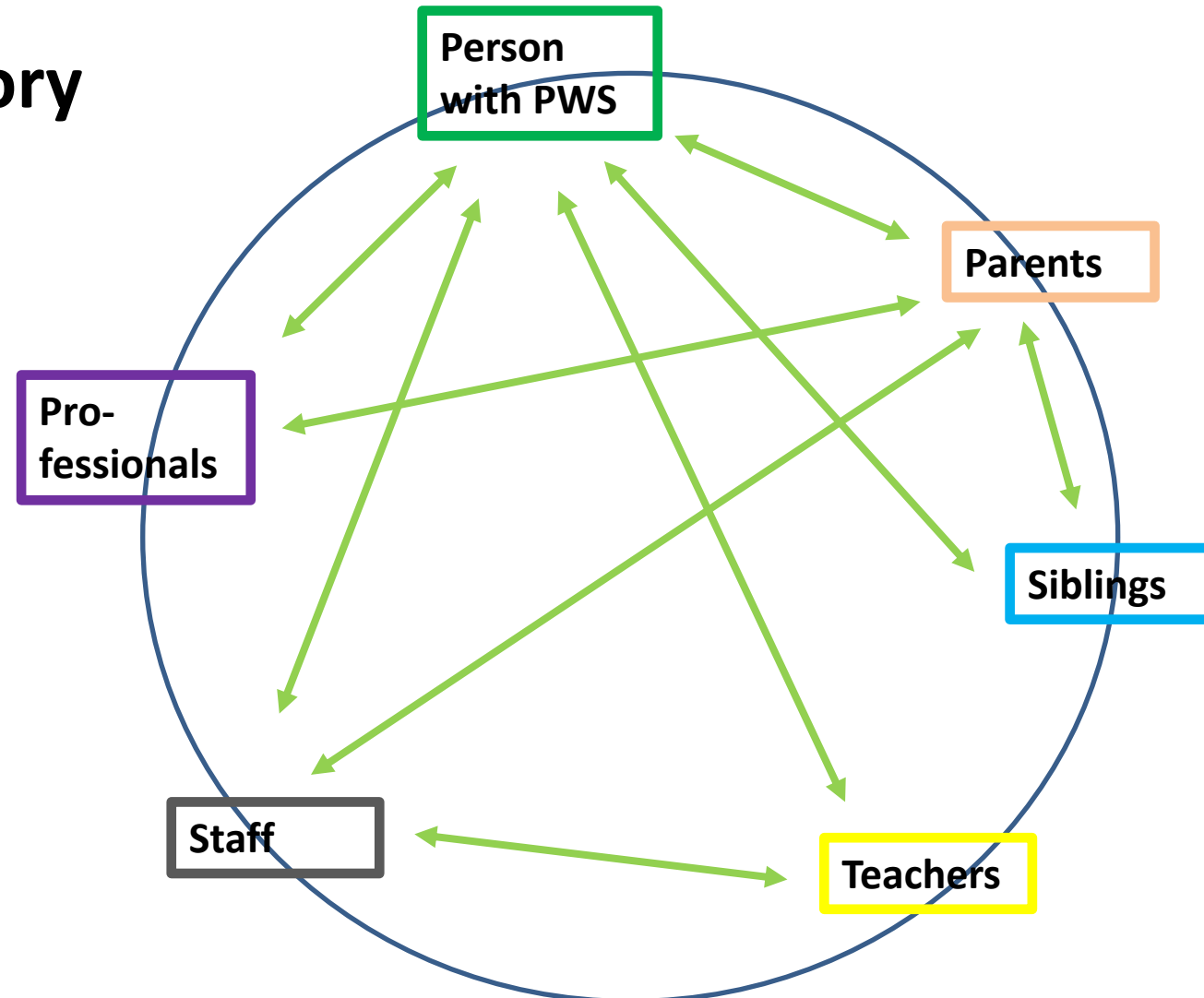


# ... to the systemic thinking

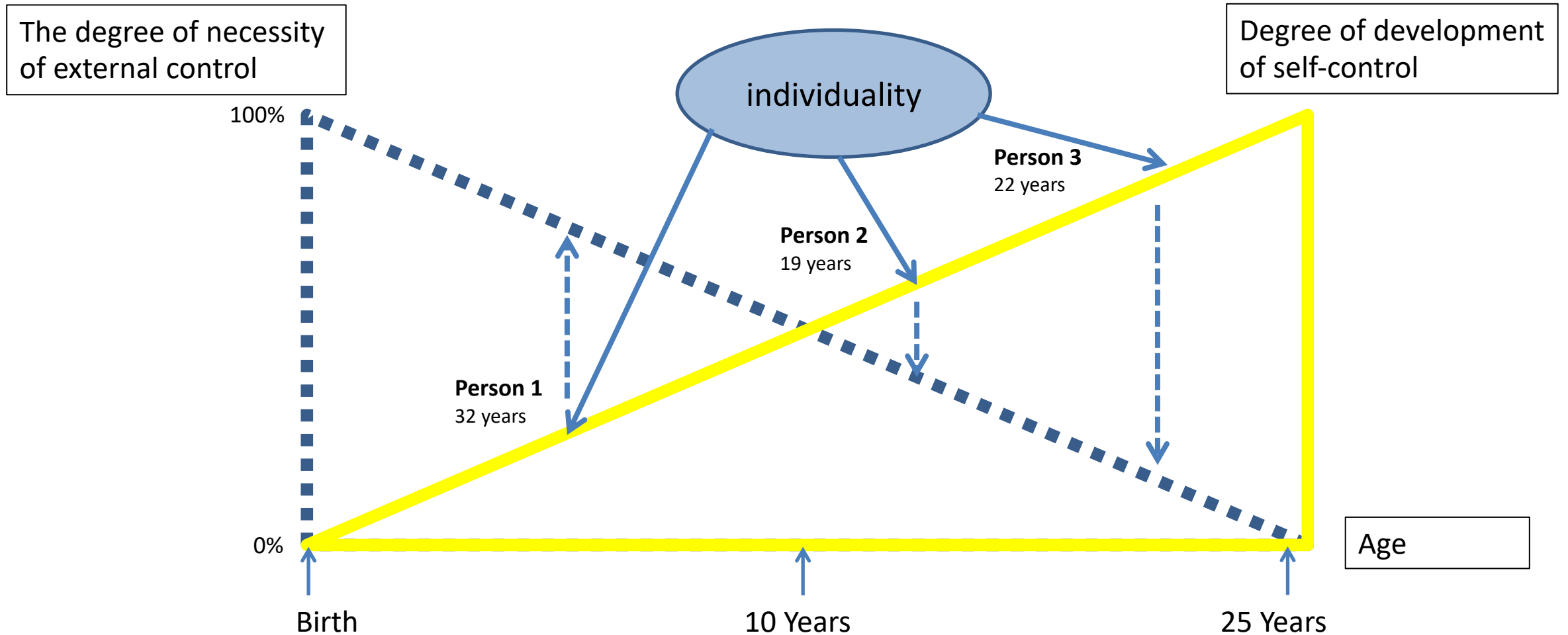


# Systemic-Theory

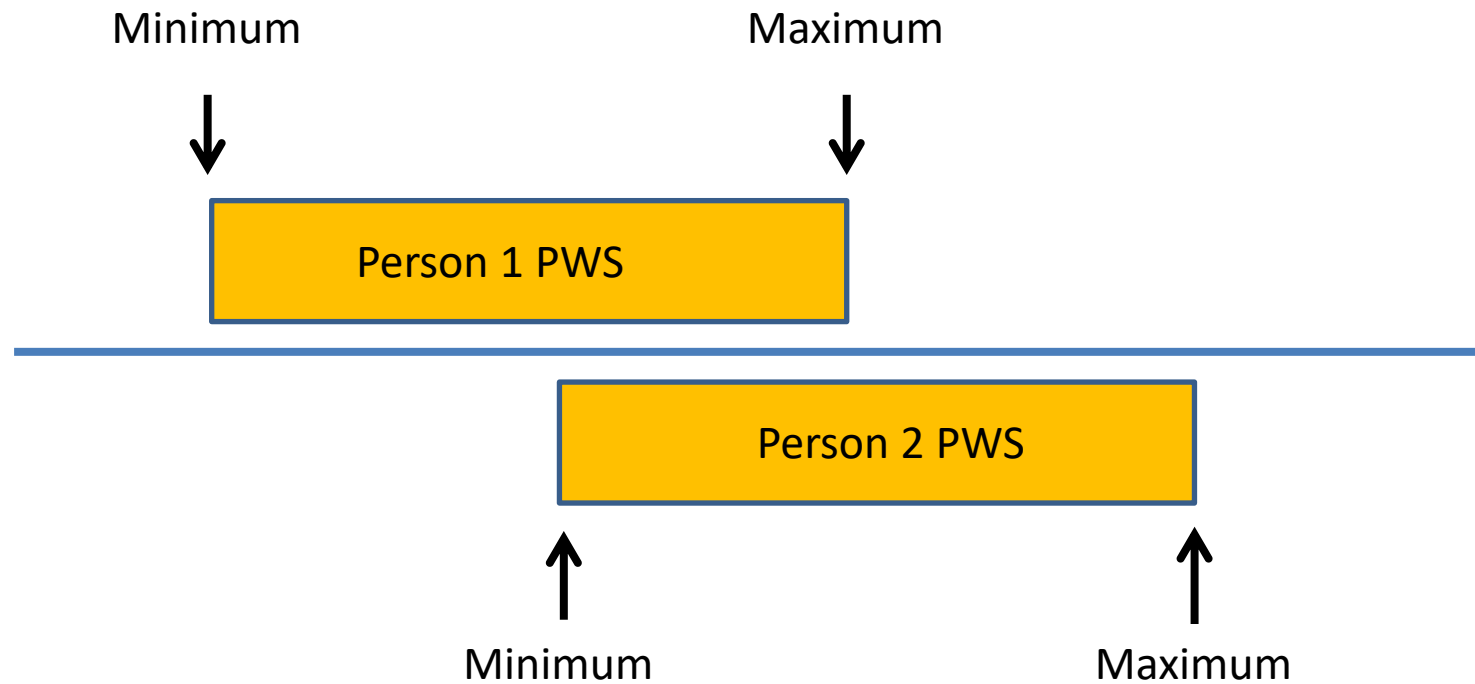
The importance of the interactions between the stakeholders in the system for understanding the behavior of the person with PWS



## Development of self-control in a normal environment



## Individuality of the limits of support





To see the person with his behaviour:

- as a part of the environment (system)
- having self-determination as a goal
- but also accept the individuality of the person's limitations

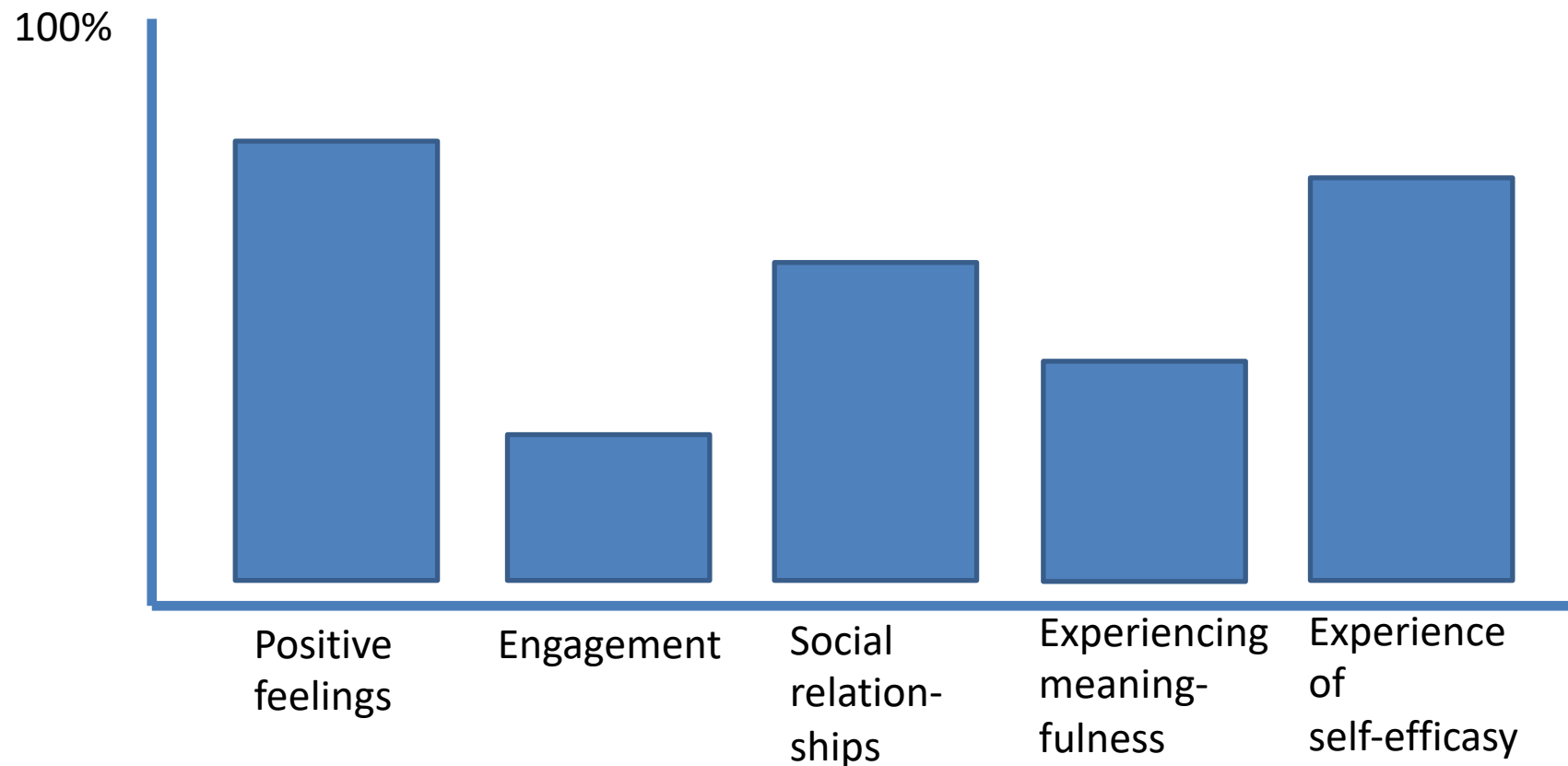
forms today the basis for the care of people with PWS In which they can experience “well-being”.

What are the basic needs to reach wellbeing?

What does wellbeing mean concrete in all day work?

# The individual profile of the five elements of well-being?

## Individual Profile - Development



### 1. Element: **Positive Emotions**

Examples: Joy - Cheerfulness - Hope - Gratitude - Inspiration - Interest – Love - Fun - Pride.

Criteria: Often other people think that people with PWS feel an emotion and it looks like, but not always they perceive it.

Only the emotions which are perceived by the person are (positive) emotions.

## 2. Element: **Engagement**

Engagement means: An intrinsic motivated action fills the person completely, without being overwhelmed or having an interest in extrinsic rewards - “flow” (doing puzzles, reading a book, listening music, ...)

### 3. Element: **Social Relationship**

Social relationships means: The realisation of the basic need for social belonging (in the family, in school, in the dancing group, in the neighbourhood, ...)

### 4. Element: **Sense, experiencing meaningfulness**

Experiencing meaningfulness means: Being able to classify one's own actions in a superordinate goal, being able to recognise a superordinate goal in one's actions.

### 5. Element: **Experience of self-efficacy**

Experience of self-efficacy means: One's own actions are perceived as (partial) cause for success, for reaching the goal.



# 5 Elements of well-being

## Individual Profile - Development

