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Quality of life and quality of support for children with severe and multiple disabilities and their families

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Content

- What is the meaning of the concepts of Quality of Life (QOL) and Family Quality of Life (FQOL)?

- How can they be measured in children with severe and multiple disabilities?

- What are effective strategies and interventions to optimize (F)QOL for children with severe and multiple disabilities in the context of early education?

The concepts of QOL and FQOL

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Individual:
Quality of
Life

Family:
Family
Quality of
Life

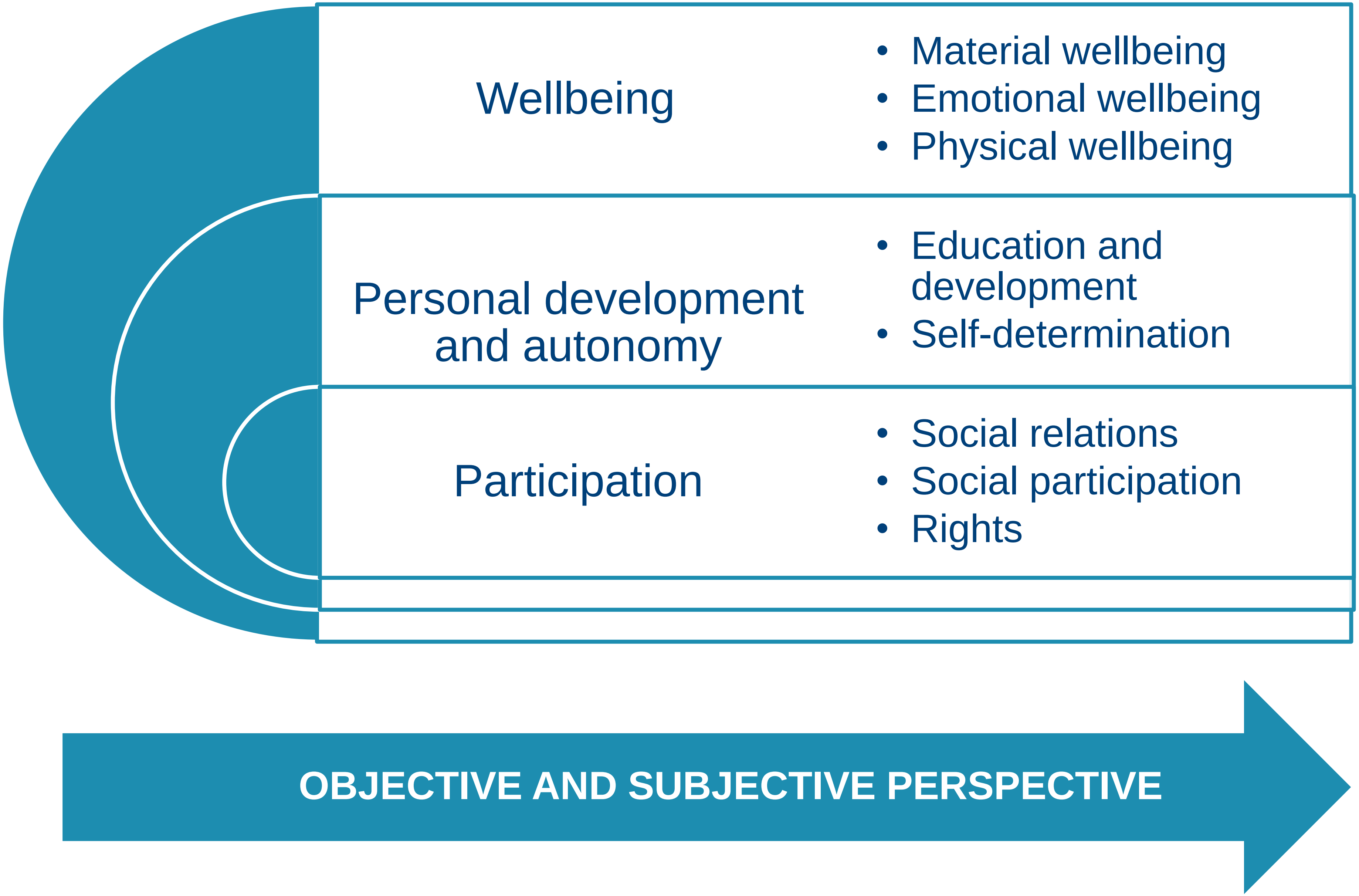
Society:
Inclusion
and full
citizenship

Definition QOL

- ‘Quality of life’ directs the attention to what is important and desirable from the perspective of the person with a disability.

- It aims to maintain and optimize what is meaningful for and contributes to a good life, and to change and improve what negatively influences a good life for an individual.

(Brown, Schalock, & Brown, 2009; Cummins, 2005; Schalock, 2004; Schalock et al., 2002)



Wellbeing

- Material wellbeing
- Emotional wellbeing
- Physical wellbeing

Personal development and autonomy

- Education and development
- Self-determination

Participation

- Social relations
- Social participation
- Rights

OBJECTIVE AND SUBJECTIVE PERSPECTIVE

Definition FQOL

- Conditions that meet the needs of the family, in which family members enjoy life together as a family and have the chance to do things that are important to them (Beach Center on Disability, 2003; Park et al. 2003)

- A dynamic sense of family well-being, collectively and subjectively defined by family members, where individual and family levels interact (Zuna et al., 2010).

Inclusion and full citizenschip

- Equal opportunities and rights to participate fully in society
    - being recognized as a competent individual who can take valued social roles into society and provide his own contribution
    - active participation in meaningful activities and relationships
- Recognition and appreciation of diversity
- Experience of involvement and commitment to one or more groups

The measurement of (F)QOL in persons with severe and multiple disabilities

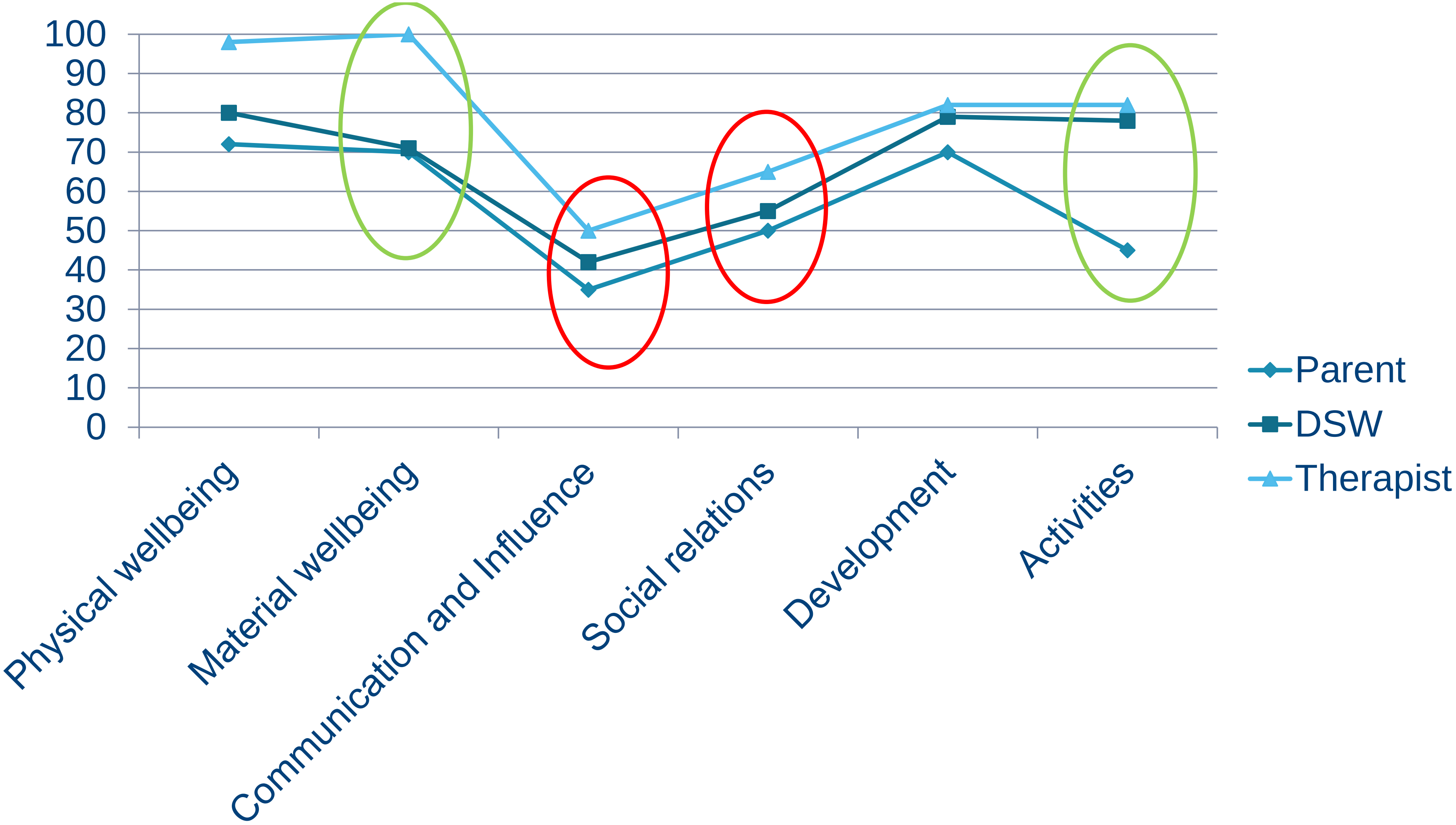
QOL-PMD (Petry, Maes & Vlaskamp, 2009)

- 55 items, 3-point likert scale

- 6 subscales
  - Physical wellbeing (n=8)
  - Material wellbeing (n=9)
  - Communication & Influence (n=10)
  - Socio-emotional wellbeing (n=9)
  - Development (n=9)
  - Activities (n=10)

QOL-PMD: Assessment procedure

- Selection of 3 key-informants: a family member, a direct support worker and another (more indirectly involved) staff member
- Questionnaire separately filled in by the three informants
- Quantitative and qualitative analysis of the data
- Discussion of the scores (and differences between scores) with the three informants and the coordinator
- Selection of action points to optimize quality of life for the person


100
90
80
70
60
50
40
30
20
10
0
Physical wellbeing
Material wellbeing
Communication and Influence
Social relations
Development
Activities
Parent
DSW
Therapist

Life situation of persons with PIMD

- 49 persons with PIMD (5-57 years) (Petry, Vlaskamp & Maes, 2009b; Vos et al., 2010)
- 71 adults with PIMD (20-67 years) (Maes, Vos et al., 2014)

→ Large variability in scores

→ Scores for Physical wellbeing, Communication and influence and Social relations at the lower end

→ Scores for Material wellbeing, Development and Activities at the higher end

Influencing factors on QOL

- Client characteristics
  - developmental age (+), number of limitations (-), medical problems (-) and feeding problems (-)
- Staff and Support characteristics
  - frequency of day activities (+), frequency of activities outside the group home (+)
  - hours of physiotherapy (+)
  - staff training (+), number of staff in the group (+/-)

San Martin scale (Verdugo et al., 2013; 2014)

- 95 items, 4-point likert scale
- 8 subscales
  - Self-determination (n=12)
  - Rights (n=12)
  - Emotional wellbeing (n=12)
  - Social inclusion (n=11)
  - Personal development (n=12)
  - Interpersonal relationships (n=12)
  - Material wellbeing (n=12)
  - Physical wellbeing (n=12)
- Questionnaire filled in by persons who know the person well

Subjective wellbeing

- Self-reporting about their life satisfaction is not possible, due to severe communicative and cognitive limitations
- Proxy reports may not be reliable measures of subjective wellbeing

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- Behavioural observations of their affect
  - Mood: positive or negative feelings over a certain period of time
  - Emotions: direct positive or negative feelings elicited by concrete stimuli or situations

Mood – MIPQ (Ross & Oliver, 2003; Petry, Kuppens, Vos, & Maes, 2010)

- Questionnaire, filled in by a staff member, based on observations during the previous 3 weeks
- 25 items, 5-point Likert scale
- behavioral indicators of Positive mood (n= 9), Interest (n=7) and Negative mood (n=7)

Subjective wellbeing in persons with PIMD

- 360 persons with severe and profound ID (Petry, Kuppens, Vos, & Maes, 2010)
- 71 adults with PIMD (20-67 years) (Maes, Vos et al., 2014)

→ Large variability in scores

→ Highest score for Positive mood, lowest score for Interest

Influencing factors on mood

- Client characteristics
  - Age (-), behavioral and psychiatric problems (-), sensory problems (-), medication (-)
- Staff and Support characteristics
  - Presence of other clients than clients with PIMD (+)

Behavioral observations

- Video-recordings of activities, interactions or daily situations
- Coding of different behavioral categories of wellbeing, active engagement, participation (Likert scales)

Wellbeing and engagement during multisensory storytelling activities

20 persons with PIMD (4 – 70 years)

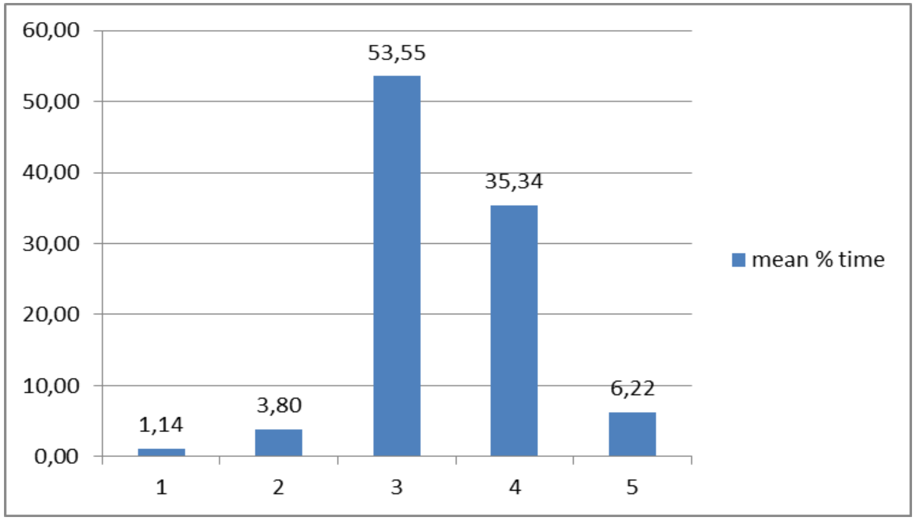


Figure 1: Percentage of time a certain wellbeing score is given during the sessions

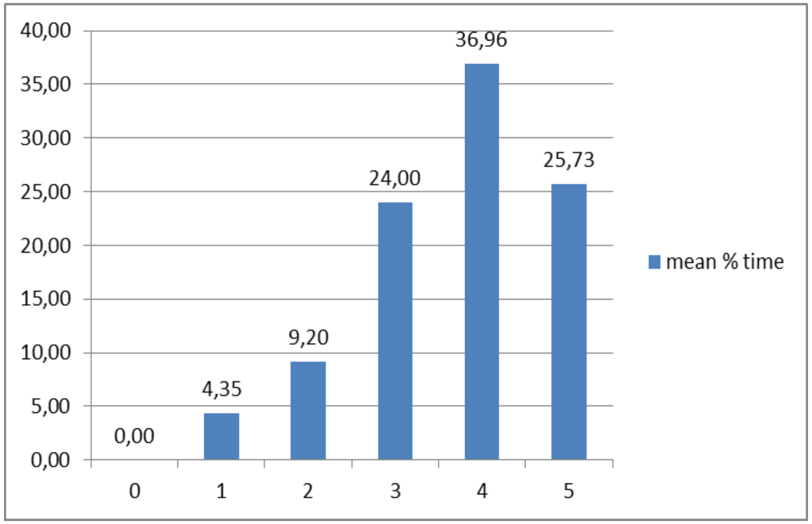


Figure 2: Percentage of time a certain engagement score is given during the sessions (n=20)

Grasping the experiential knowledge of parents and DSW

- Making up an affective profile (Petry & Maes, 2006)
- Asking parents or persons who know the person with PIMD very well to indicate in which ways the individual usually expresses his positive or negative emotions

Category	Operationalisation
Gaze direction	E.g. look at, look away
Facial expression	E.g. smile, make grimaces, make a lip
Sounds	E.g. moan, shout, yell, laugh, cry, jabber, scream, whine
Head posture	E.g. hang one’s head, slope one’s head
Head movement	E.g. move one’s head in the direction of a person, sound or object, turn, nod, shake one’s head
Body posture	E.g. sitting, standing or lying position, tensed posture
Movement of lower limbs	E.g. kick with one’s feet, stamp one’s foot, move one’s feet
Movement of upper limbs towards the person himself	E.g. caress, stroke, rub oneself
Movement of upper limbs towards an object	E.g. reach, touch, push, grab an object
Movement of upper limbs towards a person	E.g. reach, touch, push, grab a person
Mouth movements	E.g. suck one’s fingers or hands, gnash one’s teeth
Physiological reactions	E.g. blush, sweat
Aggression	E.g. bang one’s head, hit, scratch
Conventional gestures	E.g. wave, nod yes, nod no, point, clap one’s hands

Beach Center FQOL Scale (Hoffman et al., 2006)

- 25 items

- 5 subscales
    - Family interactions
    - Education
    - Emotional wellbeing
    - Physical and material wellbeing
    - Disability specific support

- Assessment of satisfaction on a 5 point Likert scale

FQOL Survey (Isaacs et al., 2007)

- 9 subscales + general assessment FQOL
  - Health
  - Financial wellbeing
  - Family relations
  - Social support
  - Professional disability support
  - Values
  - Job and education
  - Recreation
  - Participation in society
- Assessment of 6 dimensions on a 5 point Likert scale
  - Relevance; Opportunities; Initiative; Realisation; Stability – Changes; Satisfaction

What are effective strategies and interventions to optimize (F)QOL for children with severe and multiple disabilities in the context of early education ?

Strategies to support wellbeing, personal development and participation

- Creating the right conditions for learning and participation
  - state and patterns of alertness
  - position in space
  - stimulating materials and technological aids
  - objects of reference to structure the situation
  - stimulating, varied and age-appropriate activities that are tailored to the individual’s capabilities, limitations, interests and preferences and that offer opportunities to experience, learn, enjoy and interact with others

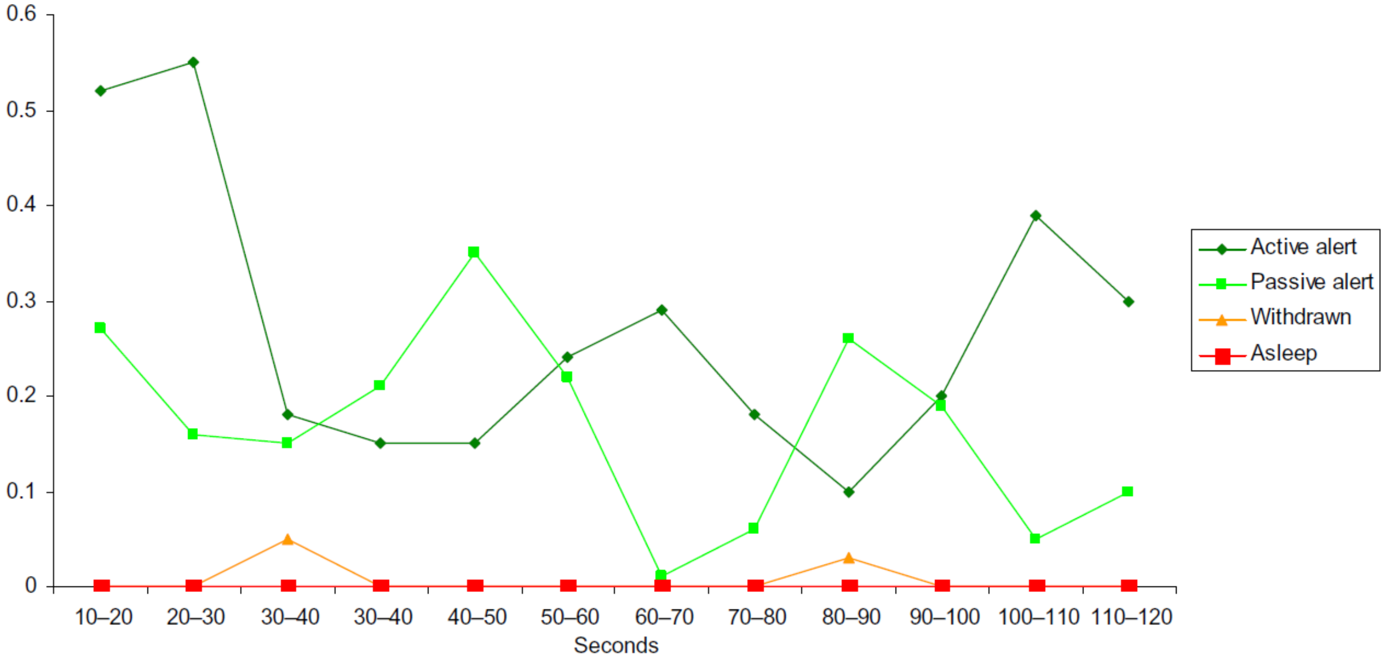
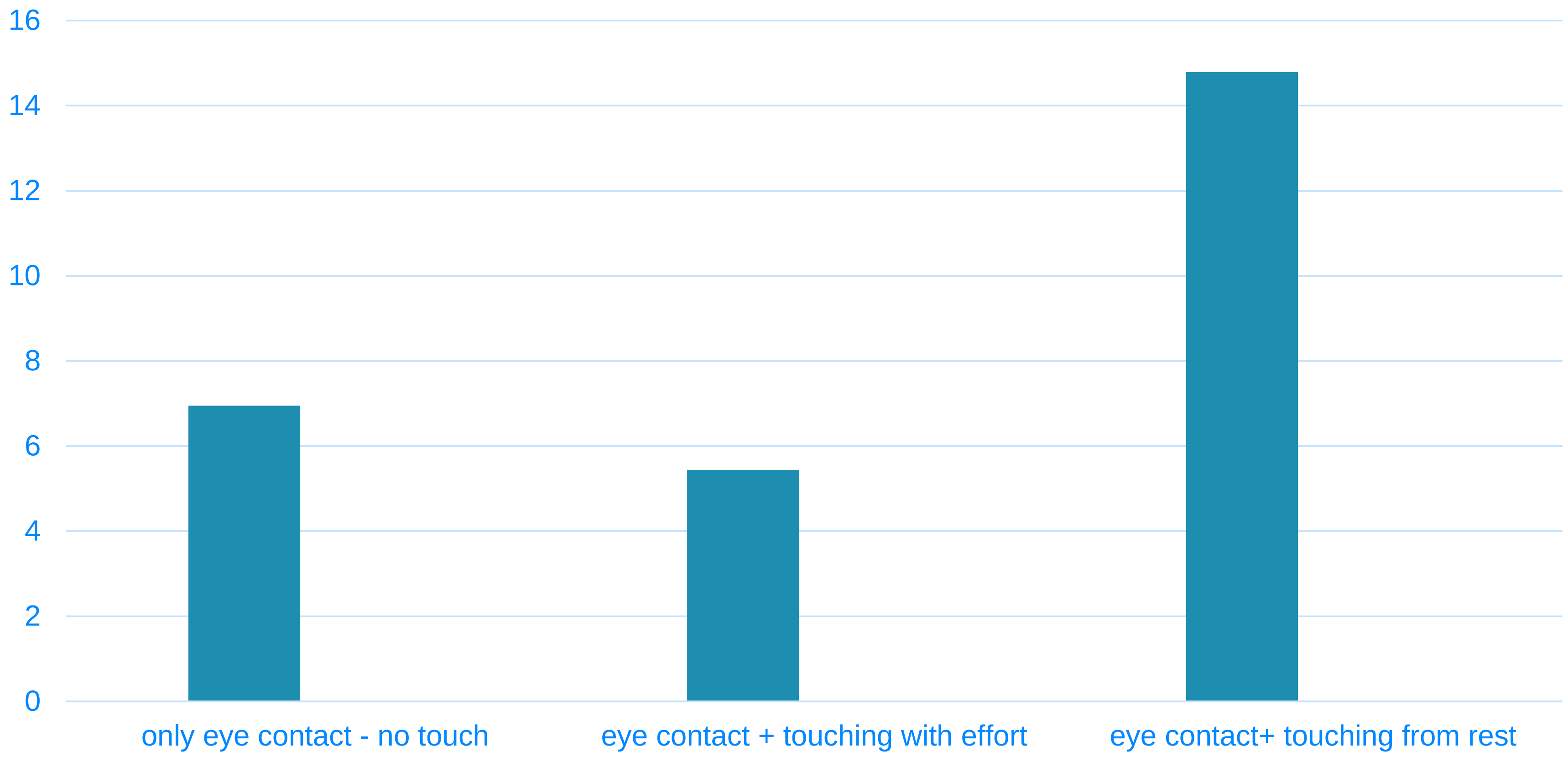


Figure 1. Plotted transitional probabilities of the different alertness levels following the visual stimuli.

% of peer directed behaviour according to position



- Systematic and individualised planning and evaluation
    - starting from wants and needs of child and family
    - clearly described long term and short term goals
    - choice of adequate strategies
    - systematic follow up and evaluation

- Pivotal role of parents, personal assistants, teachers and direct support workers

  - stimulating, scaffolding and motivating behaviour
  - creating opportunities to indicate preferences and make choices
  - ensuring that the child is able to understand and to influence what happens in his/her environment
  - positive attitudes and expectations

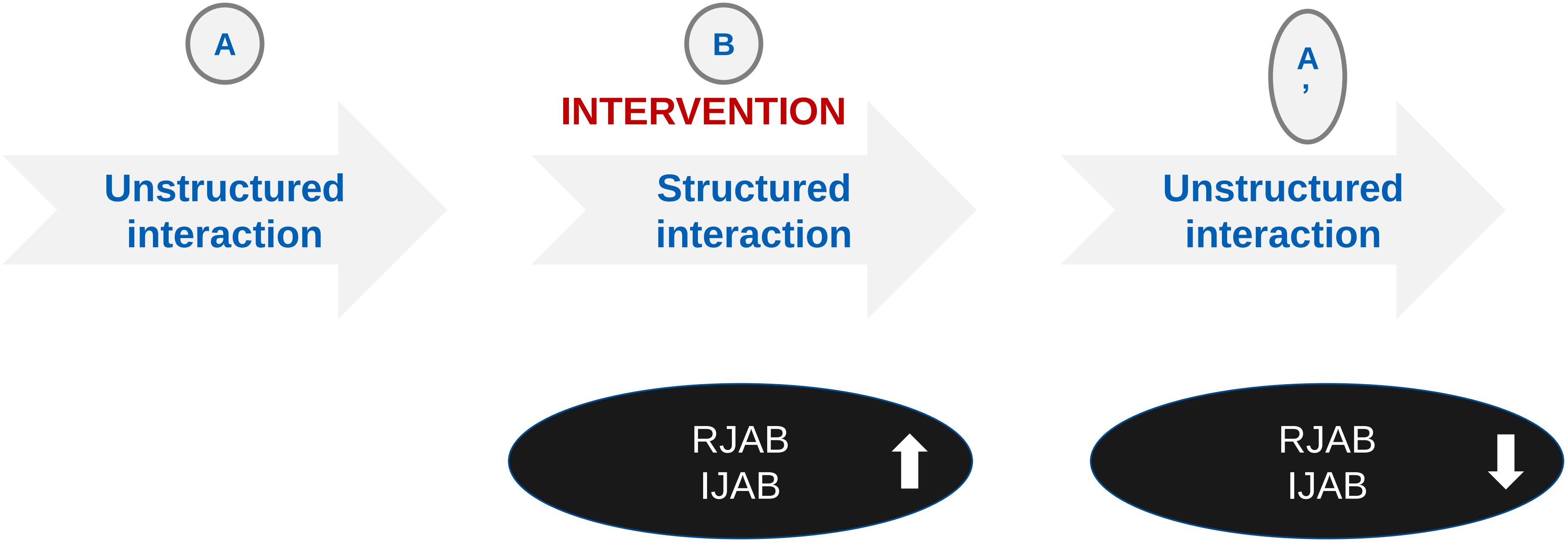
- Good quality interactions, characterized by
  - positive feelings (pleasure, warmth, affection, …)
  - aligning communicative behavior towards each other (coregulation)
  - adequate timing in interactions, giving children time to react
  - openness and respect
  - sensitive responsivity
  - shared and joint attention

Neerinckx & Maes (submitted)

- Impact of staff behavior on joint attention behavior
- 4 persons with PIMD

3 intervention strategies

Strategy 1	Presenting objects in a multimodal way: *1x visual, 1x auditory, 1x tactile presentation*
Strategy 2	Waiting at least 10 seconds after offering an object
Strategy 3	Confirming reactions / initiatives of the person



A

Unstructured interaction

B

INTERVENTION

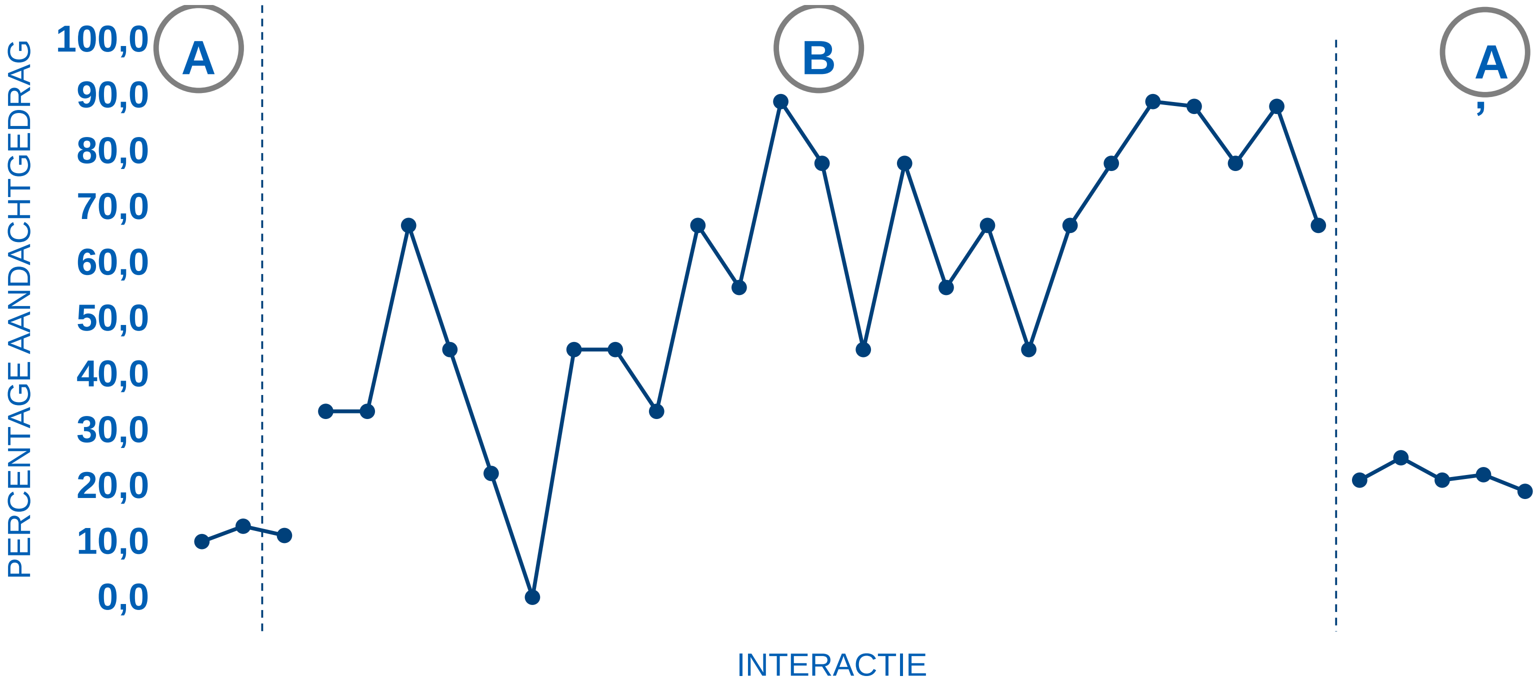
Structured interaction

RJAB
IJAB ↑

A’

Unstructured interaction

RJAB
IJAB ↓

A
B
A
’
PERCENTAGE AANDACHTGEDRAG
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70,0
60,0
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30,0
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INTERACTIE

Nijs, Vlaskamp & Maes (in press)

- Effect of training DSW in social scaffolding behavior to promote peer directed behavior of persons with PIMD
- 4 dyads of persons with PIMD

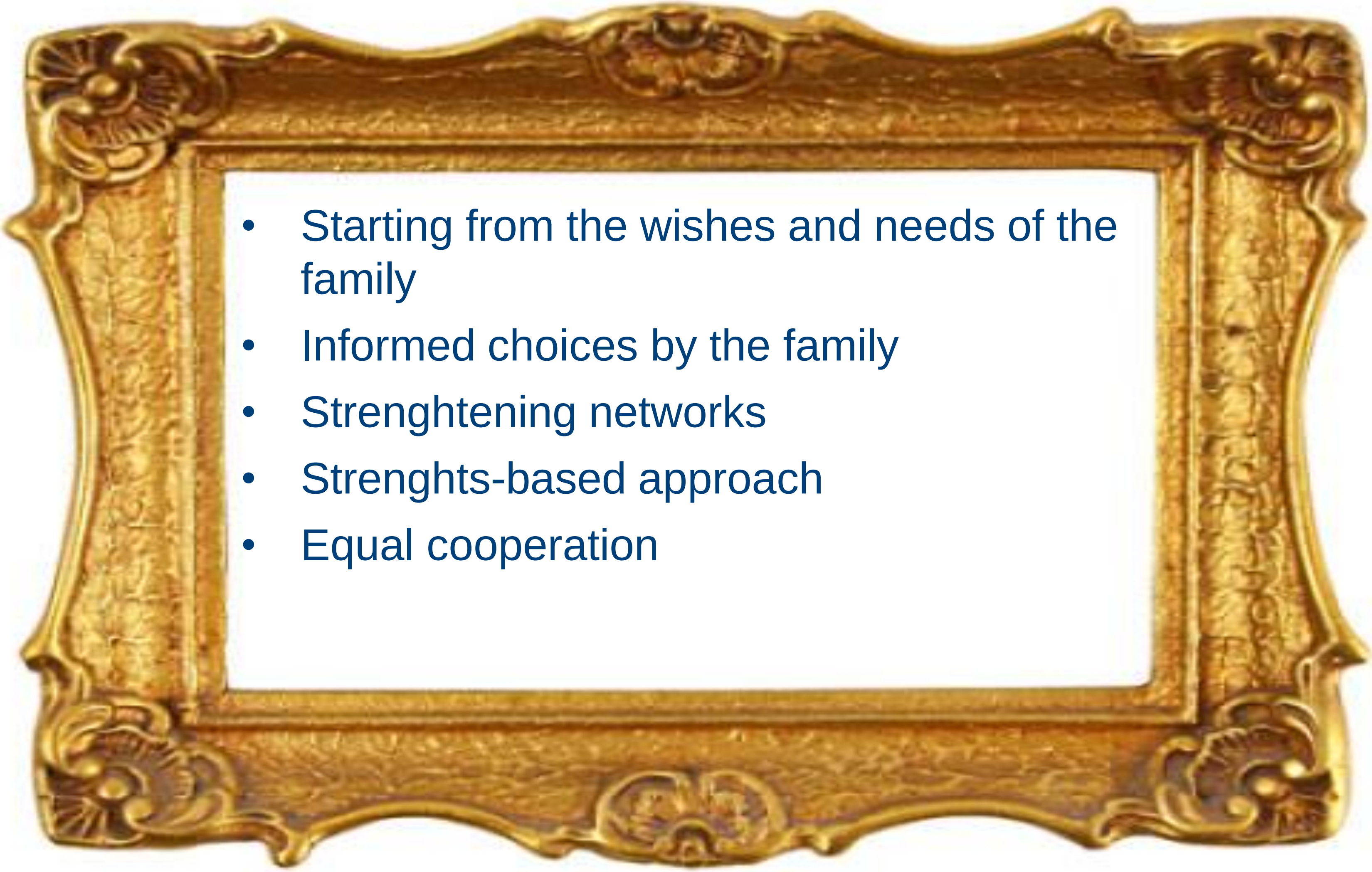
Intervention – Training for DSW

- Recognizing peer directed behaviour in persons with PIMD
- Creating opportunities for peer interactions
- Positioning persons with PIMD so that they can interact with each other
- Searching for materials and an activity that promotes peer directed behaviour
- Being aware of their own behaviour and social scaffolding or distracting behaviour

- Significant increase of social scaffolding behavior after the intervention for 3 of the 4 DSW; but decrease at follow up
- Significant increase of singular peer directed behaviour and a significant decrease of multiple peer directed behaviour during intervention compared to the baseline; but decrease at follow up

Strategies to support family quality of ife

Family centered approach



- Starting from the wishes and needs of the family
- Informed choices by the family
- Strenghtening networks
- Strenghts-based approach
- Equal cooperation

(Brown, Galambos, Poston, & Turnbull, 2007; Dunst, 1995).

Care – Work - Life balance (Maes, Seghers & Vanderkerken, 2015)

163 parents of a child with a disability (0-14 years)

- 70.4% indicate that they are not satisfied with the care-work-life balance
- 85.5% want more time for personal life; 79.3% more time for the partner and 52.8% more time for the other children
- 46.8% would like to spend even more time on care tasks and 42.8% state that care tasks can not be taken over by others if their child is sick for example
- of the parents who do not have paid jobs, 53.8% say they are unhappy with this situation

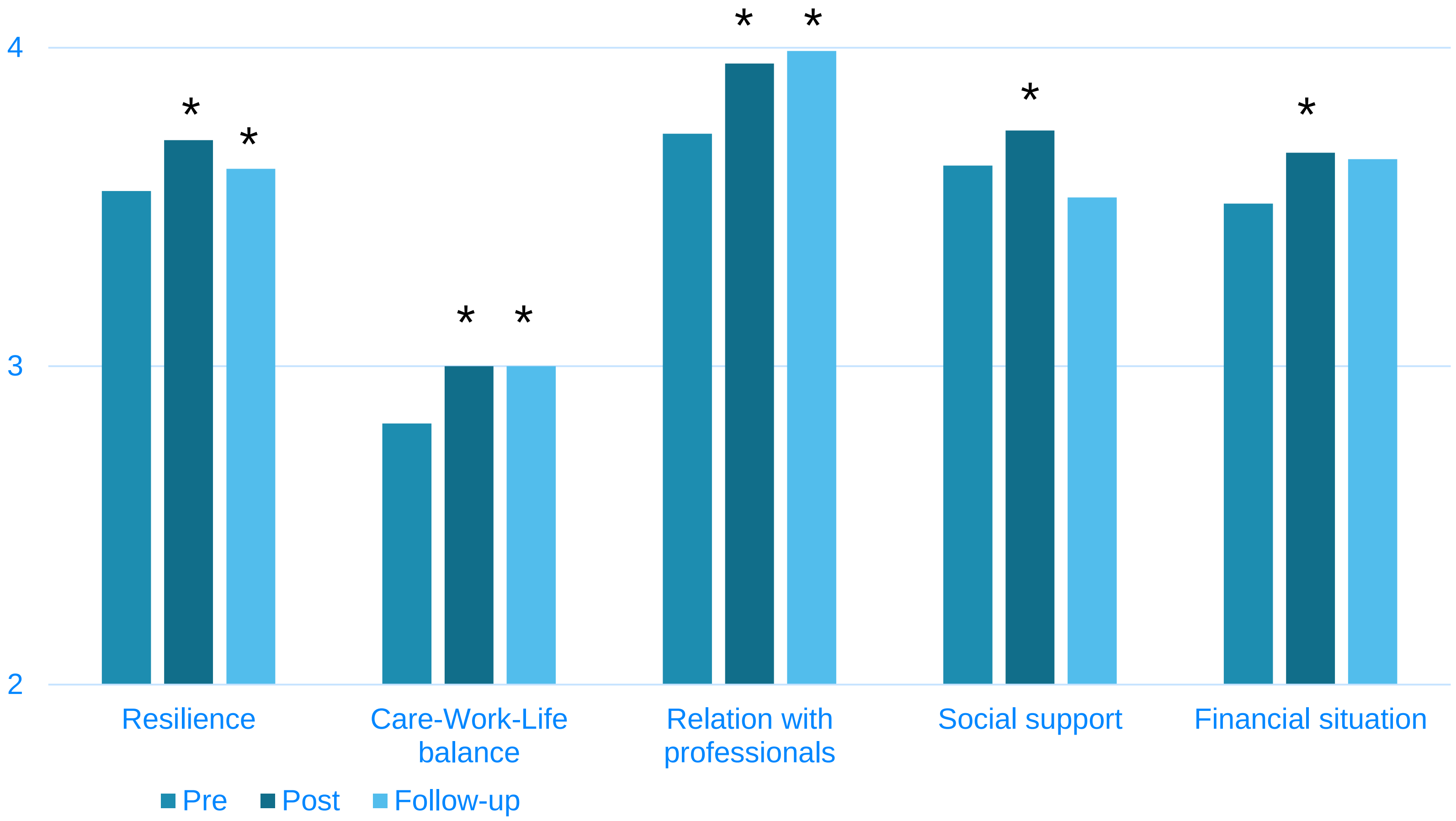
Supporting the care situation

- Giving information about forms of support, interventions, tools, etc.
- Sharing care tasks with others (family, volunteers, professionals)
- Offering respite care
- Using technological tools
- Hearing inspirational ideas of peers
- Empowering strategies to cope with the care-work-life balance
- Strengthening faith in their own abilities and capacities
- Supporting an active, solution-oriented coping style
- ...

Magenta workshops

- 4 workshops in group for parents of a child with a disability (0-14 years)
- Application of management principles in daily care situations
- Goals:
    - Parents can take more care of their care-work-life balance
    - Parents can better manage the daily organization of care and household tasks
    - Parents can better manage their financial situation
    - Parents are building supportive relationships with other people and professionals

Results Magenta-workshops



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