

COFACE: Work-Life Balance Strategies in Family Policy

Presentation Vilnius

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Caring for the caregivers

1) Presentation Magenta

2) Caring for caregivers

SELF CARE : Work life-care balance: new model!

CARE by professionals :

*Family Quality Of Life framework

*Career with Care Project

3) Recommendations : support by policy makers



PARENTING AND SPECIAL EDUCATION RESEARCH UNIT
Faculty of Psychology and Special Education KU Leuven
Research Teams

Autism
PIMD
Families



2012 initiated by Noor Seghers
2019 funded by Flemish Government

Team Magenta: 5 staff members + 14 volunteers:
parents as experts by experience



Magenta



Parents



Children
0-14 years



Children
15-25 years

Professionals



Toolbox



Career with care



To be or
not to be

Expertise

- Triathlon project: combining care and work
- Recommendations Flemish Informal Care Plan 2022-2027
- Respite care
- Training courses for the future (Equal Partnership in care 2023)
- Different regional, national and international networks



Aims towards families

- Empowering parents
- Increase resilience (first 10.000 days!)
- Supporting the search for a personal balance between life, work & care taking!
- Facilitating making informed choices and decisions



Aims towards professionals



- Raising awareness for families' experiences with caring
- Raising awareness and offering tools for FAMILY quality of Life (FQOL)
- Raising awareness for the topic informal carers and their different roles + long term care
- Offering tools for equal partnership

Aims towards policy makers

- Advocating for defending the interests of parents by sharing research insights
- Underlining the urgency of measures for informal carers by sharing experiences from families

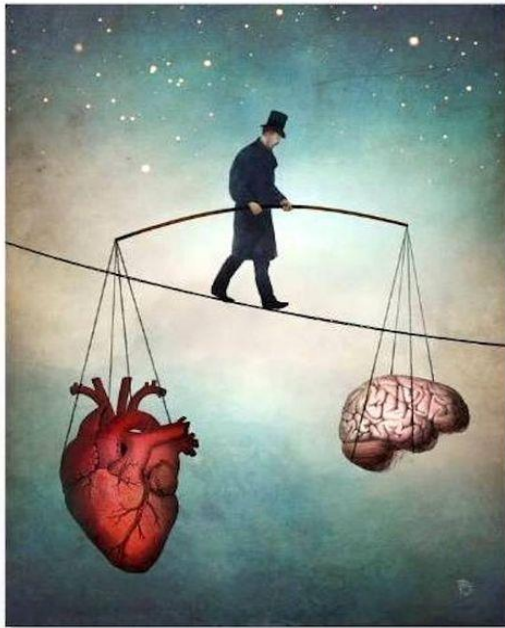


Expertise

Triathlon project: combining care and work (2021-2022)
Recommendations Flemish Informal Care Plan 2022-2027
Respite care
Training courses for the future (Equal Partnership in care 2023)
Different regional, national and international networks

WORK – LIFE – CARE – BALANCE

Parents experience a lot of struggles and challenges



Informal carer – triathlon athlete - endurance sport – combination of several disciplines

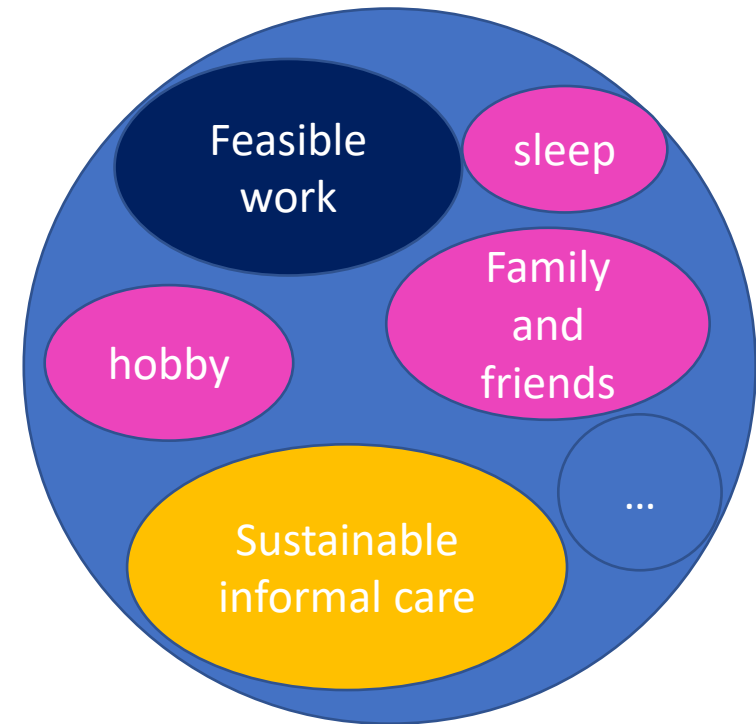
Informal carers at the center

Basic image Triathlon project

Quality of Life of an informal carer = making own choices



Facilitate Sustainable (informal) care and feasible work
And personal quality of life (QOL)



Sustainable care and feasible work are
part of Quality of life

CARING FOR THE CAREGIVER: SELF CARE → Magenta

Workshops

Focus on Care Work Life Balance (CWLB) of the parents
Managerial point of view

Time, energy, resilience

Sharing care

Partnership with professionals

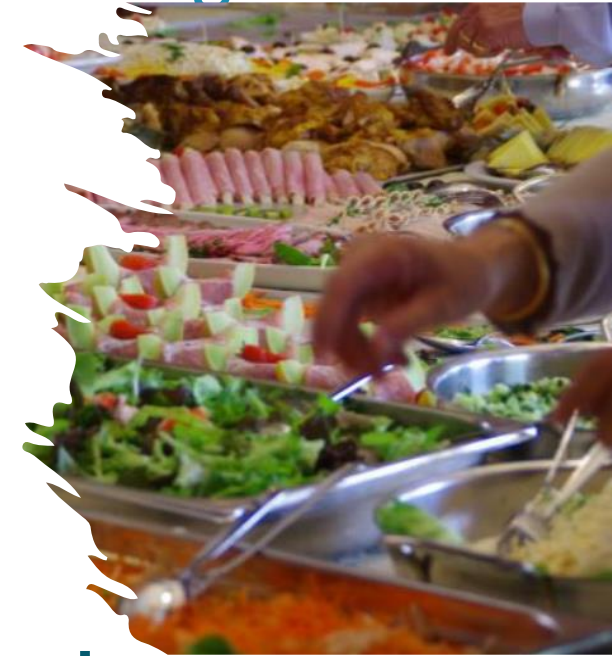
Time management

Delegation

Meeting skills

Exchanging with peers and trainers who are **experts by experience**

- → encouraging parents to act on the basis of their own strengths and wishes and arrive at their own choices and approaches
- “Lotgenoten” = peers/ Other parents



CARING FOR THE CAREGIVER: SUPPORT BY PROFESSIONALS

Professionals in Care Sector

- Sector of disability (institutions, Early childhood intervention services (ECIS), respite care, ngo's...
- regular service providers



Family Quality of Life Framework



Professionals in Career Sector

- Career coaches
- Job coaches
- Employers (HR management, etc.)



Toolbox Magenta

Family Quality of Life

From stress model to a coping model

- Perspective of the family members on their quality of life
- Fulfilment of individual needs of all members
AND
Quality of Family life as a whole
- Dynamic system
- Several dimensions



Family quality of Life

Isaacs et al. (2007)

- Health
- Finances
- Family relations
- Support from others
- **Support from services**
- (Family) Values
- Careers
- Leisure
- Community

Hoffman et al. (2006)

- Physical/material well-being
- Emotional well-being
- Family interaction
- **Disability-Related support**
- Parenting

Long term care and FQOL: Findings Research Bhopti

Compares parents of young children (preschool 0-7) and school-aged children (8-18) both with disabilities in Australia

- Parents are **not prepared** for long-term caring
- Loss of work, lack of time for caregiver health, lack of respite care and interim residential care → detrimental impacts on parents' **long-term well-being** + lower scores on FQOL
- Hardships and challenges of caregivers increase as the child gets older!
- Both groups of parents were unable to return to **work** in the same capacity as before having a child with a disability
- **Supports and services** are important mediating and moderating factors that impacted FQOL in both groups
- Despite the negative experiences, parents describe the FQOL as good or reasonable
- Bhopti, A. Brown, T. & Lentin, P. (2022). [Does family quality of life get better as the years go by? A comparative mixed-methods study between early years and school-aged children with disability in Australia \(wiley.com\)](https://onlinelibrary.wiley.com/doi/10.1111/jocd.12500)

Findings

Parents from young children (0-7)

- Focused on well being of their young child and not focused on their own needs
- Parents think they will have time for themselves when their child gets older
- Parents did not expect services such as ECIS to look after their family needs and were more focused on child-specific outcomes



Findings



Parents from school-aged children (8-18)

- Recognize that they were **child-focused** because it was difficult to see the future and were focused on the progress of child with disability
- Confirm they continue to neglect their own needs and that they are exhausted and unwell
- Many parents are diagnosed with chronic health conditions since early years

Recommendations from Bhopti et al.

→ Professionals need to take responsibility for providing information around the caregiver's **health and well-being** rather than just provide programs that are targeted toward child-focused outcomes

→ *Professionals need to help parents in **advocating** for better support and resources at mainstream schools to enable better inclusion and participation, working towards an equitable society for people with disability*

→ *Access to **respite care** needs to be urgently reviewed and caregivers need to be able to access respite care for a better FQOL*

→ **Policy makers** responsible for service evaluation need to consider **family-focused outcomes** such as FQOL, caregiver health and caregiver capacity building, alongside child-focused goals

CARING FOR THE CAREGIVER: SUPPORT BY PROFESSIONALS

- Tools from Magenta for career coaches and family workers, used by both
- Workshops for professionals
- Career coaches receive a certificate

TOOLBOX : [Online](http://www.loopbaanmetzorg.be/toolbox.html) available (Dutch)
<http://www.loopbaanmetzorg.be/toolbox.html>

Some examples



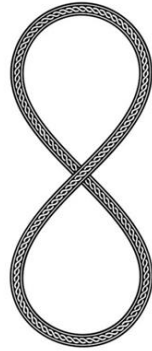
CARING FOR THE CAREGIVER: SUPPORT BY POLICY MAKERS

- Policy makers have direct impact on the life of civilians (care givers) of a country
- And they have indirect impact via their policies and regulations for organisations, companies etc.

- → Recommendations

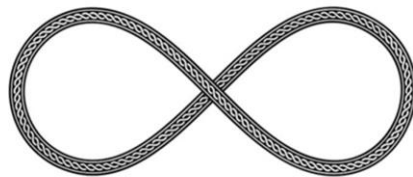


The voice of informal carers



Recommendations

Starting blocks for action



Infinite challenge
Infinite invitation



1. Integrated policy

care and work on equal footing

At this moment far more investments in 'getting people to work' versus 'support people to care'
European Strategies and directives were the first step
→ Now we need Programs focused on (informal) care and balance between work and care



2. Right to make own choices

- Creating the possibility to have a choice as a caregiver
 - *Creating sufficient capacity of professional support and care services
 - *New services (e.g. Respite care at home)



3. Tailored support for informal carers

- Accessible information about:
 - * sharing care
 - * combination of care and work
- Coaching for caregivers (care coaching and career coaching)
- Peer support



4. Time – Leave systems

Carers' leave of five working days per year as a **right**
(Thanks to the European Life-work directive!)

Leave systems are necessary for parents, grandparents, siblings, children

- Flexible systems are necessary
- Funding for appropriate allowance



5. Role of Employers

- Work-life balance part of HR-strategy
 - Tailored solutions with some flexibility
- Example: Small things with big impact (e.g. allow private calls, last minute decision to take a day off)



6. Recognition of informal carers

- Recognize importance of different roles – own quality of life
- Care professionals should be aware that work can be strengthening
- Social protection of informal carers is necessary



7. Invisible tasks of the informal carers

Cares do more than direct support of the person in need, also:

Seek appropriate support - contact (during working hours)

Organising, coordinating, coaching

Submitting applications/ administrative procedures

.....

→ Funding for developing tools and support for these invisible tasks



8. Balance carrying capacity and burden

Peaks in care – Ebs en Flows

Pivotal moment: increased appeal to informal carer

e.g. Parents: transition from adolescent with disability to adult life

Burnout – low energy level

Quitting work and still not catching your breath

→ Prevention: take care of the carers in time!

→ Urgent aid should be available, accessible



A lot of challenges for the carers

A lot of challenges for the Member States

Europe already set out appealing **frameworks** for the future

(work-life balance directive; long term care strategy; focus on children and persons with disabilities),...

→ need for translation in more dedicated **programs** and **calls**

European funding programs focused on **care for caregivers** can help to make it happen

Local and transnational programs: to innovate

to implement and scale up

to share best practices

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