

# Net-Flex

Exploring secondary networks  
of adults with acquired brain injury  
in Flanders

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ARTESIS PLANTIJN  
HOGESCHOOL ANTWERPEN

# Background and purpose

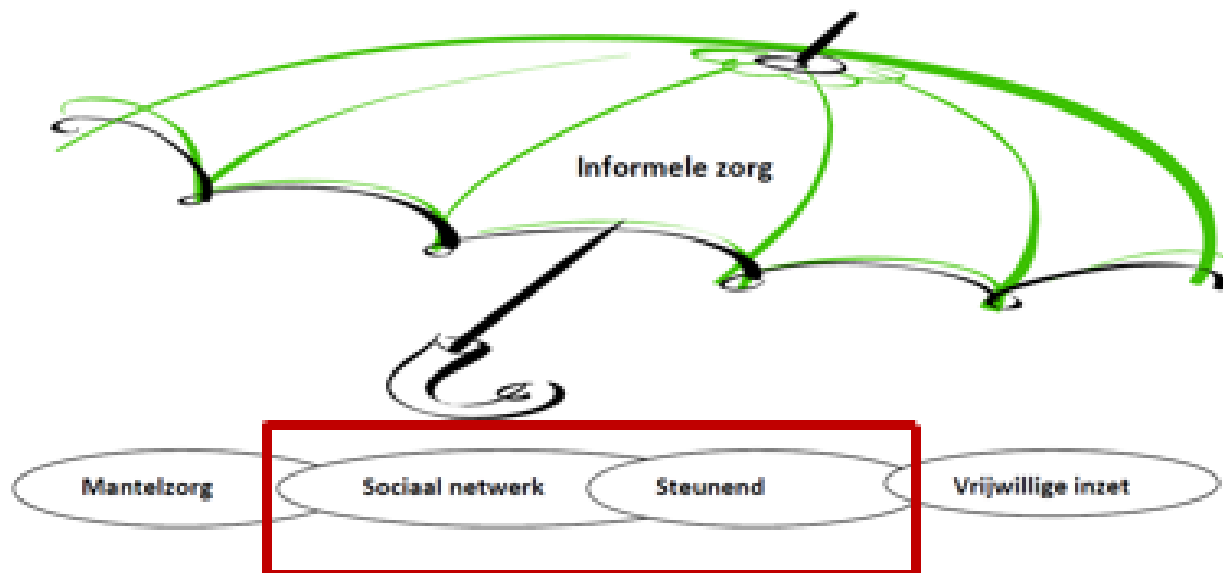
# 'Community Care': stronger commitment of informal care

(policy note Van Deurzen , 2014-2019)

- Disability policy stimulates **the provision of care by the client's own/natural network**
- Policy makers expect that, in addition to professional care, informal care has to be stimulated.
- **Increasing attention** to the strength of social networks

# Informal care as an umbrella term

informal care as an overarching (umbrella) term of all care which is not performed professionally



= key figures, other informal caregivers (the social and support network) and volunteers

# Secondary networks

⇒ focus on “secondary network”

= informal caregivers who somehow play a role in the support of people with disabilities

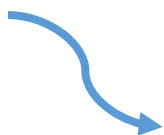
They circulate as a kind of satellite around central person and/ or the primary caregiver

**Expectation government:**

**secondary networks will also be called upon  
and that care providers will activate them**

# Changed care situation

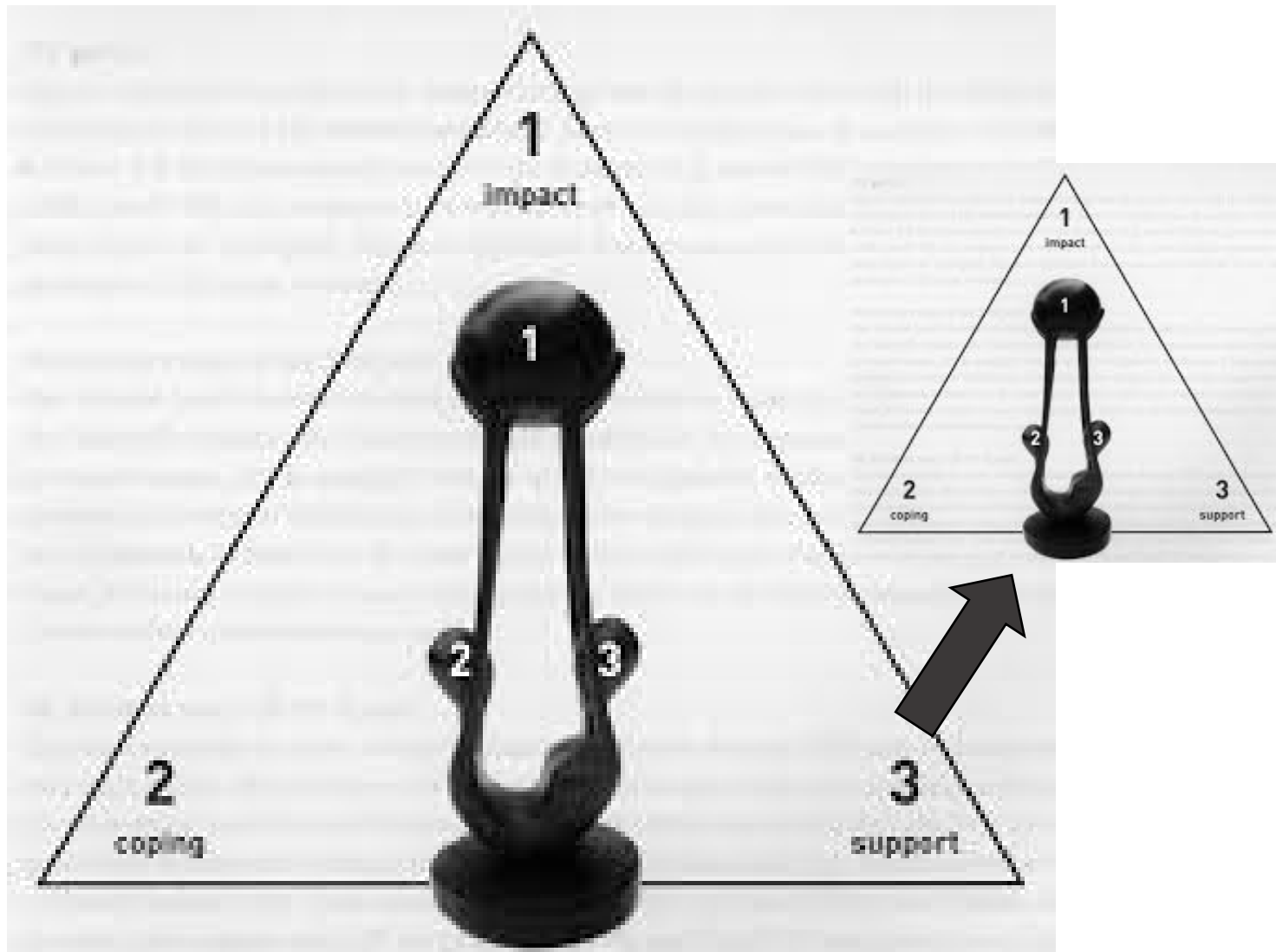
- persons with acquired brain injury : fracture in lifespan



renewed position= care relationship

- Reciprocity no longer in balance: **dependancy**. How to achieve a new balance?
- Need for care leads to an impoverishment of the network (foremost in the chronic fase)

# Changed relationship: triadic process model (de Mönnink, 2018)



# Role/ position of the professional

- The professional caregiver supports the central person (and the primary caregiver).
- Are there expectations from the secondary network towards the professional? If so, which one?
- Should the professional take a role? Is the professional the right person to facilitate networks?

**! What about the spontaneous care based on a relational involvement?**



# Research questions

Our research aims to formulate answers to the following questions:

- What are **motivations, expectations and needs** of secondary networks of adults with acquired brain injury living at home, within current disability policy and practice in Flanders?
- Which **role/position can professionals adopt to facilitate** these secondary networks and which knowledge, skills and attitudes are desired?

# Conceptual framework

## Care system: changed (care)situation

IMPACT

secondary network

SUPPORT

COPING

Context  
Professional

Care  
reciever  
(central  
person)

relational perspective

1. What do I want to do?  
General beliefs
  2. What do I have to do?  
Normative beliefs
  3. What can I do?  
Percieved beliefs
- ⇒ motivations

social perspective

4. What do I need to  
want to?  
Needs and expectations to (want  
to) give support

primary  
caregiver  
(key figure)



Provide support

Context  
Social network

# Methodological framework

# Method: the responsive research methodology

(Abma & Widderhoven, 2006)

- Participative research
  - Active stakeholder involvementat all stages of the research process



- phase 1: exploratory phase
- phase 2: consultation phase
- phase 3: deepening phase
- phase 4: integration phase

- grounded on a social constructivist knowledge theory:
  - poses dialogue on key theme's
  - creates reality in interaction with stakeholders



- Theme 1: Claims
  - Statements in favour of the subject matter
- Theme 2: Concerns
  - Statements unfavourable to the subject matter
- Theme 3: Issues
  - Major issues for discussion

# Preliminary Results

## interviews

# Results

persons from the secondary networks with:

1. A family relationship ( $\neq$  primary informal caregiver)
2. No family relationship (friends, neighbours,...)

**motivations – needs - expectations**

# Preliminary results of the interviews:

## IMPACT



FAMILY	NO FAMILY
<ul style="list-style-type: none"><li>• Care system: WE are confronted with... (no choice)</li><li>• GREAT impact on own life (relationship, leisure time,...)</li><li>• NICE to have pleasant moments</li><li>• Kind of support: mostly CARE-ORIENTED</li></ul>	<ul style="list-style-type: none"><li>• Care system: THEY are confronted with... (own choice)</li><li>• MINIMAL impact on own life, impact on (changed) relationship</li><li>• NECESSARY to have pleasant moments</li><li>• Kind of support: mostly WELL-BEING</li></ul>



# Preliminary results of the interviews: COPING

FAMILY	NO FAMILY
<ul style="list-style-type: none"><li>• <b>More needs towards professional care provider (after first years)</b></li><li>• <b>Need to peer-to-peer contact</b></li><li>• <b>MOTIVATION:</b><ul style="list-style-type: none"><li>➤ <b>Intergenerational solidarity (loyalty: taken for granted)</b></li><li>➤ <b>Guilt/ sense of duty: strong</b></li></ul></li></ul>	<ul style="list-style-type: none"><li>• No needs towards professional support</li><li>• No need to peer-to-peer contact</li><li>• <b>MOTIVATION:</b><ul style="list-style-type: none"><li>➤ Need for reciprocity (satisfaction in support when mutual and the same interests are present)</li><li>➤ Guilt/ sense of duty: less strong</li></ul></li></ul>

# Preliminary results of the interviews: SUPPORT

FAMILY	NO FAMILY
<ul style="list-style-type: none"><li>• Support= <b>NECESSARY</b></li><li>• <b>Towards network:</b> need for understanding their situation, to be able to tell their story, others listening (friends, partner, colleagues)</li><li>• <b>Towards professionals:</b> information, communication, follow-up, involvement</li></ul> <p>⇒ <b>TO MAKE DECISIONS</b></p>  <p><b>need for casemanager</b></p>	<ul style="list-style-type: none"><li>• Support= <b>DESIRABLE</b></li><li>• <b>Towards network:</b> asking understanding for the situation of the central person</li><li>• <b>Towards professionals:</b> information, communication, follow-up, involvement</li></ul> <p>⇒ <b>TO UNDERSTAND</b> the situation</p>  <p><b>need for casemanager</b></p>

# Conclusion

- **Difference** between persons from the secondary network who have a family relationship vs. who have no family relationship
  - **Family relationship**
    - similar to research on primary caregivers
    - Whole family should be invited/involved and/or supported by the professional.
  - **No family relationship**
    - Should they be activated by professionals? (in order to maintain the spontaneous relation between people)

However at this stage of the research process the specificity of the responsive methodology doesn't allow to formulate implications.

## More information:

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