

# SPECIAL INFORMAL CARE

Experiences of informal carers of people with an intellectual disability  
or psychiatric disorder

Research and Development Centre for Society and Law (HvA)  
in partnership with The Netherlands Institute for Social Research (SCP)

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BACKGROUND AND RESEARCH QUESTIONS (SHEETS 3 AND 4)

THREE WAYS IN WHICH THIS INFORMAL CARE IS 'SPECIAL' (SHEET 5)

THE VIEWS ON (THE COOPERATION WITH) PROFESSIONAL CARE WORKERS (SHEETS 6 AND 7)

ABOUT INFORMAL CARERS' SUPPORT NEEDS (SHEET 8)

RECOMMENDATIONS (SHEET 9)



# INFORMAL CARE IN THE NETHERLANDS

3,5 million informal carers;

1,1 million of them: > 8 hours per week, > 3 months

*of 16,7 million people in The Netherlands*

15% provides care to someone with PD, 7% to someone with ID

*compared to 37% to physically disabled and 27% to elderly*

City councils are responsible for support services informal carers

Support services are mainly focused on providing care to the elderly

# TWO RELATED QUESTIONS

1. What is the nature and extent of informal care provided to people with an intellectual disability or psychiatric disorder?

*Secondary analysis on data from national survey of informal carers (SCP 2007), N = 2379 (all informal carers)*

2. What is the need for support among informal carers of people with an intellectual disability or psychiatric disorder?

*53 interviews with representatives of the two groups, in and around Amsterdam (HvA 2010)*

# 'SPECIAL' INFORMAL CARE

Because the two groups (ID and PD):

1. Are different from other informal carers
2. Experience caring for a loved one in a different way
3. Have a different view on professional care

More about 1 and 2 in the summary. Today: focus on 3 

# PROFESSIONAL CARE (GROUP ID)

Mainly positive about professional care:

- Personal experiences with care professionals
- Committed
- Interest for informal caregiver

Some negative experiences:

- Organisation of care (bureaucracy, poor accessibility, number of referrals)
- Level of expertise
- Worries about defrayment

# PROFESSIONAL CARE (GROUP PD)

Mainly negative:

- Not acknowledged (expertise and rights)
- Disappointed in expectations
- Organisation of care

Negative experiences contribute to burden of providing care

Would appreciate arrangements on the division of care tasks

Attitude of professionals (way they approach informal carers) seems of crucial importance

# SUPPORT NEEDS

Heavy burden, small social networks, negative about formal care  
*but: only a small amount of support-users*

Providing care is 'natural'

No need for support or no knowledge about the existence of it

Caregivers who do want / need more support services:

*For themselves: practical support, financial support*

*For their loved ones: more / different / more coherent care*

More involvement in care provided by professionals!



# RECOMMENDATIONS

For policy makers:

- The support that is offered is too general
- Incorporate social network in professional care
- Make support more outreaching
- Focus on interventions to support and activate social networks

For healthcare providers:

- Invest in cooperation between formal and informal care
- Focus on family policy

## MORE INFORMATION AND CONTACT

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Summary of the research report? Just ask..

