

Development of Best Practice Recommendations to enhance access to formal community care services



Actifcare

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Access to timely formal care

Challenges

- People with dementia and their informal carers
 - ➔ often do not receive services of the type and quality that they need
 - ➔ experience difficulty accessing home- and community-based services

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- Access to Timely Formal care (Actifcare)
- EU Joint Programme - Neurodegenerative Disease research (JPND)
- 3 years duration (2014-2016)
- 8 participating countries:
Netherlands, Germany, UK, Sweden, Norway, Ireland, Portugal, Italy



Overall aims - Actifcare

- to better understand access pathways to formal care for people with dementia
- to identify factors that determine the appropriateness of timely access to formal community services at macro and individual levels
- to analyse costs and consequences of access pathways to formal home care
- to evaluate the utility of two recently developed patient and carer outcome measures
- to develop and promote best-practice recommendations

Several research methods

- 2 Literature reviews
- Focus group interviews with:
 - ➔ People with dementia
 - ➔ Informal caregivers
 - ➔ Health care personnel
- Interviews with decision makers
- One-year cohort study
- In-depth interviews with people with dementia and their informal carers
- Evaluation of costs and consequences

Which barriers exist?

Home-dwelling person with dementia

Don't know about existing services

Don't know how to access the services

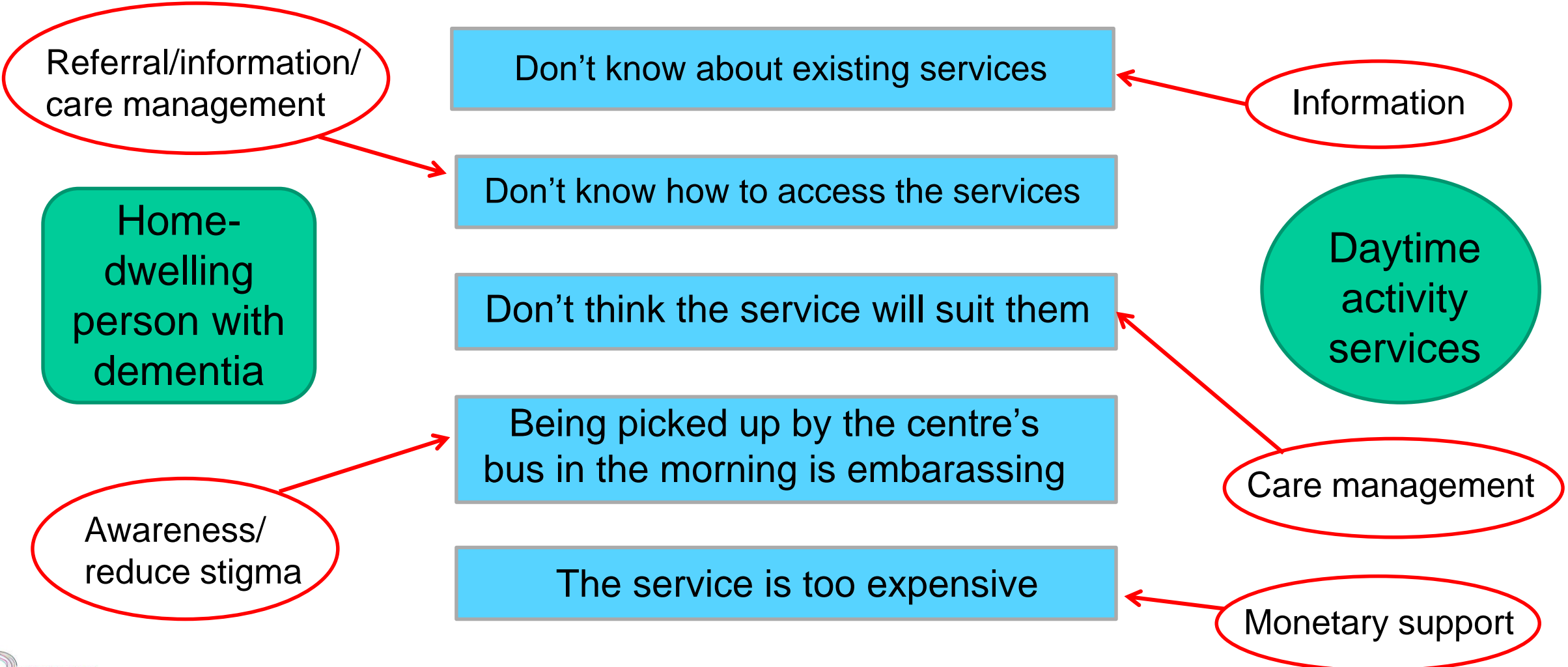
Don't think the service will suit them

Being picked up by the centre's bus in the morning is embarrassing

The service is too expensive

Daytime activity services

Which interventions may help?



Overall aims - Actifcare



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- to analyse costs and consequences of access pathways to formal home care;
- to evaluate the utility of two recently developed patient and carer outcome measures
- **to develop and promote best-practice recommendations**

A Delphi process with 3 rounds

Preparing for Best Practice Recommendations

- Purpose:
To reach consensus on statements considered important enough to be included in the Best Practice Recommendations
- Experts participating in the Delphi-process:
 - ⇒ 5-8 **professional experts** recruited by each national Actifcare team
 - ⇒ 3 **experts by experience** recruited by each national Actifcare team
 - ⇒ 5 **experts by experience** recruited from the European Working Group for People With Dementia

Experts in the Delphi process



- Experts by experience:
 - ➔ People with dementia
 - ➔ Caregivers of people with dementia
 - ➔ Dyads of people with dementia and caregivers participating together
- Professional experts:
 - ➔ Scientific/researcher
 - ➔ Clinical
 - ➔ Administrative/ decision or policy maker

Delphi process – 3 rounds

- **Round 1:**
The Actifcare research teams provided statements about measures which can enhance access to formal care.
- **Round 2:**
The first round of rating, 72 statements (Importance - scale 1 to 7)
 - ➔ Experts by experience (34)
 - ➔ Professional experts (48)
- **Round 3:**
The second round of rating, 44 statements
 - ➔ Experts by experience (29)
 - ➔ Professional experts (42)

Delphi process – Results



- **First rating - 72 statements :**
 - ⇒ 28 statements reached consensus as important (limited range + median of 6 -7)
 - ⇒ 44 statements did not reach consensus and needed to be rated again
- **Second rating – 44 statements:**
 - ⇒ 35 statements reached consensus as important
 - ⇒ 9 statements did not reach consensus

Actifcare Best Practice Recommendations



The next step:

- 23 Best Practice Recommendations were made based on
 - ➔ the statements which reached consensus in the Delphi process
 - ➔ supporting findings from the Actifcare project
 - ➔ other available supporting findings
- The recommendations categorised as:
 - ➔ A. Recommendations to enhance access
 - ➔ B. Recommendations to enhance use
 - ➔ C. Recommendations that can *facilitate* access or use indirectly: enabling factors

Acknowledgement



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- For invaluable feedback in the preparation and phrasing of the accessible statements for experts by experience
- For participating as expert in the Delphi process

Best practice Recommendations



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Thank you for your attention!