The Preferences of Older Self-funders in Navigating Community Social Care

(The PRESENCE study)

Speaker: Rowan Jasper
International Conference on Evidence-based Policy in Long-term Care, September 2022

Background

Adult social care

(a) includes <u>all forms of personal care and other practical assistance</u> for individuals who, by reason of age, illness, disability, pregnancy, childbirth, dependence on alcohol or drugs, or any other similar circumstances, are in need of such care or other assistance, but:

(b) <u>does not include</u> anything provided by an establishment or agency for which Her Majesty's Chief Inspector of Education, Children's Services and Skills is the registration authority under section 5 of the Care Standards Act 2000.

Care Act, 2014

Social Care - a wider definition

Lots of people need help with everyday living as well as social support
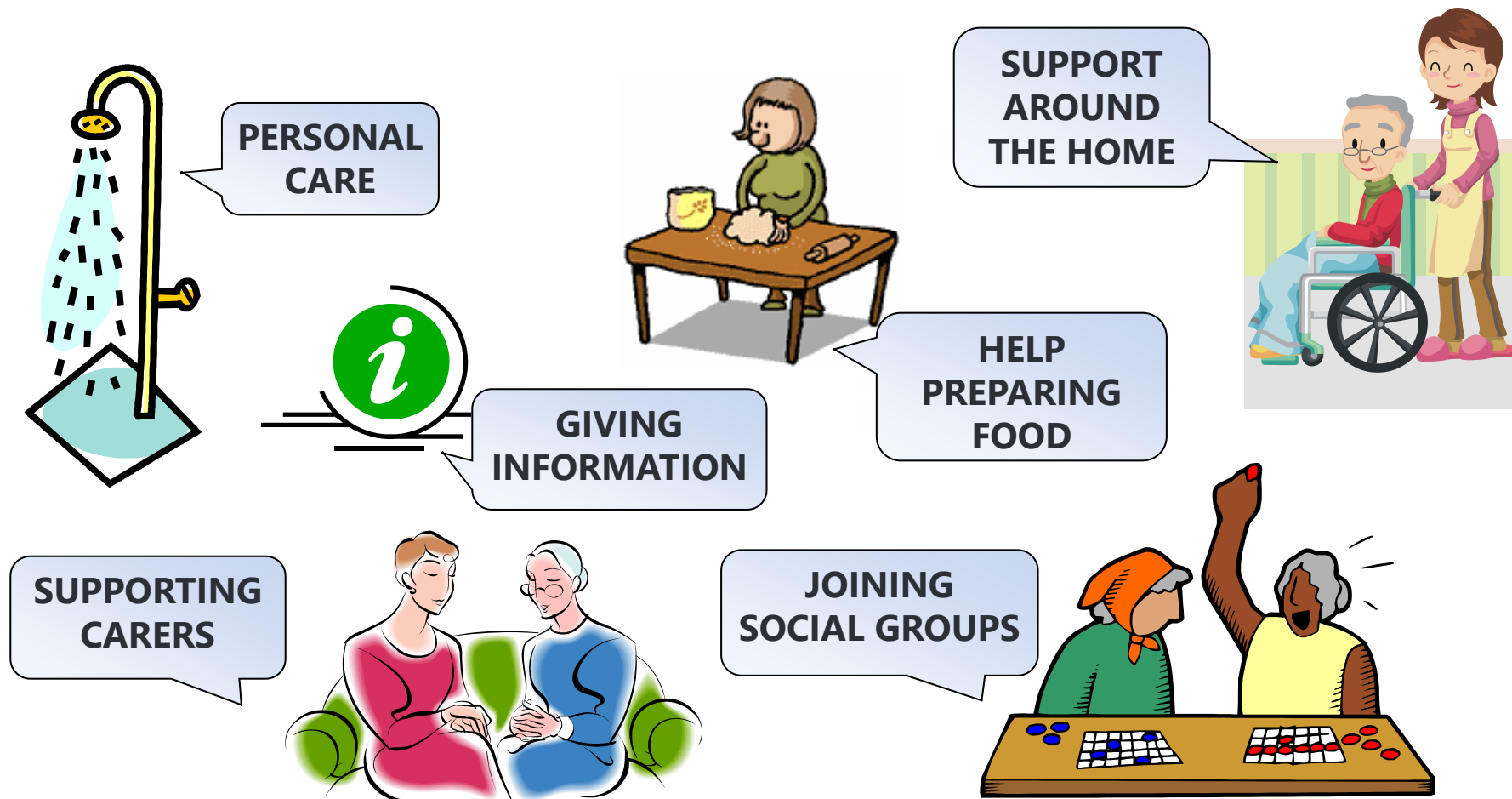
Social Care & Eligibility

- State-funded social care in England is a Local Authority (n=152) service:
    - It is not a universal service (compared to i.e. NHS health care)
    - Eligibility criteria = level of need taking into account savings

- <u>As such, self-funded care is significant</u>– people (and families) who pay privately for their own care are a growing part of the system of care and support, but hard to quantify.

- Most long-term social care provision for **older people (65+)** relies on an element of self-funding
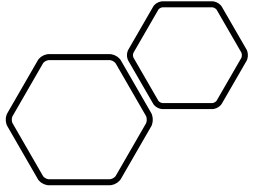
What do we *already* know

1	2	3	4
People feel ill-equipped at the moment they need to arrange their care	Self-funders often go without assessment or discussion of their needs	People tend to stick to decisions made - even if they feel they have made a mistake	Making the 'wrong' decision can sometimes have profound consequences

Some narratives from recent research

Everybody said, "Social Services will help you", and they were very good at first when [my husband] was in hospital. But once they discovered that we had more than £23,000 pounds in the bank …they really didn't want to know.

ROBERT'S WIFE (1)

Well, more by, well, by pure accident. One of my other stepdaughters lived across the road from someone who was managing an agency that provided, not 24-hour care, caring, so we arranged to try this person for nights.

ISABEL (1)

Older people:
Care and Self-funding
Experiences

Research Report and Findings

Lizzie Ward, Mo Ray and Denise Tanner

What do we know less about?

- How people want to be helped when navigating the care system
- Their willingness to pay for such help
- How to serve people who want to be supported in different ways
- How people make decisions

The PRESENCE study

Lots of self-funders are left to 'go it alone', making some very important decisions they have not considered before, and often at quite a troubling time of life.

What can we do to make things better?

Study aims

1. What do 'self-funders' most value when seeking, choosing and arranging their social care?

2. How do different groups of self-funders make their decisions"?

Study Methodology

A discrete choice experiment (DCE) survey of preferences in being supported when finding care (using a navigation service to help them) n=182

Qualitative interviews to examine how different approaches to finding care are linked to decision-making (n=37)

Discrete Choice Experiment (DCE) development

Developing our DCE

- Previous research

- Service user and carer group

- Advisory group

- Think aloud interviews

- DCE finalised late Summer 2020

spru | Social Policy Research Unit

UNIVERSITY of York

The Preferences of Older Self-funders in Navigating Community Social Care
(The PRESENCE study)

Do you have experience of looking for social care which is paid for privately, either for yourself or someone else living in their own home? Or perhaps you are thinking about your care needs in the future?

This research study is trying to understand what support people like you might find helpful when looking for care and making your choices.

This study will take **about 20 minutes** to complete, and there is an opportunity to enter a prize draw to receive a £20 high street voucher for your time.

If you would like support to complete this or have any questions please call Rowan Jasper on 07385 341573.

DCE Attribute summary

- The nature and type of support that the navigation service provided (1-4)
- Navigation service design features (5-7)
- How much respondents would be willing to pay for each navigation service (8)

1. Information about quality
2. Information about finances
3. Information about availability
4. Help to 'think things through'
5. Who will help me?
6. What organisation runs it?
7. Waiting time
8. Cost to you

If you were organising social care, which of these navigation services would you use?

|	Navigation Service A	Navigation Service B	No Navigation Service
Information about quality	Not provided	Provides detailed information on the quality of care provision	I would not use a navigation service and find care myself
Information about finances	Not provided	Provides information about how to manage your finances to meet the cost of care	
Information about availability	Not provided	Provides up-to-date information on which care providers have availability	
Help to "think things through"	Provides help by talking you through the things you need to think about when making choices	Not provided	
Who will help me?	One person you do get to know	Several people you do not get to know	
What organisation runs it?	The local authority	A local, private sector organisation	
Waiting time	You will have to wait a few weeks	Available immediately	
Cost	£0 (free)	£600	
	☐	☐	☐

DCE Recruitment (during Covid-19)

Range of sources, including:
- Local community organisations
- Domiciliary care providers
- Hull City Council People's Panel
- Existing research studies
- Care navigation and independent provider organisations
- Involvement@York

DCE respondent characteristics (n=182)
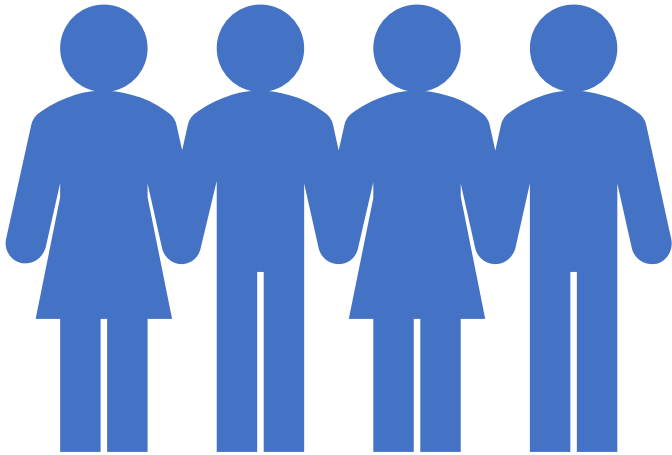
Two-thirds: female

Almost all: white British

Average age: 68 years old

All regions represented across England
- Majority Yorkshire and Humberside

Two-fifths were family members

A smaller number (11%) were older people
- Of this group, four-fifths entirely paid for care themselves

People who may need care in the future (46%)
- Almost all had a long-term health condition

Attributes	Willingness to pay (£)
Information about quality	285
Help with finances	198
Information about availability	192
Help organising appropriate care	212
Information from one person (ref: vs information from multiple people)	130
Council provides service	-10
Charity provides service	59
Private company provides service	-49
Service available immediately (ref: vs wait a few weeks)	69
Cost of the service	-
Constant	-58
No. of individuals	

DCE findings

Generally, most self-funders were willing to pay for help with care navigation.

Self-funders valued what navigation support was on offer, more than how it was provided.

Information about quality, and help to 'think things through' were the most important features of navigation support
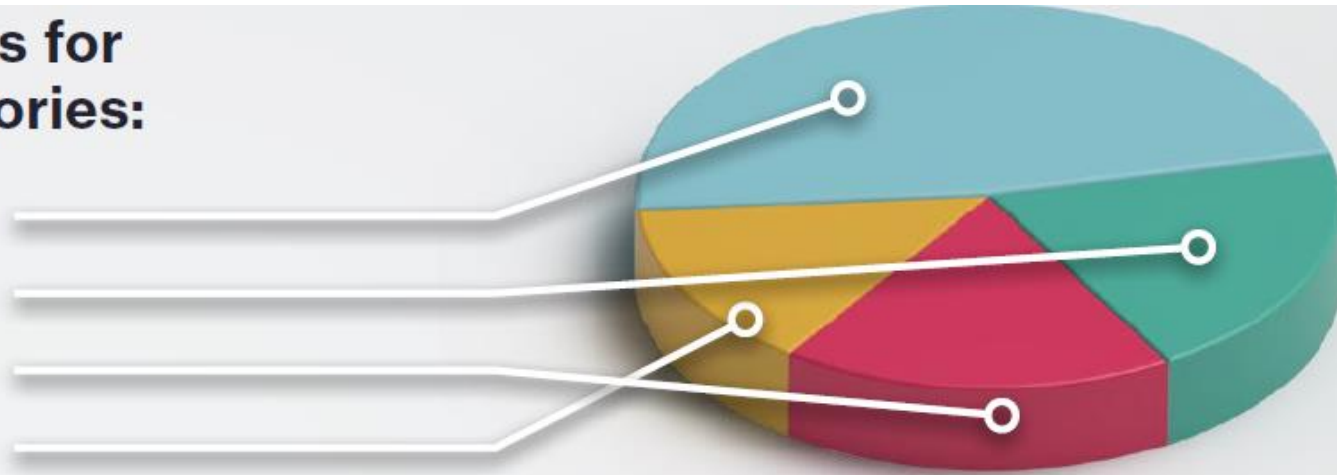
Groups of self-funders with similar preferences

The study found that people's preferences for care navigation fell into one of four categories:

- **48%** wanted comprehensive help and were willing to pay
- **20%** wanted fast access to information
- **18%** wanted affordable help to 'think things through'
- **14%** just wanted information from their local council.

Early PRESENCE findings presented via poster at The Curiosity Partnership launch event, July 2022

Qualitative Interviews

Aims

To explore and examine how people make decisions when arranging community-based care

- How are 'decisions' made?
- What factors influence decisions and how?
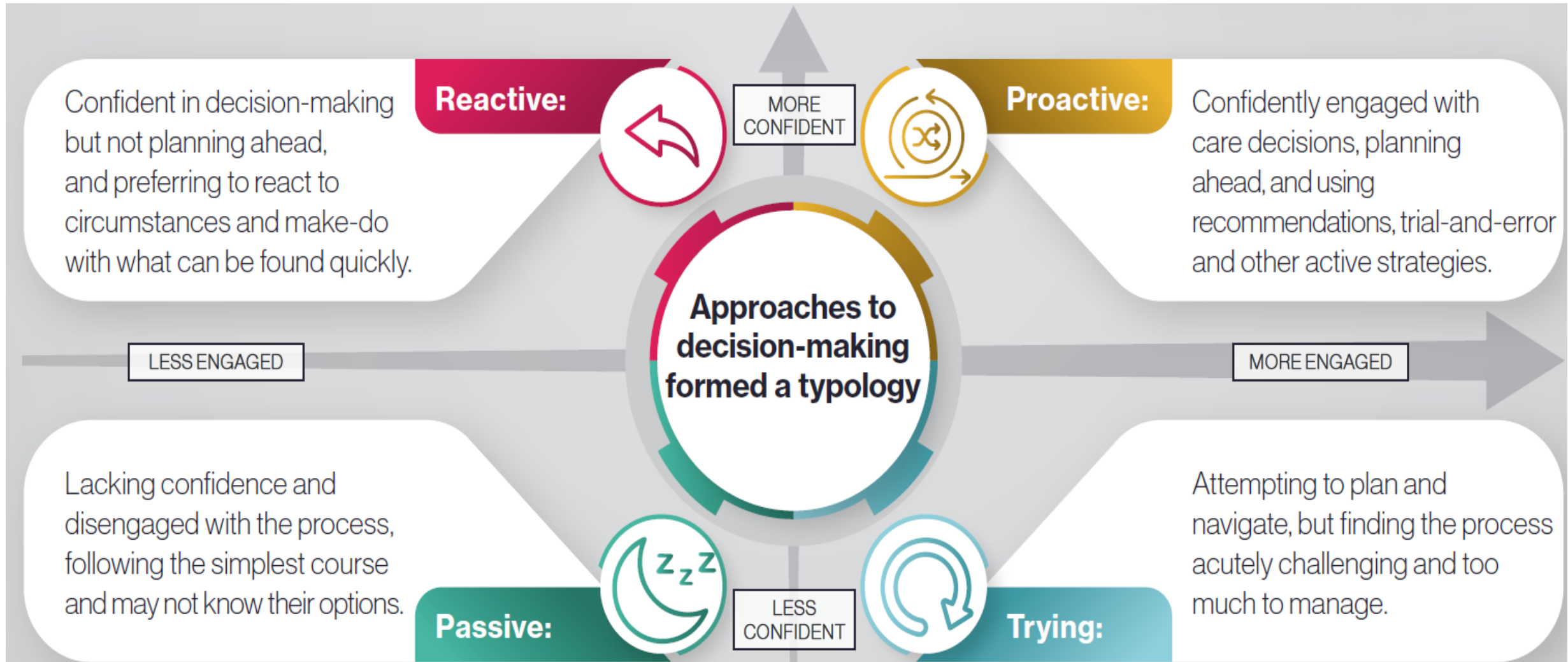
Methods

Interviews (n=37) conducted over Zoom or by phone

Analysis:

- One-page summaries
- Full coding – themes/framework
- Using existing theories on decision making
- Typologies developed around how people make decisions when navigating care

Findings

Reactive: Confident in decision-making but not planning ahead, and preferring to react to circumstances and make-do with what can be found quickly.

Proactive: Confidently engaged with care decisions, planning ahead, and using recommendations, trial-and-error and other active strategies.

Passive: Lacking confidence and disengaged with the process, following the simplest course and may not know their options.

Trying: Attempting to plan and navigate, but finding the process acutely challenging and too much to manage.

MORE CONFIDENT

LESS CONFIDENT

LESS ENGAGED

MORE ENGAGED

Approaches to decision-making formed a typology

Further qualitative findings

Managing the process was far easier where people had 'navigation capital' such as:

Experience of working in public services

Had a supportive family network

Experience of advocating on behalf of others

Had sources of recommendations

What have we ascertained so far…

- People who pay privately for social care (self-funders) prefer help to navigate the care system.

- People tend to value 'what' navigational support is available, over 'how' it is provided.

- If councils made 'navigation services' available to self-funders, most would be prepared to pay a fee.

- People approach the decisions around care in different ways.

- Some people are in a much better starting point than others in navigating social care.

Acknowledgments

Research to make a difference in the real world.

Thank you for listening. Any questions?

Contact details: rowan.jasper@york.ac.uk
@RowanEJasper