



Managing money in later life: mental capacity assessment and support

Final report

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Main messages

- In this study, we explored how social care/social sector professionals, older people and their families address the challenge of declining mental capacity to manage money in later life.
- The ability to manage money is vital for independent living, but is highly sensitive to changes in thinking and reasoning skills, which particularly affect older people. In England and Wales, the Mental Capacity Act 2005 (MCA) provides the legal framework for determining someone's ability to make decisions, but it is unclear how useful it is to assess financial decision-making ability.
- We interviewed 28 social care/social sector professionals, and 13 older people/family members, to explore their experiences of support for older people to manage money. We focused on how challenges in managing money are identified, and what support is available. We also looked at information resources to guide professionals and the public.
- Judgements about someone's capacity to manage money tend to be made informally and generally. There is a lack of formal, detailed assessment of specific aspects of money management according to the MCA.
- Knowledge about legal issues and procedures regarding mental capacity and money management are highly variable, among professionals and the public. There is a lack of training for professionals in applying the MCA in the context of financial decision-making and in how to provide appropriate and timely support for people with day-to-day money management.
- Professionals often feel uncomfortable in raising the topic of money management and in providing support to older people. There is a lack of clear roles and responsibilities around assessment and support. There is an emphasis on signposting people to other sources of information, aligned with an approach to care that focuses on empowering people to make decisions for themselves. Given the generally poor financial literacy levels in the population, it is not clear how far this approach is empowering in this particular context.
- Managing money is extremely personal and emotional, both for older people who
 may be experiencing difficulties and for people who are attempting to provide
 support. There is limited recognition of this in the available information resources,
 which focus more on procedures such as how to set up Lasting Power of
 Attorney.
- There is a need for a dedicated strategy for the topic of mental capacity and personal finances within the social sector. This should contain greater clarity around roles, responsibilities and support. It should also advance a more sophisticated approach to training about mental capacity in the context of managing money that is realistic, context-specific and embedded as core training. Development of training and support approaches may benefit from co-production with older adults and unpaid carers.

Executive summary

Context

This research focuses on what happens when older people experience difficulties in managing their money. The ability to manage money is one of the most important skills a person needs to be independent, but many people lack financial skills and understanding. It is particularly important for older people, who in addition to managing day-to-day finances, are required to make major financial decisions associated with later life. However, the ability to manage money is highly sensitive to changes in thinking and reasoning skills, which may occur naturally through ageing, or through illnesses such as dementia that tend to occur later in life. These changes are stigmatised and often hidden by families. People who struggle to manage their own money are particularly vulnerable to financial abuse. We know very little about how older people who may be experiencing cognitive decline are supported to manage their money.

In this study, we aimed to explore how social care/social sector professionals, older people and their families attempt to address challenges in managing money.^a Over the last two decades, there has been interest worldwide from policymakers and researchers in the financial capability of older people. This is an increasingly critical topic for the United Kingdom, where there are rising numbers of people with cognitive impairment and dementia in a population that is ageing and becoming more diverse. Older people are required to interact with financial products and services at later and later ages. This is because of a proliferation of increasingly complex products and services, and the rise in scammers; but also because of key policy changes such as the ability to cash in pensions at age 55. In the last 20 years, there have been substantial changes in the ways that financial services are presented and sold to consumers, including the dominance of telephone and online methods of communication, and digital apps. Some older people are unwilling or unable to use digital technologies and are sceptical about the safety of online banking. As we expect individuals to manage ever more complex financial decisions until the end of life, concerning housing (including equity release), income, savings, pensions, debt, benefits and the costs of care and health, it is vital to understand what happens if older people start to experience difficulties with managing money.

Since 2007, the Mental Capacity Act 2005 (MCA) provides the framework for determining someone's ability to make decisions and how to make decisions for those that are unable to decide. Capacity must be assumed at the outset and any assessment of capacity is decision and time specific. Managing money involves a broad range of decisions and skills; in practice, a person may have the capacity to buy a pint of milk for their breakfast but could struggle to enter a pension investment

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^a We use the terms 'social care' and 'social sector' in a broad sense to refer to the range of nonclinical support services available outside the National Health Service. This includes local authority adult social care services, other public and private sector roles and organisations such as housing associations, charities and private care providers.

plan. A person with cognitive decline may understand the decision that must be made and be able to make the decision ('decisional capacity') but may not have the ability to carry out the decision in practice ('executional capacity'). Since the enactment of the MCA, there has been considerable debate about the relationship between the law and people with cognitive decline. This discussion has principally focused on the loss of capabilities to make medical, social care and welfare decisions. The ability to make financial decisions has largely been ignored. In health and social care, MCA knowledge and practice is patchy and irregular, marked by inconsistencies and substantial gaps in support. In the context of dementia, post-diagnostic support with financial management is a major area of unmet need, as over a third of people are not offered any discussion about financial-legal aspects of future planning such as Lasting Power of Attorney.

Aims and approach

This study had three aims. The first aim was to identify the professional and public information resources that are available to guide assessment and support to manage money. We searched the websites of major relevant national organisations relating to health, ageing and consumer/money advice, and relevant occupational groups. We extracted key information about how declining mental capacity and personal finances is presented in the resources that we identified. The second aim was to explore the experiences of social care/social sector professionals, older people and their families of this topic. We spoke to people in Greater Manchester between October 2021 and October 2022. We interviewed 28 professionals working in a range of roles in local authority, private sector and charity/non-profit organisations that provide support for older people. We interviewed 13 older people and/or family members with experience of supporting an older relative to manage their money. We analysed the interviews by looking for key themes. The third aim was to look at how the information resources and interview themes came together into a bigger picture.

We consulted extensively with members of the public before and during the study. The initial idea was explored in 2019 with 52 older people and care professionals. During the study, we were supported by an advisory group of seven people with personal experience in the topic area.

Findings

We identified four main themes, relating to (i) the **identification** of problems with capacity to manage personal finances, (ii) the complexities of the **law and procedures** in this area, (iii) the **support** that is available to people, and (iv) the role of **emotions** in managing money.

In summary, formal and detailed assessment relating to specific aspects of money management appear to be lacking, and judgements about someone's ability to manage money are often made informally and based on general impressions of ability to live well. Understandings of legal issues and procedures regarding mental

capacity and money management appear to be highly variable among the public and professionals. This highlights the challenges of developing both a factual understanding of laws and procedures, and a sophisticated understanding of how to navigate support. There is a lack of training for professionals in the application of the MCA to financial decision-making. There is a lack of clarity around roles and responsibilities for providing support to older people to manage money, and a reluctance of professionals to become involved. The support available often takes the form of signposting to other sources of advice, under an approach to care which seeks to empower people to make decisions for themselves. Given the generally limited levels of financial literacy at a population level and the difficulties leading to the referral, it is not clear how far this approach is empowering in this context. Underpinning behaviours in relation to money are a deeply complex array of emotions, both for those who are yielding control of money management and those providing support – either family or professional.

In the public information resources, there is some recognition of the complexity of what is meant by capacity to manage money, but it is often portrayed as one overall skill with a clear threshold of competence (e.g., 'when a person can no longer manage their money'), whereas in reality, it involves different types of decisions that require different levels of capacity. Lasting Power of Attorney is usually presented as being a safety net in place for 'when it is needed'. This implies that all involved will be able to identify this moment and will agree that it has arrived. There is very little indication that people may change their perspectives, or that progressive cognitive decline may cause people to become in denial that they are experiencing difficulties, or suspicious of their relatives to whom they have previously granted Power of Attorney. There is also little in the documentation to suggest that the role of surrogate decision-maker may be challenging. Although appointing surrogate decision-makers is acknowledged as being a potentially difficult conversation, it is then presented in terms of processes that are supposed to happen (i.e., once Lasting Power of Attorney is registered, the attorney will be able to interact with financial institutions seamlessly). There is little advance warning for people that these processes may not always work as they should and that it may be an extremely demanding experience, within families and externally.

In the professional resources, overall there is a lack of clarity about how people's capacity to manage money should be assessed and how people may be supported to manage money. In general, the topic of personal finances is explicitly mentioned under safeguarding and financial exploitation, and is alluded to in more general discussions of person-centred care. Given the centrality of managing money to social functioning, and the known sensitivity of money management skills to cognitive decline, it is surprising that the topic is not explicitly addressed in detail around daily support, particularly when there is detail on other specific aspects of care such as nutrition and medicine. The emphasis on signposting mentioned by many of the participants in this study aligns with practice guidance. However, given the complexities of finance, the extent to which signposting genuinely represents the empowerment and support for autonomy that is in so much of the practice guidance is not clear.

Multiple combinations of the four themes exist, for example:

- i. The lack of formal, specific assessment ('identification') may be related to a lack of clear legal understanding among the majority of professionals who see themselves as unqualified to make this assessment ('law and procedures') or as not responsible for practical support ('support').
- ii. The lack of formal, specific assessment ('identification') may be related to the deeply personal nature of money and the threat posed by the implications that one does not have capacity ('emotions').
- iii. The emphasis on signposting people to other sources of information ('support') may be justified by an empowerment ethos but also may arise in part from professional discomfort and reluctance to become involved in the topic of money management ('emotions'). The extent to which signposting constitutes empowerment in the context of managing money ('support') is debatable given the complexity of the area ('law and procedures') and the emotional labour involved in decision-making and surrogate decision-making around money ('emotions').
- iv. The emphasis on bureaucratic procedural fidelity—and misunderstandings—by some financial and consumer organisations ('law and procedures') may be insensitive to people's experiences of taking on responsibility for managing the finances of someone who has lost capacity, which may be extremely distressing, frustrating, and difficult to manage ('emotions').

Conclusions

There is a need for:

- A dedicated and proactive strategy for the topic of financial capacity within the
 social sector to ensure timely support that may prevent crises. Such strategy
 should contain greater clarity around roles, responsibilities and approaches to
 the provision of support, including greater attention on advocacy services.
 Strategy development may benefit from a multi-agency approach involving the
 social, legal, debt and financial services sectors to enable critical
 consideration of what support the social sector can provide that does not
 extend into the domain of regulated financial advice, and also what constitutes
 regulated financial advice in this context.
- Better training for professionals in a wide range of social care and social sector roles regarding financial capacity assessment and support. Training should be realistic, context-specific and embedded as core training, and be able to address issues of fluctuating capacity. It should involve older people in its design and delivery.
- More concise and accessible information about the key issues regarding financial capacity and surrogate decision-making.
- More support to be available to people regarding the practicalities of day-today money management.
- More explicit recognition of the emotions that underpin (surrogate) financial decision-making, and the likelihood that decision-making and acting on someone's behalf will not necessarily be straightforward.

1. Context

1.1 Introduction

This research focuses on what happens when older people experience difficulties in managing their money. The ability to manage money is one of the most important skills a person needs to be an independent member of society, but many people lack the necessary skills and understanding, and over-estimate their own abilities. It is particularly important for older people, who in addition to managing day-to-day finances, are required to make major financial decisions associated with later life. However, the ability to manage money is highly sensitive to changes in thinking and reasoning skills, which may occur naturally through ageing, or through illnesses that are more common in later life. These changes are stigmatised and often hidden by families. People who struggle to manage their own money are particularly vulnerable to financial abuse. We know very little about how older people who may be experiencing cognitive decline are supported to manage their money. We aimed to explore how social care/social sector professionals, older people and their families attempt to address these challenges, and how older people and families can be supported.

Box 1. Terminology used in this report

Financial capability: the ability to manage money well. It refers to skills and attitudes that are necessary for successful management of personal finances throughout life, both day-to-day and in being prepared for the future.¹

Mental capacity: the ability to make and communicate decisions. Someone may lack mental capacity if they cannot understand, remember or weigh up information to make a decision, or communicate their decision.²

Financial capacity: the relationship between financial capability and mental capacity; the extent to which someone has the mental capacity to manage their money.

Mental Capacity Act 2005 (MCA): the legal framework in England and Wales for determining someone's ability to make decisions and how to make decisions for those who are unable to decide for themselves.

Social care/social sector: the broad range of non-clinical support services available outside the National Health Service. This includes local authority adult social care services, other public sector roles and social sector organisations such as housing associations, charities, voluntary sector organisations and private care providers.

This report is structured as follows: this first section provides the study context, outlining the financial capability agenda, the legal framework of the MCA, relevant research in a health and care context, and the overall aim of our study; section two describes the approach and methods used in the study; section three presents the study findings; section four discusses the implications of the findings; section five concludes with suggestions for further research.

1.2 Financial capability agenda

Over the last two decades there has been interest worldwide from policymakers and academics in the financial capability of populations, with increasing interest in financial capability at older ages. Financial capabilities in later life are becoming more critical for the United Kingdom, principally due to four factors. First, population ageing: not only the well documented increase in proportions of the population over 65, but the proportion of the population over 85 is growing at the fastest rate.³ Around 42 percent of those aged 75 and over live alone. Two-thirds of those over 75 living alone are women, 4,5 who are at greater risk of financial disadvantage than men because of a more varied life course that may have included part-time working and breaks from paid work.6 Second, ageing populations without disease and illness may itself bring societal challenges, but in addition, the incidence of undiagnosed and diagnosed cognitive impairment and dementia is increasing as the numbers of people over 75 increase. In the United Kingdom, we anticipate population growth of people aged 75 and above from 5.8 million (8.6 percent of the population) in 2020 to 9.7 million (13.7 percent) by 2045.3 Between 850,000 and 1 million people currently have a dementia diagnosis, of whom 60 percent live in the community. Moreover, the National Health Service estimates that approximately 40 percent of people with dementia remain undiagnosed.8 Third, the necessity for older people to interact with financial products and financial services at later and later ages is increasing all the time. This is because of a proliferation of products and services, increasing complexity in the financial services market, and the rise in scammers; but also because of key policy changes such as the ability to cash in pensions at age 55, which then need to be managed for the rest of a person's life, and changes to the ways that pensions can be drawn down and invested.9 An estimated £45 billion has been cashed in from pension funds since this policy was introduced in 2015.10 Funding late life care as life expectancy is extended has also become a critical issue and is laden with increasing complexity. Fourth, there have been substantial changes in the last 20 years in the ways that financial services are presented and sold to consumers and how people are expected to interact with and use them. These include, amongst other things, the prevalence of telephone and online methods of communication, and the increased use of websites and digital apps on smartphones and mobile devices.

Greater knowledge is urgently needed, therefore, about how cognition and ageing impact on people in financial domains, and how to build resilience against problems in these arenas. This is to ensure optimal outcomes for individuals and their families, inform government policy, understand how best to protect consumers, and inform the

ways that markets for financial products and services work competitively and efficiently to the benefit of people of all ages. This issue is one of great complexity, requiring a multi-disciplinary understanding. For example, vulnerability to financial abuse and scams is known to depend on biological (changes in cognition), social (e.g., degree of social vulnerability) and contextual (e.g., the kind of transaction) factors. Ta-15

This complexity is then compounded by a number of further factors. Financial capability in the population at large varies greatly and so as people age, they are not all starting from the same base. Government research on UK financial capability suggests that most of the population, of all ages, have limited financial skills. ¹⁶ Furthermore, the ageing brain and its functioning, under normal ageing conditions, and the progression of diseases such as dementia, may affect people's abilities and interactions with money: loss of financial skills may be one of the earliest cognitive domains to decline, well before – potentially years before – any formal interactions with health professionals or diagnoses. ¹⁷ Then, cognitive ageing may interact with other health problems associated with ageing, such as illness, mobility problems, pain, and vision and hearing loss, thus creating particular problems in the delivery of financial services, the protection of consumers, and achieving optimal financial outcomes for individuals and their families.

The psychological and social context for cognitive change is known to be critical in determining outcomes. Interactions with money in later life depend on psychological factors such as personality (e.g., are you the sort of person who plans things), how prior experiences shape your attitudes to money (e.g., your parents' attitudes to money, whether you had children, got divorced, etc.), whether you have experience of handling money, are confident about it, and so on; and social factors such as family circumstances (e.g., having adult children, widowhood), living arrangements, social isolation, gender, and cultural attitudes to money. 18-21 But how we deal with money in late life and as we age also depends on how finance for later life is structured by government and the markets, for example, if people need to manage their own pensions and savings, they require far more financial competencies as they age than if defined benefit pensions are provided by the government or former employers. In the UK, as we increasingly expect individuals to manage ever more complex financial decisions until the end of life concerning housing (including equity release), income, savings, pensions, debt, benefits, and the costs of care and health,²² understanding what happens if difficulties start to occur with financial management is an increasingly critical endeavour, with implications for the law and for supportive practice.

1.3 Legal context of the Mental Capacity Act 2005

Since 2007, the Mental Capacity Act 2005 (MCA) provides the framework for determining someone's ability to make decisions and how to make decisions for those that are unable to decide. It provides a legal framework for decision-making in respect of health and welfare decisions and for decisions in respect of property and financial affairs. The legislation is guided by five key principles that those working

within health and social care must abide by.^{23,24} Capacity must be assumed at the outset; all practicable steps to help a person decide must be taken before incapacity is established; unwise or bizarre decisions are not indicative of incapacity; all decisions or acts undertaken on behalf of a person who lacks capacity must be done, or made, in their best interests; and a least restrictive approach minimising the impact on a person's rights and freedoms of action should be adopted.

The MCA endorses a functional approach to capacity.²⁵ Under this approach, a person is not deemed capacitated or incapacitated, but rather, that decision-making capacity fluctuates and any assessment of capacity is decision and time specific.^{26,27} In practice, a person may have the capacity to buy a pint of milk for their breakfast but could struggle to enter a pension investment plan. An important distinction drawn here is between 'decisional' capacity and 'executional' capacity. A person with cognitive decline may understand the decision that must be made and be able to make the decision (decisional capacity) but may not have the ability to carry out the decision in practice (executional capacity). Within the context of financial capacity, decisions regarding the running of a household, paying for care or services and avoiding debt may become increasingly more difficult with declining cognition.²⁸ The assessment of capacity to make a particular decision maximises a person's decisionmaking freedom, while also affording appropriate protection when needed. The functional approach encourages the provision of full support to enable a person to maximise their ability to make the decision themselves or participate in the decisionmaking process. When a person is deemed incapacitated, a proxy decision is made in their best interests.

Incapacity is assessed using a two-stage test under the MCA. The diagnostic test asks whether the person has an impairment of their mind or brain through illness or other external factors. This is then followed by the functional test which asks whether the impairment prevents the person from making specific decisions when they need to. The MCA sets down that if a person cannot understand information they receive, retain the information to enable them to make a decision, weigh up the information or communicate their decision, then they are unable to make their own decision and a proxy would step in. While this test has given some focus to the task of assessing capacity, it remains far from straightforward in practice.^{29,30}

Since the enactment of the MCA, considerable academic and policy debate relating to the relationship between law and people with cognitive decline has emerged. This discussion has principally focused on the loss of capabilities to make medical, social care and welfare decisions. Financial capacity has largely been ignored within the jurisprudence. This presents very serious implications for those with declining cognition, their families and those providing care, not least because the financial landscape has become increasingly complex and difficult to navigate.

Inherent challenges lie within the MCA framework and its implementation, as it relies on the use of alternative, non-judicial capacity assessors. Administratively, this makes the MCA far more cost-effective and user-friendly, but reliance on these types of assessors can only be justified if they understand the legislation and have the skills to undertake a mental capacity assessment effectively. The risks attached to

an inadequate assessment are significant, not least that a person with cognitive decline could have their decision-making choices removed from them illegally, or that they are not given the necessary protection that the MCA seeks to offer. Failure to identify or assess the financial capacity of a person with cognitive decline reinforces existing vulnerabilities and hampers the overall effectiveness of the law.

1.4 The MCA and financial capacity in health and social care

The majority of capacity assessments occur in clinical settings with decisions around medical issues. Decisions that have serious consequences will typically lead to a doctor or other healthcare practitioner undertaking the mental capacity assessment.³¹ However, health and care practitioners face difficulties when trying to carry out the 'legal task of capacity assessment'³¹ and the challenge of operationalising a normative process that is influenced by assessor biases. Although the MCA has been a very welcome development, knowledge and practice is patchy and irregular, with practitioners finding it difficult to translate its principles into their specific areas of practice.^{32–34} There may be a reluctance among practitioners to conduct capacity assessments, confusion over responsibility,³⁵ and concerns that subjective, value-based judgements are lent pseudo-objectivity by the language of the MCA.³⁶ Overall, there is a need for more opportunity for practitioners to engage with the MCA in their specific care contexts, and for more research into methods to implement MCA principles in practice.³⁷

Research into capacity for financial decision-making is lacking. The little research on financial capacity assessment has mainly investigated responses to financial abuse of older people. The MCA has been shown to be of limited use to practitioners working with people with mild dementia who lacked vigilance to exploitation but retained ability to make financial decisions in the moment.³⁸ Care staff may find it challenging to balance the right of people to make unwise financial decisions against the need to protect people from undue influence from another person.³⁹ It is not clear how these intricacies are accounted for in financial capacity assessments and support, or in staff training and skills development. Support staff may feel better able to assist people with day-to-day matters such as purchasing toiletries, but find more complex legal-financial aspects like wills and Lasting Power of Attorney very challenging, partly because they themselves lack understanding of these issues in their own lives. 40 Most recently, the Alzheimer's Society's June 2022 report 'Left to Cope Alone' highlighted that post-diagnostic support around financial management is a major area of unmet need among people with dementia and their carers: over a third of people are not offered any post-diagnostic discussion about arrangements like Lasting Power of Attorney, and carers often have to find information regarding financial entitlement and management options themselves, which is complex and time-consuming. 41 This picture of poor post-diagnostic support is amplified globally. as only 10-15 percent of people with dementia and under 10 percent of carers report being offered legal or financial advice.42

2. Approach

2.1 Study aim

We aimed to explore how social care/social sector professionals, older people and their families attempt to address challenges of declining financial capacity in older people, focusing on identification, assessment and support.

2.2 Research questions

We had three main research questions, addressed in three work streams:

- 1. What are (a) the legal, policy, professional and practice frameworks, and (b) the public information available to guide financial capacity assessments and support?
- 2. What are the experiences of social care/social sector professionals, older people and their families of assessing and supporting people with diminished capacity in the management of their finances?
- 3. How fit-for-purpose are (a) the professional frameworks and (b) the public information available to guide financial capacity assessments and support?

2.3 Work stream/research question 1: document review

We conducted an overview of key documents to guide financial capacity assessments and support.⁴³ The main purpose was to identify how the topic is presented within professional frameworks and information provided to the public. For public information, we searched the websites of major national organisations relating to health, ageing, money advice, and those that advocate for people with illnesses that tend to occur later in life and are associated with cognitive impairment. For professional documents (e.g., standards, ethics, codes of conduct), we searched the websites of major professional membership bodies of relevant occupational groups, regulators and the major national body for voluntary organisations. We concentrated on organisations operating in England and/or Wales, as this is the jurisdictional reach of the MCA. We also searched the Internet using the terms 'Dementia AND finance' and 'Dementia AND money' in Google. A list of the organisations searched, and sources identified is provided in Table 1 and Table 2 in the <u>Appendix</u>.

We extracted key information from the identified documents relating to how declining financial capacity is presented. We wrote analytic memos of thoughts and interpretations of this information, which we subsequently used to triangulate findings from interview data collected in work stream 2.

2.4 Work stream/research question 2: interviews with professionals, older people and families

We conducted semi-structured interviews with social care/social sector professionals, older people and their families in Greater Manchester (GM), to explore their experiences of assessing and supporting people with diminished capacity in the management of finances. We focused on GM as a specific region able to provide generalisable insights.⁴⁴ GM is a city-region with a population of 2.8 million people. Following health and social care devolution in 2015, there are collective strategies across GM including for health and social care and for ageing, led by the GM Combined Authority, which comprises the 10 GM local authorities.⁴⁵ These 10 boroughs also function independently from one another and are characterised by substantial sociodemographic variability.

We interviewed professionals working in the broader, non-NHS infrastructure of public, private and third sector organisations providing social care and support for older people. We also interviewed older people (65+) about managing money in later life, or relatives (18+) with experience of supporting an older adult to manage their money.

2.4.1 Recruitment

We recruited professionals from a range of roles in different localities within GM. We were supported by the GM Ageing Hubb to employ a targeted strategy across their extensive professional network, publicising the study across a wide range of professionals working in different localities, organisations and roles across the cityregion. We also adopted a snowball approach (where professionals passed on information to colleagues) and independently contacted other relevant organisations. Through these approaches, we contacted local authority social services departments, the GM Principal Social Workers' network, local authority finance departments, local authority neighbourhood/community teams, housing providers, Department of Work and Pensions, local Citizens' Advice Bureau offices, charitable organisations, community support groups, carer support organisations and advocacy services. For domiciliary/home care (a highly fragmented market of 10,000 providers in the UK),46 we searched the homecare.co.uk website and contacted a variety of organisations across GM. This included a mixture of individual privately owned organisations, small regional-chain providers and franchise branches of national providers, with for-profit and non-profit models. We did not approach residential care providers; for the vast majority of people, the impact of declining mental capacity on management of finances would have become apparent some time before residential care was required.

To recruit older people and families, we were supported by the GM Ageing Hub, the GM Older People's Network^c and the GM Public and Community Involvement and

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b https://www.greatermanchester-ca.gov.uk/what-we-do/ageing/

c https://www.gmopn.org.uk/

Engagement (PCIE) Panel,^d who distributed study information to their contact lists. We also contacted local, sociocultural-specific support organisations asking if they would be able to share study information via their networks. We contacted carer support groups and attended coffee mornings in person to promote the study. Our advisory group members (see section 2.6) promoted the study within their communities and networks. We also contacted relevant professionals who had participated in the study to ask them to share information among the people they supported.

In total, we recruited 28 professionals and 13 members of the public (Table 3 and Table 4; Appendix). Professional participants were 19 women and nine men, mainly White British, with a median length of time in their current post of four years (IQR 2.75-12; range 1-23; data provided by 24 participants). Public participants were six men and seven women, mainly White British, with a median age of 70 (IQR 62-73; range 49-81). We cannot be certain how many people received information about the study. However, we know that our information directly reached over 100 individual professionals and 47 domiciliary/home care organisations, and was circulated among multiple mailing lists of several hundred people.

2.4.2 Data collection and analysis

Interviews with professionals covered their experiences in assessing financial capacity and providing support to people with declining capacity, as well as the information, training and guidance they had received relevant to this topic, their confidence in addressing this topic, and the perceived effectiveness of current practice. Interviews with older people and family members covered their history of managing money, their experiences of the topic of declining mental capacity and future planning, and discussion of information and support around this topic.

Data were collected between October 2021 and October 2022. We conducted 33 interviews with 41 participants (25 individual interviews; eight with two people). The majority were conducted remotely via Zoom or MS Teams (n=27 participants; professionals: 13 individual interviews, five with two people; public: four individual interviews); a smaller number were conducted via telephone (n=6 participants; professionals: five individual interviews; public: one individual interview) or in person (n=8 participants; public: two individual interviews, three with two people). Interviews ranged from 38-79 minutes, with mean lengths of 60 minutes (professionals) and 53 minutes (public). They were audio-recorded and transcribed verbatim by a professional transcription company.

Transcripts were imported into NVivo software for management. Data were analysed using thematic analysis.⁴⁷ We read the transcripts through for familiarisation, coded the data, refined the codes and grouped them into four main themes. We discussed our emerging thoughts and interpretations during the coding process. Coding was informed partly by our prior understandings of issues relating to mental capacity and

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d https://arc-gm.nihr.ac.uk/public-involvement

skills involved in managing money, but stayed close to the data to be largely inductive. The results from this analysis are presented in sections 3.1 - 3.5.

2.5 Work stream/research question 3: synthesis

We considered the themes from the interviews in work stream 2, augmented by detail from the documents retrieved in work stream 1, to examine the fitness-for-purpose of the MCA and other frameworks and methods for financial capacity assessment in the context of real-life decision-making, and the provision of support for people with diminished capacity. Our synthesis intended to determine what exactly is meant by 'financial capacity', what exactly is being assessed in current practice, and how support is provided to people with diminished capacity. We also shed light on what is not being assessed and supported, and limitations to current practice. The results of this synthesis are presented in section 3.7.

2.6 Public involvement

We consulted extensively with members of the public before and during the study. 48 The initial study idea was explored in consultation work in 2019 with 52 older people and social care professionals, supported by the Manchester Institute for Collaborative Research on Ageing (MICRA), the GM Ageing Hub and the GM Older People's Network. All consultees felt that the topic area was of high importance and made suggestions regarding key methodological and ethical aspects of the study, including sensitive recruitment, flexible data collection and handling potential disclosures of financial abuse. The current study built on this preparatory work with the support of the GM Older People's Network, the GM Ageing Hub and the GM PCIE Panel. We assembled a project advisory group of seven people, all of whom had personal experience or interest in the topic area. We consulted with this group at three main points: (i) to support the development of interview questions; (ii) to provide a sense-check on emerging findings; (iii) to support dissemination. The advisory group members also promoted the study within their communities to support recruitment.

2.7 Ethics and consent

Ethics approval was obtained from the NHS Social Care Research Ethics Committee in August 2021 (ref. 21/IEC08/0020). The study was endorsed by the Association for Directors of Adult Social Services (ADASS) Executive Council in October 2021. All participants provided written or verbally recorded informed consent; older people were only eligible to participate if they had the capacity to provide consent. Data were recorded, stored and managed in compliance with University of Manchester protocols and Research Ethics Committee requirements.

3. Findings

3.1 Key themes from interview data

Findings are organised around four key themes: (i) **Identification**: problems with capacity to manage money may often be informally appraised rather than formally assessed in granular detail; (ii) **Legal complexity**: understanding of legalities and procedures around mental capacity and personal finances are highly variable; (ii) **Support**: there is a lack of practical support, and it is not clear how appropriate approaches such as 'signposting' under the ethos of empowering people to make individual decisions are in this context; (iv) **Emotions**: managing money is deeply personal and imbued with emotions, but this may not always be recognised. We present each of these themes in turn, before triangulating with the documentary evidence and outlining a synthesis of themes.

3.2 'The Cinderella of capacity assessments': capacity to manage money may often be informally appraised and based on general judgements

This theme captures the extent to which financial capacity is formally assessed. In general, formal and detailed assessment relating to specific aspects of money management appeared to be lacking. Judgements about someone's ability to manage money were often made informally, generally and based on other knowledge about someone's ability to live well.

Informal appraisal based on observations of general functioning

Most participants highlighted the importance of informal or indirect signs that led them to suspect someone may be having problems with capacity to manage money. There were many references to Activities of Daily Living (ADLs; fundamental skills to manage physical needs, like personal hygiene) and Instrumental Activities of Daily Living (IADLs; higher-order skills including shopping and meal preparation). Participants gave examples such as seeing unopened letters, no food or too much of the same food in people's houses. The importance of 'gut feeling' was often cited, which usually arose from home visits and being physically able to see into someone's house. Several participants raised concerns about the increased digitalisation of personal finance and, more recently, remote working because of COVID-19, as being challenging.

It used to be we'd train people as a real sort of red flag that if you went into somebody's house and you saw a pile of unopened letters, that was a real indicator that somebody was struggling... It's harder now with lots of benefit and financial things being online because

^e Managing money is also an IADL, of which unopened letters (about financial issues) could be an example, but it also includes making transactions etc., which participants did not report observing.

there isn't that very easy sign for workers to see when something's going wrong, so that is a concern of ours. (P15, debt & welfare team, local authority)

Although the home visit was cited as being extremely important for informally gauging someone's mental capacity, by the time some professionals visited people in their own homes, people may have been experiencing increasing difficulties with a range of (I)ADLs — and perhaps their mental capacity — for quite some time:

We go out to people's homes and we have a conversation... basically about everything... to find out what's going well, and what's not going so well and help them improve those areas... I saw a gentleman on Monday who is living with no toilet, no bathroom facilities, no gas, his gas had been disconnected and his boiler is gushing. And I mean gushing out with water. And he's been living like that for like some time.... Hadn't I gone upstairs, and the social work team had been out to this gentleman, I wouldn't have seen the toilet. I wouldn't have seen the situation he was living in. I had a look in his fridge and all his food was out of date, it was all mouldy. And it's things like that that I would be thinking to myself do I need to raise concerns about this person's capacity? (P26, community team, local authority)

Since the ability to manage money is very sensitive to cognitive decline, somebody in a scenario like the above could have been experiencing difficulties in managing money for a long time before there was any professional intervention. These difficulties could be more pronounced in certain areas than others, or may oscillate with fluctuating capacity.

If in doubt, professionals refer to social services

The vast majority of professionals stated that they would make a referral to social services if they had any doubts about a person's mental capacity, which was often talked about quite generally based on their observations and intuitions about someone's ability to live well. Some professionals felt that in theory they would be capable of conducting a formal capacity assessment, but would prefer to bring in social services, even if the resulting capacity assessment was rather generic because of a lack of resources:

I just felt more confident always looking to social services and to ask specifically what capacity assessment is needed. But on the face of it they tend to just do a bit of a generic one which are just given indicators that maybe they need the proper memory assessments and then look towards a proper diagnosis. That's the best we can do because it's so underfunded, the services, and we're all firefighting to an extent. So that's how it ends up. I think I'm capable of doing a capacity assessment, but not confident, so while we're all under pressure I'd rather make a referral to social services for that particular part of it. (P11, advisor, housing provider)

At times, this could result in people being passed between social services and the referring organisation, with blurred lines of responsibility around formal assessment. One participant from another housing provider gave a detailed example regarding a resident who was having problems with their rent payment:

We had three social workers; the first said, 'well, as long as she ticks the boxes in setting up direct debits... as long as the payment comes out next month, I'll close the case'. And we said, 'well, hang on... our rent support officer did this and it worked for three months and then it all stopped again. And we can tell you why it stopped'. And they said, 'no, we have to go through least restrictive, I've got to follow a process, you know, in terms of the Mental Capacity Act... we're going to go for this direct debit'. [So] it got set up, the case got closed and it fell apart. So, again, re-referral back in. Social services... pushed back onto our service to then go out and almost do the capacity assessment, which we said, no. (P19, manager, housing provider)

The above example seems to highlight an underlying bureaucracy to this process in which the social work team needed to document the failure of the proposed solution themselves to demonstrate legal compliance, despite other professionals telling them the proposed solution had already failed. It also highlighted a lack of clarity in who should be responsible for conducting any formal capacity assessment, or, indeed, what form that should take. It was therefore unclear whether there was appropriate support available for the person in the interim.

Formal capacity assessment

One social worker gave a detailed example of how they had conducted a formal financial capacity assessment via the MCA framework, using granular evidence to highlight discrepancies between what someone was saying they understood and their actual actions:

...he understood his finances, where his bills were coming in, what his money was, he could communicate how he wanted it managed. But he couldn't weigh it up, because he kept getting in arrears, debt and he didn't understand. And I used that evidence that I had to support him with his finances... he understands all the elements within his financial situation, but he just could not weigh up that he doesn't have access to cash for when the carers come in to buy day-to-day things... he knew he had bills, but again, he couldn't weigh up that he wasn't paying the bills. (P14, social worker, local authority)

Across an older person's lifetime, someone may have skills in more common aspects of money management, but not develop more advanced skills that become necessary because of changing circumstances, as one participant reflected on when talking about his late mother:

...my mother came from a very humble background... but also, was very canny in the sense of penny wise but pound foolish, in that she accumulated an awful lot of money... she never lost control of those minute details, she went through her bank statements and everything, but the bigger picture, she couldn't get... when she actually had a lot of money, she had no idea what to do with it. (F7)

Examples like this further highlight the need to consider different skills and abilities regarding specific aspects of money management. Granular, formal capacity assessments were seen to be important, but uncommon. An independent advocate was critical of the lack of formal assessment and the more universal assumptions often made by professionals about people's ability to manage money:

...finances, I'd say, would be the Cinderella of capacity assessments, it's often an afterthought, not really done thoroughly as in not breaking it down into chunks... You will often find that attitude... 'well, how are they supposed to manage their finances if they've got dementia?' (P27, independent mental capacity advocate)

What is meant by capacity to manage money in contemporary society?

The complexities of managing money raised questions about how clear it might be to identify that a problem is a genuine mental capacity issue, and pointed to deeper conceptual challenges in understanding what actually is meant by capacity to manage money in contemporary society:

...we're so used to people without capacity issues being totally overwhelmed and confused and not understanding that system because it's incomprehensible to anybody... perhaps maybe [we] don't pick up where it is an actual mental capacity issue... a very high proportion of people that will come into our service will not know what their money is, will not know how it's made up, they don't understand why they're getting what they're getting, they don't realise that they're getting too much or usually too little... it's so, so common for people to have no clue what their money is made up of... (P15, debt & welfare team, local authority)

Summary

In summary, formal assessment of financial capacity was less apparent than general assumptions. The majority of professionals tended to defer to social workers to conduct this assessment, but sometimes there was confusion about who should or could conduct an assessment. We expand on this theme in the following theme which highlights variable understandings of legal and procedural matters in relation to financial capacity, both among professionals and the public.

3.3 'You've got to know how the game works': legal and procedural understandings are important but are highly variable among the public and professionals

This theme explores participants' understandings of legal issues and procedures regarding mental capacity and money management. Findings highlighted the challenges for both the public and professionals of developing factual understanding of laws and procedures, and in the importance of having a sophisticated understanding of how to navigate the landscape of support.

Mixed understandings of bureaucratic processes

Professional and public participants had mixed views on understanding bureaucratic processes relating to financial capacity issues. Some suggested that Power of Attorney paperwork was straightforward to complete without professional support, and there was no need for people to pay 'an arm and a leg for this if they don't need to' (P1, support co-ordinator, charity). Others suggested that they had drawn up the documents using professional legal support as reassurance:

That was a spinoff from the financial advisor. He said, 'I know somebody who I think could help you to do that'... we took proper legal advice on that. And it's all properly drawn up (F3, couple)

Some professionals reflected more widely that other forms related to financial entitlement were intimidating, lengthy and potentially posed challenges for mental capacity:

...the forms that we fill out for disability benefits... they're 30 pages long... and just the fact that a form's that long puts people off, whether it's to do with mental capacity or just the overwhelming thing of it... they can't actually cope with the look of the form. (P7, advisor, charity)

Differences between lower level support and Power of Attorney

There were queries around people's understanding of the extent to which Power of Attorney differs from lower level arrangements of support. Lower levels of support may work successfully for a long time if there are family members or friends willing to step in informally, but eventually, people may run into problems without the legal status of Power of Attorney:

People still don't understand the importance of Power of Attorney... we give them examples of our experience of when people have come unstuck because they've not got that Power of Attorney, but I think bottom line is they don't want to pay to get it done, even though it's only £300-£400... The other problem is, it's quite easy for next of kin to be set up as a signatory on an account and they see that as enough because they've got access to mum or dad's

account, they can help pay the bills, they can send cheques, they can do online payments. (P18, director, domiciliary care)

We interviewed one couple in which the wife was living with dementia, and had previously taken the lead in managing the household finances. The husband described a sense of gradually taking the lead in their financial management, but although they had set up and registered Power of Attorney, they had not felt the need to use it:

I just knew that it was something I was going to have to take over. Our things are fairly simple. You've got your own account and I've got my account, and we have the joint account. So it is very straightforward, there's no great difficulty in doing it... we haven't actually had to put that [Power of Attorney] into effect as far as finance is concerned, because...we're with [name of bank], so we've got the app on both our phones. And [F12] just gives me the phone and says, can you see what's in there? We haven't had any dealings with [name of bank] where we've needed to both sign documents and things like that. (F13, husband)

Their arrangement was one in which they both used the same bank, had a joint account and individual accounts, and the husband has access to his wife's bank account informally and so was currently able to provide sufficient support without having to establish any further formal arrangements. They had not informed the bank of the wife's dementia diagnosis; during the interview they began to query whether they might need to do this, saying 'that's something we should make them aware of, do you think?' (F13), but did not know what the consequences of this might be and whether it would be detrimental to an informal system that was currently working for them.

Another participant illustrated the uncertainty around informal arrangements of support, highlighting a tension and grey area for relatives. The participant gave several examples in which relatives who were providing practical were also wondering whether they were legally compliant:

...the simple things, the day-to-day like if someone needs shopping, taking their card to get some milk or a few bits from the shop. And then thinking, with the best intentions, 'but what if someone's looked at the card? Or that thing of 'am I doing the right thing, am I going to get in trouble for this?'... So, I think little things like this, or just paying a bill, especially with online banking, you can log on and do a little transfer, manage the bills, or household costs online from anywhere, you're really helpful. You know, in the moment, especially for carers who have got so many other things to do as well. But then again, logging onto someone's account and making a few transactions, while that's really helpful it's not necessarily, you know, the right...maybe, not the right thing to do. It'd be a case of a grey

area of helping, the person has given their consent, but... (P22, support worker, charity)

One relative described how formally taking on the role of Attorney presents a threshold of change from a lower level of arrangement that only became apparent in retrospect. This raises a question about how far people understand Power of Attorney at the point at which they assume the role:

It's only after that you start to understand... okay, so what does that actually mean as a Power of Attorney when it comes to managing someone's money? Because it certainly isn't just almost having a virtual card that you had in that informal setting... You do get the feeling that you've got these outside agencies keeping tabs on you. Which, in a way, is certainly a good thing because it needs to happen, but in a way it changes the financial relationship you would have with a parent. (F9, son)

Mixed experiences in using Power of Attorney

Public participants reported mixed experiences in using Power of Attorney. Some reported that it had been straightforward to lodge Power of Attorney with financial organisations. One couple who had registered Power of Attorney following the wife's dementia diagnosis had not yet used it, but felt that the process would be straightforward should they need to do so:

I assume I just tell the organisation or institution that [name of daughter] and I both have Power of Attorney and show them the evidence of it... So that's what we're hoping on anyway. I think hopefully we'll have done the hard work. (F13, husband)

The feeling here that 'the hard work' was in the setting up of Power of Attorney is entirely understandable. However, some of the other evidence showed that there may be more hard work to come when trying to use it. Other participants had experienced substantial delays and queried the extent to which some financial companies understood Power of Attorney:

Sometimes it hasn't been easy to lodge a Power of Attorney, because some of them wanted mum's authorisation... which just defeats the whole object... the insurance company wanted mum to sign something... and I said, 'well, first of all, she's not going to open it, she's not going to understand what the correspondence is'... It's probably taken about 12 months to get that lodged with them, because they couldn't understand the implications of contacting somebody who has Alzheimer's to ask. (F2, daughter)

The specific requirements for identity documentation may not always be made clear by financial institutions, which can be frustrating and time-consuming:

That's actually what has really started to irritate me... trying to prove you've got Power of Attorney and to prove your mother's identity... I

spoke to a girl [at the bank] and she said, 'oh, yeah, this is what you have to send us'. She didn't tell me they wanted the original Power of Attorney document. They wouldn't even accept a photocopy... My mum no longer has a passport. She no longer has a current driving licence. And... although I'm the first person named on the Power of Attorney, my brother is the second person named, and it's one of these jointly and severally things. So, they wanted identity and residency documents from my brother as well... it was just ridiculous. (F1, daughter)

Challenges in navigating legal bureaucracy were not just limited to members of the public. There were also examples of inter-organisational difficulties, with one local authority financial services manager highlighting challenges in the council acting as a Deputy to manage people's money:

We've actually got an issue at the moment with a couple of people who are in residential care that have an account with a particular bank and they won't even recognise our court order, so they won't give us the money that's been sitting in the account. We've even been into branch. [Name of colleague] has been into branch with all her ID and everything... One of the staff went in again last week for the fourth time and they said they were in the process of changing their own policies internally... because they don't recognise an organisation as a Deputy as opposed to an individual person. Because on our court orders, [name of council] are the Deputy, not an individual. So, yeah, we're having a nightmare... (P23, financial services, local authority)

These kinds of challenges led to suggestions that people need to understand how specific organisations such as those responsible for care and finances work, and the particular contexts in which they are operating, and then modify their interactions with these organisations accordingly:

I think a lot of the companies now are having a greater... well, I'd like to think they're having a greater understanding, or whether it's me that has now learned to say, when I phone these companies up, I've got a Power of Attorney that was lodged on such and such a date. (F2, daughter)

Understandings of Power of Attorney in relation to the MCA and other legislation

Professionals reported confusion among families about the relationship between Power of Attorney and the MCA, citing potentially erroneous global assumptions of lack of capacity based on the presence of illnesses such as dementia:

...that's where the mental capacity test comes in because the family sometimes think if they've got Lasting Power of Attorney, mum's been diagnosed with dementia, I can overrule that and sort her finances out. Oh no, no you can't, you know, they have to lose capacity before you do that. So, that can be very, very difficult to explain to the carer that, no, you can't do mum's finances without her permission to do it because she has got some capacity. (P24, support worker, charity)

One extension of this was that there were concerns about potential abuse by family members who either lacked or did not acknowledge a nuanced understanding of mental capacity law:

Sometimes I see people and I think how the heck have you got Power of Attorney? Because once they get it, I think some people can't wait to use it. Some family members can often be 'we've got Power of Attorney, we're not using it because my parents or my family or my neighbour still have capacity and so they don't need it, they can sign'. But you'll get clear-cut cases where somebody who has chronic dementia or chronic Alzheimer's and a family member's got Power of Attorney, and it can make their eyes light up. (P16, debt & welfare team, local authority)

These two quotes help to show that within understandings of the MCA and Power of Attorney, there is a complex continuum between surrogate financial management and financial abuse. The lines along this continuum may be unclear.

At a deeper level, there were concerns from professional and public participants about the importance of people needing to be knowledgeable about their rights and to be able to stand their ground. One relative, reflecting on his interactions with a local authority as his mother's Attorney, stressed the importance of knowing 'how the game works' in negotiations about care funding:

...it's quite naive to go to a local authority and say, 'I'm struggling here'... It's hard to not describe it as an adversarial situation sometimes when in effect it is... You've got to know how the game works and you've got to realise your part in that game and the other actors' part in that game. If you go in otherwise, you're going to be eaten alive by some local authorities... Regardless of whether you're a formal PoA [Power of Attorney] or you're providing informal care [i.e., not formally as Attorney], ultimately you're advocating for that person. And in a way, people don't realise what that actually means when it comes to the structure of health and social care and financially... (F9, son)

Some professionals reinforced this picture:

...usually it's carers of people with dementia [who] don't know their rights... You might have the Care Act there but most of them haven't read the Care Act so their rights are ridden roughshod over (P1, support co-ordinator, charity)

The need to be informed about the law and to have a sophisticated understanding of how to navigate interactions with authoritative institutions potentially places a

substantial burden on individual people. One professional reflected how even experienced professionals may struggle in the financial-legal landscape:

It's amazingly complicated... you've got people in my team who've been welfare rights officers for 25 years who are at the top of their game, they're really passionate about the law and peoples' rights, and they will tell you how complicated that makes explaining that system to people... I could walk out of here tomorrow, have an accident, and need to claim benefits and I would struggle because it's so complicated. (P15, debt & welfare team, local authority)

Other complications included attempting to act on behalf of someone who lacked capacity to grant a surrogate decision-maker, but whose financial affairs were in a different country. One participant described at length the challenges she was facing in trying to support her father:

He has Alzheimer's, so in order to do any Power of Attorney, it's too late. On top of that, there is no embassy here in the UK... So anyone who wants to do anything, they have to go to either France or, I don't know, Belgium. And as my passport now is the travelling document, I can't go there, they require a visa. And my dad's [name of nationality] passport will expire on [date]. So we are in a situation, and we don't know what to do. (F5B, daughter)

Training and learning from experience

Understanding of Power of Attorney and mental capacity among professionals was also variable. Most had received some training around the MCA, but this was often generic, with hypothetical examples that might not relate to their own context, and rarely if ever related to finance. Professionals in various roles suggested they would like more specific training:

...they talked us through it and then gave us an example and it was giving a kidney to a family member of somebody that didn't have capacity to make that decision... So it didn't go too deeply into, you know, like different areas where you might be looking at that... (P1, support co-ordinator, charity)

I would love to do more training on safeguarding and... somebody who knows all about Lasting Powers of Attorney and the different levels... I'd love to have somebody talk to us from the Office of the Public Guardian. That'll be really interesting. (P16, debt & welfare team, local authority)

Finances, no, none at all. From my previous job, yes but not via [name of current organisation]. As in mental capacity, again, no, not really... (P12, manager, housing provider)

...it would be really interesting to have something around cognitive decline and finance management... my main knowledge is around

dementia and having just done things like [name of programme] which was really great, but it's very kind of surface level and that course doesn't talk about management of someone's life in any kind of way, so I would definitely be interested in more and more around that. (P17, programme lead, charity)

Some professionals highlighted that their knowledge and understanding in this area was gleaned from experience:

If you put in Power of Attorney, Google is very good because it gives you that small synopsis right at the beginning that breaks it down into sort of layman's terms, so I try and explain it that way. (P2, support co-ordinator, charity)

...because I've seen [dementia] progress with people, I'm able to sort of predict to our members our experience in this and I can actually say: this is what's going to happen, you need to get ready for this. (P3, project co-ordinator, non-profit)

The onus is on yourself really to see where's your gap in in your knowledge. Maybe you've got a case coming up that you'll think about what needs to happen, maybe do I need to get clued up on something. (P14, social worker, local authority)

One participant reflected on learning by experience regarding financial capacity issues, including from families: 'I go to one family, they'll know something. I think, well, that's really useful, I'll write that in my note of things to be able to talk about with others'. This participant later said, 'I haven't had training, that's quite bizarre to hear myself say that out loud' (P1, support co-ordinator, charity).

Summary

In summary, this theme has highlighted that understandings of the law and procedures regarding support for someone with declining financial capacity are highly variable, both among professionals and the public. There are questions, uncertainties and different experiences of the appropriateness of informal support and in establishing and using formal legal instruments such as Power of Attorney. The public may need to develop sophisticated understandings of both the law and the reality in which authoritative organisations are operating in order to be able to effectively perform the role of surrogate financial decision-maker. Training for professionals working in social care and the social sector around mental capacity and finances appears to be lacking.

3.4 'Putting the onus back on the citizen': support, 'signposting' and 'empowerment' may be found wanting in the context of capacity to manage money

This theme describes the picture of support for people to manage their money, focusing mainly on the professional support available from the social care/social sector.

Who provides support?

Family members and professionals both felt that family would naturally represent the first port of call in providing support to someone to manage money, with some participants making reference to assumptions that a large family will have someone who can help out, or a sense of obligation. However, this picture was complicated by a perceived dependence of the adult care system on familial obligation, which may lead to erroneous assumptions that families would be available to help and would be competent to provide support to manage money. Some professionals recounted situations when families could not or would not provide support to an older relative to manage money. This could be for various reasons, including a lack of a trusting relationship (see the 'emotions' theme below), but also for reasons such as being unable to take on a role that meant providing a high level of support, exemplified by one case regarding a housing tenant who was having difficulties managing money:

Social services... came out and met with her and determined that there was no case. They spoke very briefly to the next of kin and said, 'listen, the family can manage this.' We then spoke with next of kin and they had a very different interpretation of that conversation. And, basically said, 'no, we've not agreed, and we can't and we've actually got our own issues here and we can't provide that level of support'. (P19, manager, housing provider)

When people entered support services – often prompted by third party referral – measures could be geared towards support for ensuring correct administration of (often state-provided) personal finance. For example, some community professionals described their roles as liaising with relevant government bodies and third sector agencies:

We work closely with the job centres... and the DWP [Department for Work and Pensions]. So for people of 50 and upwards we will liaise with them... trying to get them on the correct benefits. We work with the local energy advisory services to make sure people are on the right energy tariffs... We talk to them about reductions in council tax... Travel vouchers... we're linking with Age UK who help fill out attendance forms for DWP... Anything that person needs. (P26, community team, local authority)

As a last resort, where an individual was assessed as lacking mental capacity to manage their money at all and had no family, avenues of social support were (seemingly) straightforward, as the local authority could take over:

We support and manage the finances of adults that lack mental capacity. So we claim their welfare benefits, we pay their bills for them if they're in the community, pay utilities, pay their care fees... if they come to us with quite a lot of assets, we also apply to the Court of Protection for Deputyship, which enables us to manage their finances in their entirety. (P23, financial services, local authority)

However, this same participant also stated that there is substantial national variation in the level of support that will be provided by local authorities to people in these situations:

Every [local] authority is different... there's no hard and fast rule. I know a couple of them... don't take on Deputyship cases at all, where someone might be referred to them with loads of assets already. Some only deal with Appointees, some refer cases to a solicitor if they've got more than a certain amount of money. Every authority is different in the way that they do things. (P23, financial services, local authority)

Signposting and empowerment

In cases where an older adult was deemed to have capacity to make financial decisions, yet was still experiencing difficulties, the practice of signposting people toward services had been adopted by some professionals in local authorities and third sector organisations:

I was going to link to Age UK, because I thought they might know some service that might be helpful... you would put the onus back on the citizen and then whether they will do it or not. Because you always try and give it to them to do it and see what happens from there. (P14, social worker, local authority)

Handing responsibilities to 'the citizen' was framed within the narrative of empowerment as a guiding principle of how much support was considered appropriate, and/or when signposting would replace it. This was reiterated by local authority staff:

So if we could we were empowering them to ring the relevant people. If they couldn't we were ringing them on their behalf... So it depends on the individual and how much support we give them. But it is about empowering them. (P26, community team, local authority)

Some professionals stressed how they encouraged people not to rely on social support too heavily and become conditioned into 'learned helplessness':

I've got to be quite firm at times saying I will not do any of this for you. I can show you how to do things but for your own sake you need to take control basically. So sometimes I have very difficult conversations because a lot of people learn to be helpless... and then they expect to be looked after. So it's not always happy

empowerment, sometimes it's difficult. (P11, advisor, housing provider)

There were different perceptions of the issue of empowerment. One family member, speaking more broadly about the issue of direct payments to finance his mother's care, queried at what point empowerment became avoidance of responsibility:

...the way that it seems that the government have gone about that now is they give you an offering of, 'okay, I'm just going to give you the cash now, you can sort it out'. So the argument I was having with the local authority social services, why would I, as a [name of occupation] rather than a care professional, take on that type of responsibility when you're the expert in that field? But it makes their life easier to give it to you... You either see that as empowerment or you see that as pushing responsibilities on to the individual instead... (F9, son)

Challenges associated with signposting: availability and accessibility of resources

In the context of managing money, one of the major problems with signposting is that it requires the availability of other relevant support services to be able to meet people's needs. This picture was rather mixed. One family member (F2) described positive support from a charity who had taken over doing food shopping for her mother, using money from a locked kitty box that she kept topped up. However, there were other examples that suggested that there were often key gaps in this kind of day-to-day, practical support to manage money:

They've been referred before to Citizen's Advice, Age UK, all of that but they haven't actually got people that go in and will help that person set up their direct debits and things like that... there was a couple of charities, but they wouldn't do the full service that we needed for that person. (P18, director, domiciliary care)

A social worker highlighted how there may be support for one-off, administrative tasks, but not for ongoing practicalities:

People don't mind ... helping you set things up or doing... the admin task, but actually the physical bits, people don't like doing that one, from my experience. (P14, social worker, local authority)

One participant highlighted the merits of the Citizens' Advice Bureau as source of comprehensive advice about issues relating to Lasting Power of Attorney and various benefits available for people living with dementia, but questioned the availability of this support:

I would say the main one that you would get full advice from is Citizens Advice. And the problem there is they're absolutely inundated. They just can't cope, so just getting an appointment, you're not going to get one. You're just not going to get one. So realistically that doesn't exist. (F11)

The personally detached approach of signposting to (often online) content also assumes that people will be able to access and understand this information. There were mixed perceptions on the accessibility and comprehensibility of online information. Signposting may neglect the variable understandings of the law and procedures (outlined in the theme above), and also not consider individual circumstances:

...the council are guilty of this [digital exclusion]. 'I can't pay my council tax'. 'Well, I tell you what, if you just go online and ask for help'... Well, they're not going to do it. 'Just go to a gateway [walk-in support centre]'. Well, they might have mobility problems. 'Oh, well just get a taxi.' Well, they might not have any money. So that kind of renders them vulnerable... because some of the things they're expected to do, they're not capable of doing. (P20, debt & welfare team, local authority)

One participant who had cared for his late wife spoke about his anxiety and confusion from trying to understand both paper-based and online information, saying 'I don't do internet at all' (F10). He described a personal, hands-on approach from a trusted professional that he had found really helpful, but which he suspected had gone beyond their remit:

She's [carer support service manager] always got time for you... even things that's not really hers to do, she'll do it, because she's that sort of a person... she comes round to the house, if it's paperwork and we do it in my front room. And if she didn't, I'd be lost. (F10)

Examples like this raise a question of how far signposting is satisfactory and empowering if it relies on people being able to understand the information they are signposted to, and if people would be 'lost' without the involvement of others who are 'that sort of a person' prepared to offer support beyond the remit of their role.

Safeguarding and the scarcity of resources to provide support

There were clear lines of demarcation around financial vulnerabilities that did not lend themselves to signposting. In serious cases where financial abuse was suspected, the power of safeguarding to mandate action by the local authority was highlighted by several professionals, with one saying 'if you're duly concerned, I would go straight to a safeguarding issue' (P10, manager, housing provider) to force input from social services. One local authority financial services manager highlighted that the amount of safeguarding referrals for financial abuse meant that any non-safeguarding requests for money management support would likely go unaddressed:

Financial abuse and safeguarding are priority one and everything else is a two. So, of course, you very rarely get round to the twos

because all the ones take precedence. (P23, financial services, local authority)

Professionals were aware that scarcity was at the root of many shortcomings in financial support provision. The same local authority manager reported a growing demand for council support to manage people's money, which was reinforced by an independent advocate who stated that the current 12-month waiting list for support was 'ludicrous!' (P27, independent advocate). It was not clear what happens during such an interim period when people need support to manage their money, but face a long wait. In another local authority, a lack of funding coupled with high caseloads for staff were suggested to act as a barrier to even raising discussions about people's ability to manage money, let alone provide ongoing support, as this could open up another complex problem that staff simply did not have the resources to address:

What we can't do is that ongoing support to people to manage their finances. A few years ago... there was a bit more money around, and the idea was that you funded financial capability projects... caseloads for staff, whatever line of work you're in now in public services, are so high... I think sometimes because people are so busy, they almost fear that if they start asking about money, it's another thing that they're going to have to deal with. (P15, debt & welfare team, local authority)

A lack of long-term support options in combination with a signposting approach justified by the concept of empowerment was felt to have led to the social safety net becoming increasingly porous:

I think the safety net is really quite broken, there are big holes... And that's not because anybody's really purposely doing a really bad job, that's just because... the system is so fragmented, the system is really complicated... I have this discussion a lot with other managers, where they go, 'well, you know, people have got to go and find out themselves'... and I just say, 'no, you're setting people up to fail'. And as unpalatable as that might be, because we know that we're all struggling to meet demand on services, that's not the answer... we'll see them in a terrible state in a year's time. (P15, debt & welfare team, local authority)

A prevailing, distinct perception of professional purview coupled with a lack of support often expressed itself in a reluctance to deal with suspected financial capacity issues. This had palpable consequences for a social worker, who gave an example of reluctantly having to shoulder more responsibility that other care staff did not want to take on:

...there does certainly need to be a bit more out there on the physical help of having access to money. From the council point of view, we end up doing it, but we don't really want to do it... the problem is you start to promote that idea... other professionals, they start to think, 'oh, you do it'... this particular person, who has

capacity, he's in an extra care scheme, he's got carers, there's people on site, I probably could have batted this one back, but it was, 'oh, he needs help going to the bank'. So, I did help him because you want to keep the relationships with the other professionals... I did think, you've got about 20 different staff, why can you not take him to the cash machine down the road?... people don't want to be involved with that or it's a very touchy area... the [case] is open to me, so, yes, I have to support him as best that I can, but they felt the need to bring [in] the social worker to go and do that, which is a very hands-on support worker-type task. (P14, social worker, local authority)

Summary

Overall, these findings suggested that it is difficult to see precisely what support is available in the social care and social sector for people to manage their money. There appears sometimes to be support for the bureaucratic side of managing money, such as completing forms and ensuring people are receiving state benefits that they are entitled to, but much less for day-to-day tasks. There were isolated examples of (often third sector) support to help people with daily tasks like shopping, but the picture more generally is one of a lack of clear roles and responsibilities, an emphasis on signposting people elsewhere, a lack of resources for support and a high volume of safeguarding concerns taking priority over providing other support. The final quote from a social worker points to an unsustainable picture in which support may be provided as a last resort when other professionals are reluctant. We develop this finding further below as part of the final theme about emotions and money management.

3.5 'A little bit of compassion would go a long way': managing money is not just procedural, it's emotional

This theme captures the personal and emotive nature of managing money. It highlights a deeply complex range of emotions, both for those who may require support with money management, and for those taking on responsibility to provide support.

Trust

Unsurprisingly, many participants talked about the importance of trust and positive relationships when it came to the topic of financial capacity and surrogate decision-making. Some family participants talked positively about this, citing strong intergenerational relationships between themselves and their parents (e.g., F1, daughter) or their children (e.g., F3 and F4, couple).

Professionals appeared to be very aware of the sensitivity of starting conversations about financial capacity and the need to build trust with people they were supporting.

There was strong recognition that this could take time, that different approaches may suit different people, and that they might not necessarily be successful:

You've got to build up trust. Because you couldn't walk into somebody and say, 'right, can I see your bank statement', you really couldn't. It is about them... And finding a way, one thing might work with one person. But I am worried about that with about three or four gentlemen where intervention needs to be, because I don't think they'll give up easily information. Which is right, it's their information, but it's knowing it's for them and letting them know I'm doing it for them. (P12, manager, housing provider)

Generational assumptions, roles and responsibilities

There were several examples of generational assumptions that were cited as influencing older people's willingness to discuss financial matters. Some female professionals perceived that traditional gendered divisions of responsibility meant that older men would be reluctant to speak to them about money:

Sometimes because of a generational thing, it's females shouldn't have anything to do with the finances, so not allowing me as a [woman]... if I knew that that was an issue, it would be finding a male colleague. (P12, manager, housing provider)

Another participant suggested that there may be a broader reluctance among older men to share issues relating to mental health and wellbeing from a sense of masculinity and paternalism:

Some of our older gentlemen, it's also not something in terms of their view on masculinity that they want to talk about... often we find with older men, it's actually [name of male colleague] who they will open up to, because they still view us as younger women and as people of sort of their child's age... So, quite paternal sort of warm feeling of wanting to protect us at times and not wanting to burden us. (P19, manager, housing provider)

This picture was more mixed among some of the public participants. In one older couple, the wife took the lead for the family finances, as she was 'super organised' and 'loves numbers' (F8). Her role was acknowledged by her husband (F7), who spoke openly about his own lack of financial skill. In another couple, the wife (F4) reflected on her employment history in various administrative roles, including working in a bank, saying 'l've done admin all my life, loved it'. Yet despite this background, she also said 'l' just don't do money' and 'l' don't like discussions with family about money', and her husband (F3) took the lead in managing the family finances. Therefore, although some of the generalisations about gendered roles in managing money may ring true, there may often be more nuance underneath that warrants further exploration.

There was a suggestion that younger people may be more receptive to discussing finances thanks to the rise of public campaigns changing attitudes:

We've got people like... Martin Lewis on his TV programme. And I think younger people now are getting educated in schools. So I think now people are starting to talk about money. But certainly, I know from my own father, he's in his 80s now, he's not going to tell you about his bills or his money or how much he's got in his bank account? What's it got to do with you? (P20, debt & welfare team, local authority)

Self-worth and identity

Money was seen to embody a strong sense of self-worth and identity. People may have strong opinions about how to use their money in relation to significant others, sometimes to their own apparent detriment:

...what we often find is we go to see people and the houses are falling apart around them. They're living in real hard conditions. They've got quite a lot of savings that they can improve their property and their life and their quality of life. And then you ask them, 'well, why aren't you using that money? And what are you saving it for?' 'I'm saving it for my great niece. It's her inheritance.' 'When was the last time you saw that great niece?' 'Six years ago' (P26, community team, local authority)

An independent mental capacity advocate gave an example of someone with dementia whose care home had provided them with fake bank notes to help preserve feelings of self-worth in someone from a generation used to handling cash:

I'd gone out to see someone. I was having a chat with her, and she thought she had to pay me. I glanced down and [saw] what I thought was like at least four or five £20 notes, and I'm saying to her, 'close that purse, put it back in your bag...' and it turns out that actually it's the [care] home that just prints off these notes and allows people to walk around with them... I can understand how people who might lack capacity globally for finances still have that sense of worth about having something in their pockets. Especially from a generation [that] very rarely dealt with anything that wasn't cash... (P27, independent advocate)

This participant questioned whether the deeply personal nature of money might influence formal assessment of capacity (as detailed above), as the implications of 'failing' such an assessment are profound:

Maybe, some social workers are worried about taking away that person's, sort of you know, perceived autonomy...independence, and that's why [financial capacity is] always the last thing that they decide to assess. (P27, independent advocate)

One participant living with dementia, who had worked in a senior administrative role prior to his diagnosis, recalled how he had been demoted twice after starting to make mistakes before subsequently losing his job altogether. He described how his status in the workplace 'went from being a person that people would approach for advice to being the person to avoid', and that he had avoided informing his wife at the time, saying 'even when I was demoted, I kept that to myself because of the embarrassment of it and the humiliation'. He also recalled his experience of applying for a council tax discount following his dementia diagnosis under the 'severely mentally impaired' criteriaf and said 'to be described as that, it was horrifying and it was depressing. And I felt like a beggar' (F11). His interview offered a powerful example of how changes in cognitive ability that affect someone's financial status and capacity can deeply affect self-esteem, and how the process of applying for entitled support may have further deleterious effects.

Setting up a 'safety net' provides reassurance but may be more complicated in reality

Many professional and family participants described the delicate area of talking about support needs in relation to money in a way that recognises the emotive nature of money:

...you usually introduce it as future planning... that's how I do it now in this role as well, you know, have you thought about the future? Have you done any future planning? Then encourage them with open questions to talk about what they've thought about, what their concerns are, things like that, and then start to introduce the ways people can get that support from family and legally... [when someone] first gets a diagnosis, it's overwhelming and it's scary and it's difficult to talk about when you lack capacity to make your own decisions. So that conversation has got to be had properly before they do lose capacity but it is an ongoing conversation. (P1, support co-ordinator, charity)

Some family participants talked about framing the formality of Power of Attorney as a safety net for some point in the future:

...we said to mum, with any Power of Attorney, that it's there if we need it, and if we don't need it, then we won't use it. (F2, daughter)

The idea of Power of Attorney being 'there if we need it' may be reassuring that there is a safety net in place, that will only be used when it becomes necessary at some (unspecified) point in the future. One participant living with dementia described making a Lasting Power of Attorney in preparation for the future as being 'liberating' (F11). However, there was other evidence to complicate this picture, as perceptions and feelings about surrogate decision-making may change with cognitive decline.

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f 'Severely mentally impaired' is the term used by local government: https://www.gov.uk/council-tax/discounts-for-disabled-people

Another relative referred to how her mother had been comfortable granting her Power of Attorney, but had since become suspicious and reticent, to the detriment of her daughter:

I'm going back a few years now where there was no problem whatsoever. Power of Attorney all came and... however, in the last two years, she said to me one day, 'give me all that [paperwork], you don't need to know anything, give me all that'. And I know nothing. All I knew was I've got, should anything happen, documentation to be able to pay her bills... I shop for my mum, I cook, I clean, I wash, I iron, I clean the garden gutters, I do the gardening, do everything. It's becoming more difficult now that when I go shopping for her, she's not forthcoming with giving me the money. Well, I don't earn good money and I've got this roof and bills. She's become very, very suspicious (F6, daughter)

This participant also felt that her mother did not acknowledge or realise all of the ways in which she supported her domestically. There was a lot of evidence of people not acknowledging problems, refusing intervention or being unwilling to discuss support:

So what generally happens is the person with dementia is in denial that they've got dementia... My mum was a very strong character... As far as she was concerned, she didn't have dementia and anything I was trying to do was about controlling her... You see that all the time. They don't want their family interfering their finances (P1, support co-ordinator, charity)

...within this kind of environment [supported housing], all the other tenants will look after [someone] and try and hide things that are going on. That happens, but usually then what happens is disaster happens, sometimes. The tenant, because it's been left, left and left, the tenant might get a bit aggressive and then tenants don't know how to deal with these things (P10, manager, housing provider)

Discomfort and reluctance in talking and supporting

Both professionals and family members referred to examples of discomfort or reluctance in discussing money matters or in providing support. One professional suggested that discomfort among families in raising the topic of surrogate financial decision-making could lead to an incremental scenario in which a supportive relative ends up taking on more than they or the other person had intended.

I think some people might not think that that's an option or, maybe, the person hadn't...or if they haven't discussed it before, before someone gets dementia, I think it could be quite uncomfortable for people to bring that up. But when you're caring for someone that's like you might go to the shops with some change one day, and then if you don't...but it builds up, so what starts as small you might end

up managing someone's money when that wasn't ever the plan. (P22, support worker, charity)

There were numerous examples of professional reluctance in talking about money. There was an overall sense that talking about finances was in some way qualitatively different to talking about other potentially emotive topics:

I worked with loads of health visitors, midwives, psychologists, family support workers, and what I soon realised was they felt really unconfident asking about financial issues, and I found that really strange, because they have really sensitive conversations about all sorts of things that I would feel awkward talking about, like how people parent their children, their state of their housing conditions, but they found it hard to ask about money. (P15, debt & welfare team, local authority)

Another professional highlighted the challenges that could be felt in talking about someone's financial information and stressed the importance of not dealing with discussions about money alone:

...you're taking a lot of responsibility on for them because it's their personal lives, it's their data, isn't it, you know, which is very, very difficult. That's why I say if we go into the finances and they're on their own, you need somebody there with you. You cannot do that on your own. Well you shouldn't do it on your own, you know? (P24, support worker, charity)

Professionals highlighted a reluctance in providing hands-on support if it means accessing someone's money. (Issues relating to practical support were analysed in <u>section 3.4</u>, but the feelings of professional discomfort in this context are relevant to highlight here):

I think finances are a bit of a, almost like a taboo subject sometimes, people don't really want to talk about it, don't want to touch it, don't want to get accused of anything... obviously, it's very uncomfortable because you can open yourself up to a can of worms there, like taking someone to the bank... We always say go in twos...if you're going to have to get money for someone. (P14, social worker, local authority)

Some family members highlighted the burden of responsibility of making significant financial decisions such as selling property, and one alluded to a broader emotional aspect related to possessions to which a person may be very attached:

I had to organise everything [with the] solicitor, and I was the person that had to go up and empty the house, and go through the whole emotional baggage of, 'right, mum, you're only moving into a single bedroom flat, you can't take this, we have to take it to the charity shop'... it was very stressful, very stressful indeed. I was the bad

person that was forcing her to get rid of the prized possessions and all this sort of thing. (F1, daughter)

There could also be frustration and worry about a potential future burden of responsibility when someone refuses to share information:

...if my mum dropped dead tomorrow, I wouldn't know what to do... she's been adamant that she would make it... I can't say make it as difficult as possible, although I want to 'cause I'm angry, she's made it so not easy. (F6, daughter)

Organisational focus on procedure and process can lack empathy

One relative described how, when attempting to communicate with organisations on behalf of her mother, the organisational emphasis on procedure and process may come at the detriment of empathy that the person acting as Attorney is in the midst of an emotionally challenging situation:

...it's not easy to have a Power of Attorney and want to speak to somebody in a financial institution about somebody who has Alzheimer's. You're taking control of their finances and it's very hard... because you know that that person that you're speaking on behalf of has lost it, they've no longer got any understanding of finances at all. And it is a great responsibility to do that. And a little bit more compassion from these utility companies, when somebody who has Power of Attorney is speaking to them, would help, because you have Power of Attorney and you are speaking to them for a particular reason. A little bit of empathy and compassion would probably go a long way. (F2, daughter)

This example stood in direct contrast to an example of very positive experiences of sympathetic support following bereavement:

...when your mum passed away and your brother did start to contact all the financial institutions, he was very impressed about how supportive and sympathetic they were when he phoned all the institutions, they all had a bereavement team. (F8, talking to F7; couple)

It is interesting to note that the above quote refers to support via specialist bereavement teams that are common within financial institutions. It is possible that financial institutions are better equipped to provide emotive support around the bureaucracy of death than they are around the bureaucracy of mental incapacity. Some of the examples mentioned earlier in section 3.3 about legal and procedural understandings about Power of Attorney within organisations would seem to support this idea.

The enduring resonance of historically negative experiences

Another challenge for people in dealing with authoritative financial institutions could be an enduring emotional resonance of historically negative experiences. We were given specific examples relating to older LGBT people:

...when people of these generations tried to get mortgages, they may have been asked to provide evidence of HIV status or denied mortgages or insurance... going back to the [19]80s... if you had that kind of experience before, of being othered or singled out and denied the right to things, actually you don't forget that, even if it's 20 years on or 30 years on. (P17, programme lead, charity)

Such experiences undermine people's trust and therefore their willingness to seek support. There was strong emphasis placed on the importance of sensitive approaches from financial services organisations that do not make any normative assumptions about people:

...the worry is that... someone makes an assumption about you. So you could be phoning a helpline or you could be going into your bank, for example, and there might be a comment, if you're a woman, 'is your husband not with you today?', that kind of thing. And that instantly throws you off and makes you think, does this company understand who I am and how important that is to me, and do I want to make this arrangement with them if they're going to make that assumption about me and don't think more broadly about LGBT identity? So what I'm hearing from a lot of people is that the welcome, the kind of inclusion right from the start is so important... this is the kind of thing that people want to see when they're approaching for support, and it's the thing that they're worried about that might happen that might undermine their confidence in an organisation. (P17, programme lead, charity)

Although these examples refer to older LGBT people, it would seem reasonable to assume that the central messages, about concerns and hesitancy based on prior negative experiences, are transferrable to people from other social groups who have experienced discriminatory treatment.

Summary

This theme shows the complex feelings and emotions that are bound up in issues relating to money, both among people who may be losing financial capacity, and among professionals who may be potentially able to provide some support. The emotional side of money management and the particular threats posed by financial incapacity to self-identity appear striking but overlooked. Focusing on processes and procedures may be (inadvertently) insufficiently empathetic or sensitive to people's individual experience and contexts.

3.6 Triangulation with documentary evidence

In this section, we consider the extent to which the themes in the interview data are reflected in the public and professional information resources.

3.6.1 Public resources

The issue of ability to manage money is often portrayed as a global judgement and as a threshold that will be crossed, rather than one encompassing a broad range of skills along a continuum which might also vary from day to day. It is also implied that this threshold will be mutually recognised by everyone involved. There are many examples of phrases like 'if there comes a time' (Table 1 in Appendix, document ID Pub6; Pub11) or that someone 'will come to a point' (Pub28) when they can no longer manage their finances. This portrayal is usually seen in factsheets or brief introductory resources to the topic of mental capacity and personal finances. Other, more detailed resources more clearly highlight a range of skills involved, that ability to manage money is a continuum, and that there may be differences in perception of someone's functional ability:

If the person's ability to manage their finances is concerning, it may help to identify why they are struggling... For some people, it might be only specific financial decisions that they struggle with. Often people with dementia can continue with day-to-day finances, such as paying for shopping, but may have difficulty with more complex decisions. For example, the person may find it difficult to change their gas supplier or make choices about investments... In time, however, it may become apparent to a carer that, even with support, the person with dementia is struggling to cope. For example, they may fail to understand what needs to be paid, overpay for some things, or leave money unaccounted for. (Pub15)

A comprehensive resource on mental capacity and decision-making after brain injury also differentiates between types of financial decision-making in terms of determining capacity:

When considering a person's capacity, the complexity and magnitude of each decision should be assessed individually. For example, someone may be able to manage £100 in a bank account, yet require assistance dealing with £1million worth of investments. Similarly, buying a bus ticket is less complicated than buying a new house. A person may be able to buy the ticket, but they may need someone to assist them with choosing and purchasing a property. (Pub31)

Many sources however suggest that there is a clear time when Power of Attorney will be needed, which echoes some of our participants' recollections of how they introduced the concept to their relatives.

...the document might sit in a drawer for years before it's needed, but it can be reassuring to know that the legal paperwork is in place should it ever be needed. (Pub65)

Once registered with the Office of the Public Guardian, it can be used immediately or held in readiness until required. (Pub57)

These examples illustrate a scenario in which all parties will agree on the point at which surrogate decision-making is required. There is very little indication that people may change their perspectives, that a progressive illness like dementia may alter people's perception and personality and that people may become suspicious of relatives who they once trusted. There is also a lack of recognition that capacity may fluctuate or may be legally different for different types of financial decisions.

In general, the public information resources portray managing money on someone's behalf as having a degree of procedural complexity to get to grips with, but ultimately, that people can expect things to be straightforward once they have understood the procedures. Many of the resources are very process-oriented, with clear descriptions of various options such as Power of Attorney and Deputyship, and how to set up and register them. This is particularly the case in Government/Office of the Public Guardian (OPG) documents (Pub33-Pub41), which is unsurprising given that the OPG is the governmental body that polices the actions of surrogate financial decision-makers. Many other resources we identified provide links to the relevant Government/OPG pages (e.g., Pub18). Where the emotional complexity of money is articulated, it tends to be around the initial discussions and conversations about someone supporting the management of another's finances. Some of the consumer resources emphasise the importance of trust and contain detail about having conversations about money (e.g., Pub47; Pub65). On the whole, there is little within the information resources to suggest the potential for surrogate decision-makers to experience ongoing challenges. Rather, it is generally presented in normative terms of what is supposed to happen (i.e., once LPA is registered, the attorney will be able to interact with financial institutions with no obstacles), with little advance warning that the process may not always work as it should and that it may be extremely stressful.

3.6.2 Professional resources

Overall, the lack of clarity articulated in our interview data about how providers and professionals assess people's capacity to manage money and support people to manage their money is also present in the professional resources. We identified one resource that specifically demonstrates capacity assessment around financial decision-making, which is the Social Care Institute for Excellence 'Making Decisions about Money' webpage (Table 2 in Appendix, document ID Pro11). This contains a 16-minute video vignette of a social worker assessing the capacity of an older man with learning disabilities to make decisions about his money. It demonstrates a granular assessment of managing money, including withdrawing and spending, the value of money and understanding paperwork, all in a person-centred rather than hypothetical way (e.g., the man likes fish and chips, so the social worker asks him questions relating to buying fish and chips). However, there is no explanation about

the assessment outcome or reasons for the outcome, nor what help is available to him after that, nor what the responsibilities of the social worker become or what action they (professionals) should then take. The viewer is left to assume that the social worker has concluded that the man has capacity, but it is not clear whether she feels his skills are stronger in some areas than others, or the granular assessment contributes to an overall judgement. The summary messages for practice also do not align well with the video. One is that 'all staff providing care should be comfortable with assessing capacity', yet the video features only a social worker; this would appear to correlate with our interview data in which the vast majority of participants see (financial) capacity assessment as being within the domain of social work. Other messages state that the assessor 'should talk to other people who know the person well' and 'could include observation of how the person copes in different situations', but the video does not show the social worker speak to anyone else or observe the man handling money in real-world situations.

The most detailed examples for supporting people how to manage money come in the Welsh Government Statutory Guidance for Service Providers (2019), under Regulation 28 (Pro 18). This places emphasis on service providers having clear policies and procedures in place for a range of different aspects of financial management, including account management, daily transactions and accessing independent support and advice. There is also guidance that focuses on separation of service users' money from that of the service and the need for record keeping. Several other resources make mention that people should be supported to manage their money if necessary, but there is little guidance about how this might actually be delivered. For example, the Skills for Health Dementia Training Standards Framework (Pro12) links dementia awareness (subject 1) to the first principle in the Skills for Care/Skills for Health Common Core Principles for Supporting People with Dementia resource (Pro13), which highlights that problems using money may be an early sign of dementia. Given this known sensitivity of money management to cognitive decline, it is therefore surprising that the topic is largely missing from the Training Standards Framework. It is plausible that money management may be assumed under broader, holistic aspects, e.g., person-centred care, which includes learning outcomes such as understanding the role of family and carers, and the significance of person's background, culture and experience. However, while other specific aspects of care such as nutritional requirements and medication administration are explicitly referred to in the Regulated Qualifications Framework, money management is not.

In cases where a local authority is acting as a Deputy to manage someone's assets, there are professional standards to guide practice (Pro19). These standards include more complex aspects of asset management, such as seeking independent financial advice to maximise a client's assets and conducting an annual review of a client's portfolio. However, as one local authority interviewee told us, practice around Deputyship varies nationally among local authorities. It remains unclear from our data as to the extent to which these standards are implemented in practice, and how precisely what happens in cases where authorities do not take on this role.

In general, the topic of personal finances tends to be more explicitly mentioned in the documentation under safeguarding, where financial exploitation is listed as a potential risk. This positioning is also represented in our interview data, in which safeguarding was highlighted as a route to trigger support for money management concerns. For example, in the Social Care Wales practice guidance (Pro8-Pro10), finances are referred to only under safeguarding, in relation to care workers not borrowing from/lending to a service user, and in the topic of gifts. In a section on 'delivering care and support', a variety of activities are outlined which cover a range of ADLs and IADLs, but there is no explicit mention of money management, despite it also being an IADL. Regulatory compliance guidance for service providers and managers from the English Care Quality Commission (Pro16) is similarly limited, only mentioning money in terms of protecting people from loss or theft.

Social work capabilities and standards (Pro1, Pro2) emphasise a rights- and strengths-based approach to working with older people and their significant others. They specifically challenge the view of all people over 65 as a homogeneous group of older people and emphasise respect for the complexity and experience of lived lives. They also emphasise taking a biographical approach during assessment of need to understand the person. The Skills for Care/Skills for Health Common Core Principles for Supporting People with Dementia (2011) resource (Pro13) alludes to support for money management under Principle 4, which refers to promoting independence. One of the 'indicative behaviours' of the workforce is to be able 'to support people with dementia to access mainstream services, such as shops and banks.' Financial planning and Power of Attorney are mentioned under Principle 6, which refers to family members and unpaid carers. One of the indicative behaviours here is signposting people to information to understand the impact of dementia, or referring them to other sources of advice. Many resources highlight in more general terms the importance of informed choice, e.g., the Social Care Wales guidance for social care managers (Pro6), which states that 'you must promote a culture that enables individuals to have a strong voice and control over their care and support. This includes providing information that supports individuals to make informed choices.'

This picture therefore largely correlates with our interview data in which participants referred to minimal (if any), generic training around the issue of mental capacity assessment and supporting people with money management. The MCA in this context being the domain of social work, and the emphasis on signposting, also echoes practice guidance.

3.7 Thematic synthesis

Our analysis has highlighted four main themes relating to (i) the identification of problems with capacity to manage personal finances, (ii) the complexities of the law in this space, (iii) the support that is available to people, and (iv) the role of emotions in managing money. In summary, formal and detailed assessment relating to specific aspects of money management appeared to be lacking, and judgements about someone's ability to manage money are often made informally and based on general

interpretations of someone's ability to live well. Understandings of legal issues and procedures regarding mental capacity and money management appear to be highly variable among the public and professionals, but extremely important. There is a lack of meaningful training for professionals in this area. There are challenges in both factual understanding of the meaning of laws and procedures, and understanding how to navigate support. The support available for people to manage their money often takes the form of signposting to other sources of advice, under the care practice philosophy of empowering people to make decisions for themselves. Given the general challenges of financial literacy at a population level, and the stresses individuals and families are already under in managing cognitive issues, it is not clear how far this approach is empowering, or whether it just leads to further unmet need. Underpinning behaviours in relation to money are a deeply complex array of emotions, both for those who are yielding control of money management and those providing support — either family or professional.

The four themes intersect with one another in different combinations, with potentially multiple directions of influence.

A lack of formal, granular MCA assessment is plausibly related to challenges in understanding law and procedures, a lack of clear roles, responsibilities and resources to provide support, and emotions regarding the challenge of declining mental capacity:

- The lack of formal granular assessment ('identification') may be related to a lack of clear legal understanding among the majority of social sector professionals who see themselves as unqualified to make this assessment ('law and procedures'), or as not responsible for practical support ('support').
- The lack of formal, granular assessment ('identification') may be influenced by the lack of resources available to provide support to someone if they are assessed as lacking capacity ('support').
- The lack of formal granular assessment ('identification') may be related to the deeply personal nature of money, the challenging nature of the conversation and the threat posed by the implications that one does not have capacity ('emotions').

There are also plausible relationship between issues relating to signposting as a form of support, emotions, and law and procedures:

- The emphasis on signposting people to other sources of information ('support') may be justified by an empowerment ethos but also may arise in part from professional discomfort and reluctance to become too involved in the topic of money management ('emotions').
- The extent to which signposting constitutes empowerment in the context of managing money ('support') is debatable given the complexity of the area ('law and procedures') and the emotional labour involved in decision-making and surrogate decision-making around money ('emotions'), which is not reflected in the public information resources.
- The emphasis on bureaucratic procedural fidelity—and misunderstandings by some financial and consumer organisations ('law and procedures') may be

insensitive to people's experiences of taking on responsibility for managing the finances of someone who has lost capacity ('emotions').

Overall, our findings suggest that the relationships between these themes are intricate and varied. We now turn to discuss some implications of these findings and thematic relationships.

4. Implications

In this section, we provide some comment on our study findings and make some suggestions regarding financial capacity assessment and support. This discussion is not intended to be critical of any of the participants in our study, many of whom are dealing with extremely challenging contexts with limited resources. It is neither fair nor realistic to expect professionals working in social care/social sector roles to be responsible for all aspects of financial capacity and support – and clearly they are not qualified financial advice professionals regulated by the Financial Conduct Authority. However, we suggest that a number of improvements could be made.

4.1 A dedicated strategy for financial capacity: clarity of roles, responsibilities and options for timely and appropriate support

The December 2022 House of Lords Select Committee on Adult Social Care states that 'at the heart of the adult social care system should be the objective of enabling independent living'. As the ability to manage one's money is so central to independent living, we suggest that there is a need for a dedicated and proactive strategy for the topic of mental capacity and money management within the social sector to ensure timely support that may prevent crises. Such strategy should contain greater clarity around roles, responsibilities and approaches to the provision of support for people to manage money, both within local authorities and for support organisations in the wider social sector.

Overall, the provision of support for day-to-day management of money appears patchy, with many professionals being uncomfortable in providing such support. The reliance on gut feeling and general observation to raise questions about someone's mental capacity to manage money may be a useful heuristic to initiate further support. However, given that money management is very sensitive to cognitive decline, it is not clear that recognition of potential financial incapacity and provision of subsequent support is timely. The predominant framing of personal finances in practice guidance as an issue to be considered within the realm of abuse and safeguarding means that support for difficulties in managing money is mainly initiated and delivered in responsive crisis mode. There may be long waiting lists for any non-safeguarding intervention, and other professionals may look to social workers to provide practical support that is arguably not within their remit. The finding that safeguarding referrals appeared to be the preferred option in response to any concerns about financial capacity, because they trigger an obligatory response from a local authority, implies a hierarchy of support needs and provision that is 'consistent with a climate of scarcity'. 50 Even this approach would seem unsustainable given the Care Quality Commission's latest 'State of Care' annual report highlighting increases in requests for care and stark resource challenges.⁵¹

We therefore suggest that there is a strong need for a clear strategy for the topic of mental capacity and money management. This may include a focus on independent advocacy for people who do not have family support. **The development of such a**

strategy may benefit from a multi-agency approach involving the social, legal, debt and financial services sectors. Our findings suggest that currently there is a vacuum, or at least, highly variable and inconsistent practice, in the actual support that is available to people, particularly for those who do not have financially competent family who are able and willing to step in. There is a need for critical examination of what support the social sector can provide that does not extend into the domain of regulated financial advice, but there is also a need for a critical examination of exactly what constitutes regulated financial advice in the context of supporting people who lack capacity to manage their money, and whether these boundaries are fit for purpose. The development of such a strategy alongside improvements in training for social sector professionals, could enhance skills and confidence in providing timely support.

4.2 Realistic, context-specific core training

As part of a clear strategy for financial capacity, there is a need for better training regarding financial capacity assessment and support. This training should be realistic, context-specific and embedded as core training, rather than one-sizefits-all generic instruction that contains little-to-no examples of financial decisionmaking within the particular population that a professional is supporting. Training would also benefit from being developed and delivered in partnership with older adults and unpaid carers.⁵² Our findings reinforce previous work highlighting a lack of knowledge and reluctance among many professionals to be involved in mental capacity assessment, 32-34 which appears to be exacerbated in this particular context by a discomfort around involvement in matters relating to personal finances. As managing money is central to people's independent functioning, the lack of specific training on financial capacity reported by many professionals in our study is concerning. A landscape in which professionals responsible for providing support may have to find out information related to such a key and complex topic by searching the Internet in their own time, or passing on what they have heard from others, seems inappropriate, particularly given that these professionals' own financial literacy will also be highly variable. 16 There is a clear need for more learning opportunities specifically related to financial capacity, how it is assessed and ways to support people.

These learning opportunities need to be carefully considered and resourced. Current MCA training has little impact in real-world settings, and under-resourced, risk-averse, hierarchical health and care environments stifle legally compliant interpretation and implementation in practice.⁵³ Interactive training with realistic scenarios reflecting practice complexity has the most positive impact. Factors likely to improve training outcomes include the chance to apply learning soon after training, well-resourced and flexible options to suit different learning styles, supported within participants' working hours (rather than online training to be completed in practitioners' own time).⁵³ This is particularly important given perceptions of evidence, training and priorities for practice change in social care. A recent extensive UK survey of adult social care staff, service users and their unpaid

carers (> 2000 respondents) about their priorities and perspectives for the sector has highlighted that there is less appetite for evidence or training, and more emphasis placed on funding and practical support on the ground.⁵⁴ Therefore, **there is also the need to consider how any training might align with delivering genuine practical change** in a sector in which there is a lack of shared vision and which suffers from a lack of priority in wider society.^{49,54}

4.3 Rethinking the role of signposting and empowerment in the context of money management

There is a need for more concise and accessible information about the key issues regarding financial capacity and surrogate decision-making; a suggestion made by academic research 15 years ago and which is still warranted.55 There is a plethora of information available, but there is a need for greater support for people to understand this information and to think through the options that will be most suitable for them. However, the complexities of finance and the relatively poor levels of financial literacy at a population level mean that it is not clear how far signposting people to further sources of information genuinely represents the empowerment and support for autonomy that is emphasised in much of the care sector practice guidance. The empowerment narrative has arguably been adopted during and after neoliberal cutbacks to welfare, based 'on the liberal idea of the autonomous individual, for whom dependency is perceived as essentially negative'.56 The 2021 White Paper on adult social care reform dedicates an entire chapter to empowerment, calls for improvements to the information and advice that people are offered about social care, and recognises the potential of peer support for unpaid carers.⁵⁷ Although calls for improvement here are broadly welcome, this approach as it currently appears may be inappropriate in this particular context. Peer support for carers of people with dementia most often includes sharing information and may have positive impacts on carers' mental and physical health, 58 but it is not clear how far peer support may be helpful in the context of managing declining financial capacity given the wide variation in financial literacy at a population level. 16 Even highly educated and computer literate people struggle to navigate the complexity and volume of later life medico-legal information that is available online.⁵⁹ Carers of people with dementia have reported that simply being given information about financial issues following a diagnosis does not go far enough, as they need practical support.41 The topic of support is not limited to the social sector as it is clearly partly an issue for the financial services, consumer and retail industries in terms of how they are best able to support their customers. 60 Yet for the social sector, there is a strong argument for the importance of co-production approaches with older adults and carers to develop information and support services in the domain of financial capacity. The principle of co-production is firmly endorsed by the Social Care Institute for Excellence and there are numerous examples of successful and innovative co-production approaches in other domains of social care.⁵²

4.4 Greater recognition of the emotional nature of managing money

There is a need for more explicit recognition of the emotions that underpin the topic of financial capacity and (surrogate) financial decision-making. People are not always rational actors and financial decision-making is strongly influenced by emotions. Our findings show that professionals are very aware of the sensitivity of the topic of financial capacity, both for the people they support and around their own discomfort in broaching the topic. However, the bulk of information resources to which people may be directed contain factual and procedural information and pay far less attention to the emotional complexity of financial capacity. Factual information may be reassuring during an emotionally challenging period (e.g. following a diagnosis of dementia), but there is a difference between laws and procedures in principle and in real life, where implementation of those laws and principles involves interaction between people and systems (e.g., within families; between the public and people working in authoritative organisations). Further nuanced recognition of this would be welcome to prepare people for future challenges. There is also likely to be a need for greater recognition of this issue within the financial services industry.

4.5 Issues with the Mental Capacity Act

So, what makes the management of money in the context of fluctuating capacity particularly challenging? This study highlights several ambiguities that raise difficult questions about how to ensure the spirit of the MCA, which seeks to both empower and protect, is operationalised. A very clear disconnect between the theory behind the legislation and its practical implementation is starkly evident in relation to financial decision-making within the social care context.

Much of the existing literature focuses on healthcare decision-making under the MCA, including the advance decisions made by individuals expecting to lose their capacity in some way in the future. Yet this type of decision-making is undertaken within the scaffolding of healthcare provision. Decision-making, both contemporaneous and advance, tends to be much more linear within health care – often driven by the progressive nature of a disease from diagnosis to treatment to outcome. This decision-making pathway is supported by a plethora of health care practitioners intervening at regular points. Yet, even within this, advance medical decision-making is recognised as presenting its own challenges. Advance decisions can be very powerful, but they are also brittle and so it is best practice to ensure a written statement of the individual's broader views/wishes is included in any advance statement, as peoples' views can and do change over time. Medical intervention is often prefixed by formal discussions around consent and these discussions may inevitably raise further questions about capacity, which are then addressed before further action is taken.

Within social care, these pathways are far more complex and navigating them is far more difficult. The identification of potential capacity issues is not necessarily

recognised before financial decision-making takes place. In practice, this may result in essentially retrospective capacity assessments occurring as a consequence of very serious and impactful deleterious financial choices being made. In situations where an older person with cognitive decline has agreed to buy an expensive, unnecessary product, families may have to contact the company to explain the situation and to ask for contractual rescission. The network of care and support within the community often relies upon a variety of sources and provision, both informal, formal and ad hoc in nature, including NHS healthcare intervention, local authority housing and welfare support, social care workers, third sector organisations and family and friends. Bound up within the myriad of community-based support is the question of money and how decisions surrounding it are undertaken, and by whom.

The MCA struggles to respond to common nuances found within the context of financial decision-making. While it assumes capacity must first be rebutted before decisions can be made in a person's best interests, and fluctuating capacity is legally recognised, in practice, these variations in capacity may present practical problems within the financial arena. The context of such decision-making is important as many, if not all, financial decisions are undertaken within the more dynamic decisional landscape of the community. A person may have the capacity to undertake micro financial decisions, such as, going shopping, but not other, more complex and impactful financial decisions. For most small day-to-day decisions, the MCA relies upon the people who are most involved in the person's care, but this results in capacity assessments being largely informal and intuitive.⁶⁴ Larger, more complex decisions may require much more formal assessments of capacity with regular review. The present study has found that the way in which micro decisions are made could have the potential to compromise the empowerment/protective objective of the legislation, either because decisions are taken out of the hands of people when they have the capacity to make them, thus disempowering them, or because inadequate protection is given to those who need more support/intervention to assist them in making financial decisions.

In 2019, the Alzheimer's Society found that 120,000 people with dementia were living alone, and this is expected to double by 2039.⁶⁵ How is financial capacity supported for people like this? Integral to the operation of the MCA is the assumption that care is provided either formally or informally, yet this is not the case for all. The December 2022 report from the House of Lords Select Committee on Adult Social Care highlights the 'embedded narrative' within social care that care and support should be provided by family first, and spotlights the invisibility of the growing numbers of people ageing without children or family to provide support.⁴⁹ While insufficient data emerged from the present study about this issue, the precarious nature of financially managing alone, particularly with cognitive decline, is evident and requires further research.

5. Further research

This study is exploratory research, the goal of which is to develop a better understanding of an unclear problem. There are some limitations to the study, which we describe here along with some suggestions for further research:

- Although we recruited a wide range of professionals, despite our extensive networks we struggled to recruit social workers and domiciliary care staff and therefore the perspectives of people working in these roles are limited.
- We were also only able to recruit a small number of public participants, who
 were almost all of white British ethnicity and who were comfortable talking
 with professional researchers after a short introduction.
- Further work could focus on exploring the topic of financial capacity in later life
 within diverse socioeconomic and cultural groups, to explore a broader range
 of experiences and priorities. This would likely require a more culturally
 diverse research team, working within specific communities, and may benefit
 from the involvement of translators and peer researchers. Such an approach
 was far beyond the resources of the current study and we would recommend
 that future research be designed with this specific focus.
- Further work with greater numbers of older people living with cognitive impairment is warranted. Such work should include a focus on people living in a variety of scenarios, including those living alone.
- Longitudinal qualitative approaches using in-depth case study methodology focusing on people from the point of dementia diagnosis onwards could be extremely illuminating to explore experiences of navigating declining financial capacity contemporaneously.
- There is a need to revisit the potential of large quantitative data sets⁵⁵ to explore the prevalence of surrogate financial decision-making, its impact on health and wellbeing, and health and wellbeing inequalities.⁶⁶
- No work in jurisprudence has been undertaken since Donnelly's work in 2009³¹ regarding how capacity is assessed by non-legal assessors. Two key issues warrant attention: (a) the assessment of capacity (both process and understanding) and (b) the assessment of best interests, both of which apply directly to the financial and social care context. One area of focus could include exploring the potential of different approaches to formally assessing financial capacity, including the use of new tools such as the Lichtenberg Financial Decision Rating Scale.^{67,68}
- Future work exploring the topic from the perspective of the financial services industry is highly warranted. This could include a critical examination of the industry's approaches to identifying 'vulnerable customers' and financial services professionals' perspectives and experiences of attempting to support older customers who are experiencing cognitive decline.

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Appendix

Table 1. Public-facing organisations and resources

ID Organisation		Page/resource	URL	
Pub1	Action Fraud	Guide to reporting	https://www.actionfraud.police.uk/guide-to-reporting	
Pub2	Action Fraud	Standards of Service	https://data.actionfraud.police.uk/cms/wp-content/uploads/2020/04/AF-service.pdf	
Pub3	Action Fraud	Victim resources	https://www.actionfraud.police.uk/victim-resources	
Pub4	Action Fraud	Vulnerable victims and the victims' code	https://www.actionfraud.police.uk/vulnerable-victims-and-the-victims-code	
Pub5	Age UK	Caring for someone with dementia	https://www.ageuk.org.uk/information-advice/care/helping-a-loved-one/caring-dementia/	
Pub6	Age UK	Planning for the future	https://www.ageuk.org.uk/information-advice/health- wellbeing/conditions-illnesses/dementia/planning-for-the- future/	
Pub7	Age UK	Power of attorney	https://www.ageuk.org.uk/information-advice/money- legal/legal-issues/power-of-attorney/	
Pub8	Age UK	What to do if you're worried about someone	https://www.ageuk.org.uk/information-advice/worried-about-someone/	
Pub9	Alzheimer's Society	Accessing and sharing information on behalf of a person with dementia	https://www.alzheimers.org.uk/get-support/publications-and-factsheets/booklet-accessing-sharing-information	
Pub10	Alzheimer's Society	Deputyship	https://www.alzheimers.org.uk/get-support/legal- financial/deputy-dementia	
Pub11	Alzheimer's Society	Lasting power of attorney for people with dementia	https://www.alzheimers.org.uk/get-support/legal- financial/lasting-power-attorney	
Pub12	Alzheimer's Society	Living alone as a person with dementia	https://www.alzheimers.org.uk/get-support/staying-independent/living-alone	
Pub13	Alzheimer's Society	Living with dementia - Managing your money	https://www.alzheimers.org.uk/get-support/publications-and-factsheets/living-with-dementia-managing-money	
Pub14	Alzheimer's Society	Living with dementia - Planning ahead	https://www.alzheimers.org.uk/get-support/publications-factsheets/living-with-dementia-planning-ahead	
Pub15	Alzheimer's Society	Making decisions and managing difficult situations	https://www.alzheimers.org.uk/get-support/daily- living/making-decisions-and-managing-difficult-situations	
Pub16	Alzheimer's Society	Making decisions for a person with dementia who lacks mental capacity	https://www.alzheimers.org.uk/get-support/legal-financial/making-decisions-mental-capacity-dementia	
Pub17	Alzheimer's Society	MCA factsheet	http://www.alzheimers.org.uk/sites/default/files/2019- 05/460lp-mental-capacity-act-2005-190521.pdf	
Pub18	Carers' Trust	Helping someone else manage their	https://carers.org/legal-and-rights/helping-someone-else- manage-their-money	

		money		
Pub19	Carers' Trust	Managing someone else's affairs	https://carers.org/legal-and-rights/managing-someone-elses-affairs	
Pub20	Carers' Trust Wales	Caring for Someone with Dementia/Gofalu am Rywun â Dementia	https://carers.org/resources/all-resources/117-caring-for-someone-with-dementia-gofalu-am-rywun-dementia	
Pub21	Carers UK	Mental capacity in England and Wales	https://www.carersuk.org/help-and-advice/practical- support/managing-someone-s-affairs/mental-capacity-in- england-and-wales	
Pub22	Carers UK	Different ways of managing someone's affairs in England and Wales	https://www.carersuk.org/help-and-advice/practical-support/managing-someone-s-affairs/different-ways-of-managing-someone-s-affairs-in-england-and-wales	
Pub23	Carers UK	Managing services on behalf of someone else – tips from carers	https://www.carersuk.org/help-and-advice/practical-support/managing-someone-s-affairs/tips-from-carers-managing-services-on-someone-s-behalf	
Pub24	Citizens' Advice (England)	Managing affairs for someone else	https://www.citizensadvice.org.uk/family/looking-after-people/managing-affairs-for-someone-else/	
Pub25	Citizens' Advice (Wales)	Managing affairs for someone else	https://www.citizensadvice.org.uk/wales/family/looking-after-people/managing-affairs-for-someone-else/	
Pub26	Dementia UK	Changes in care: capacity and decision making	https://www.dementiauk.org/get-support/diagnosis-and-nexisteps/changes-in-care/capacity-decision-making/	
Pub27	Dementia UK	Caring from a distance	https://www.dementiauk.org/get-support/diagnosis-and-next-steps/caring-from-a-distance/	
Pub28	Dementia UK	Lasting power of attorney	https://www.dementiauk.org/get-support/legal-and-financial-information/lasting-power-of-attorney/	
Pub29	Headway	A guide to the Mental Capacity Act	https://www.headway.org.uk/media/2784/a-guide-to-the- mental-capacity-act-factsheet.pdf	
Pub30	Headway	Difficulties with decision making after brain injury	https://www.headway.org.uk/media/2798/difficulties-with-decision-making-after-brain-injury-factsheet.pdf	
Pub31	Headway	Mental capacity: supporting decision making after brain injury	https://www.https://www.headway.org.uk/media/2798/difficulties-with-decision-making-after-brain-injury-factsheet.pdf.headway.org.uk/media/4108/mental-capacity-supporting-decision-making-after-brain-injury-e-booklet.pdf	
Pub32	HM Government	Personal Independence Payment	https://www.gov.uk/pip	
Pub33	HM Government / Office of the Public Guardian	A guide to making your lasting power of attorney	https://www.lastingpowerofattorney.service.gov.uk/guide	
Pub34	HM Government / Office of the Public Guardian	Deputies: make decisions for someone who lacks capacity	https://www.gov.uk/become-deputy	
Pub35	HM Government / Office of the Public Guardian	Deputy guidance: how to carry out your duties	https://www.gov.uk/government/publications/deputy-guidance-how-to-carry-out-your-duties	
Pub36	HM Government / Office of the Public Guardian	Lasting power of attorney: acting as an attorney	https://www.gov.uk/lasting-power-attorney-duties/property-financial-affairs	
Pub37	HM Government /	Make decisions on	https://www.gov.uk/make-decisions-for-someone/print	

	Office of the	behalf of someone	
	Public Guardian	bondii or comcome	
Pub38	HM Government / Office of the Public Guardian	Make, register or end a lasting power of attorney	https://www.gov.uk/power-of-attorney
Pub39	HM Government / Office of the Public Guardian	Managing a bank account for someone else	https://www.gov.uk/government/publications/deputy-and-attorney-guidance-dealing-with-banks/manage-a-bank-account-for-someone-else-web-version
Pub40	HM Government / Office of the Public Guardian	Who needs a lasting power of attorney?	https://www.gov.uk/government/publications/who-needs-a- lasting-power-of-attorney
Pub41	HM Government / Office of the Public Guardian	What happens when I can no longer make decisions for myself?	https://www.gov.uk/government/publications/who-needs-a-lasting-power-of-attorney/lp9-what-happens-when-i-can-no-longer-make-decisions-for-myself-web-version
Pub42	Hourglass	Financial abuse	https://wearehourglass.org/financial-abuse
Pub43	Independent Age	Scamwise	https://www.independentage.org/get-advice/advice-guides- factsheets-leaflets/scamwise
Pub44	Independent Age	Managing my affairs if I become ill	https://www.independentage.org/get-advice/advice-guides-factsheets-leaflets/managing-my-affairs-if-i-become-ill
Pub45	Independent Age	Power of attorney	https://www.independentage.org/get-advice/future- planning/power-of-attorney
Pub46	Money Helper	Getting informal help to manage your money	https://www.moneyhelper.org.uk/en/family-and-care/illness- and-disability/getting-informal-help-to-manage-your-money
Pub47	Money Helper	Help manage the money of someone you're caring for	https://www.moneyhelper.org.uk/en/family-and-care/long-term-care/help-manage-the-money-of-someone-youre-caring-for?source=mas#
Pub48	Money Helper	Help someone to manage their everyday money	https://www.moneyhelper.org.uk/en/family-and-care/illness- and-disability/help-someone-informally-with-budgeting-and- day-to-day-money
Pub49	Money Helper	If the person you want to help has lost mental capacity	https://www.moneyhelper.org.uk/en/family-and-care/long-term-care/if-the-person-you-want-to-help-has-lost-mental-capacity
Pub50	Money Helper	If you're worried a family member's money is being mis-managed	https://www.moneyhelper.org.uk/en/family-and-care/long-term-care/solving-problems-when-family-members-are-helping-with-your-money
Pub51	Money Helper	Setting up a power of attorney in England and Wales	https://www.moneyhelper.org.uk/en/family-and-care/long-term-care/setting-up-a-power-of-attorney-in-england-and-wales
Pub52	Money Helper	When someone needs formal help managing their money	https://www.moneyhelper.org.uk/en/family-and-care/long- term-care/when-someone-needs-formal-help-managing- their-money
Pub53	Money Helper	How to have a conversation about money	https://www.moneyhelper.org.uk/en/family-and-care/talk-money/how-to-have-a-conversation-about-money
Pub54	Money Helper	Talking with older people about money	https://www.moneyhelper.org.uk/en/family-and-care/long-term-care/talking-with-older-people-about-money
Pub55	Money Saving Expert	Power of attorney	https://www.moneysavingexpert.com/family/power-of-attorney/
Pub56	NHS	Abuse and neglect of vulnerable	https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/abuse-and-

		adults	neglect-vulnerable-adults/
Pub57	NHS	Dementia guide	https://www.nhs.uk/conditions/dementia/
Pub58	Parkinson's UK	Losing capacity to	https://www.parkinsons.org.uk/information-and-
		make decisions	support/losing-capacity-make-decisions
Pub59	Parkinson's UK	Making a power of	https://www.parkinsons.org.uk/information-and-
		attorney	support/making-power-attorney
Pub60	Parkinson's UK	Putting your	https://www.parkinsons.org.uk/information-and-
		affairs in order	support/putting-your-affairs-order
Pub61	Stroke	Looking after	https://www.stroke.org.uk/finding-support/looking-after-
	Association	someone else's	someone-elses-finances
		finances	
Pub62	The Brain Charity	Expert legal	https://www.thebraincharity.org.uk/how-we-can-
		advice you can	help/practical-help/legal-advice
		trust	
Pub63	Turn2Us	Personal	https://www.turn2us.org.uk/Benefit-guides/Personal-
		Independence	Independence-Payment-Test/Handle-money#guide-content
		Payment - PIP	
		Assessment -	
		Handle money	
Pub64	UK Care Guide	Power of Attorney	https://ukcareguide.co.uk/power-of-attorney-costs/
		Cost and Fees in	
		the UK in 2021 -	
		A definitive guide	
		including finding a	
		solicitor	
Pub65	Which?	Power of Attorney	https://www.which.co.uk/money/wills-and-probate/power-of-
		ĺ	attorney

Table 2. Professional organisations and resources

ID	Organisation	Page/resource	URL
Pro1	British Association of Social Workers	Capabilities Statement for social workers in England who work with older people (2018)	https://www.basw.co.uk/resources/capabilities- statement-social-workers-england-who-work-older- people
Pro2	British Association of Social Workers	The Code of Ethics for Social Work (2021)	https://www.basw.co.uk/about-basw/code-ethics
Pro3	Social Work England	Professional standards	https://www.socialworkengland.org.uk/standards/professional-standards/
Pro4	Social Care Wales	The social worker: practice guidance for social workers registered with Social Care Wales (2019)	https://socialcare.wales/cms_assets/file-uploads/Practice-guidance-social-workers.pdf
Pro5	Social Care Wales	Code of Professional Practice for Social Care (2017)	https://socialcare.wales/dealing-with-concerns/codes- of-practice-and-guidance
Pro6	Social Care Wales	The social care manager: practice guidance for social care managers registered with Social Care Wales (2019)	https://socialcare.wales/cms_assets/file-uploads/SCW-SocCareMan-ENG-Mar19.pdf
Pro7	Social Care Wales	The adult care home worker: practice guidance for adult care home workers registered with Social Care Wales (2020)	https://socialcare.wales/cms_assets/file-uploads/Adult- Care-Home-Worker-Practice-Guidance.pdf
Pro8	Social Care Wales	The domiciliary care worker: practice guidance for domiciliary care workers registered with Social Care Wales (2018)	https://socialcare.wales/resources/the-domiciliary-care-worker
Pro9	Skills for Care	Code of Conduct for Healthcare Support Workers and Adult Social Care Workers in England (2013)	https://www.skillsforcare.org.uk/Support-for-leaders- and-managers/Managing-people/Code-of- Conduct.aspx
Pro10	Social Care Institute for Excellence	Mental Capacity Act and care planning (2017)	https://www.scie.org.uk/mca/practice/care-planning
Pro11	Social Care Institute for Excellence	Making decisions about money (video and transcript)	https://www.scie.org.uk/mca/practice/assessing- capacity/making-decisions-money
Pro12	Skills for Health (with Health Education England and Skills for	Dementia Training Standards Framework (2018)	https://skillsforhealth.org.uk/info-hub/dementia-2015- updated-2018/

	Care)		
Pro13	Skills for Care / Skills for Health	Common core principles for supporting people with dementia (2011)	https://www.gov.uk/government/publications/common- core-principles-for-supporting-people-with-dementia
Pro14	National Institute for Health and Care Excellence	Dementia: assessment, management and support for people living with dementia and their carers: NICE guideline 97 (2018)	https://www.nice.org.uk/guidance/ng97
Pro15	National Institute for Health and Care Excellence	Decision making and mental capacity: Quality Standard 194 (2020)	https://www.nice.org.uk/guidance/qs194
Pro16	Care Quality Commission	Guidance for providers on meeting the regulations: Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 (Part 3) (as amended); Care Quality Commission (Registration) Regulations 2009 (Part 4) (as amended) (2015)	https://www.cqc.org.uk/files/guidance-providers-meeting-regulations
Pro17	UK Home Care Association	Code of practice for care provider members of United Kingdom Homecare Association (UKHCA) (2016)	https://www.homecareassociation.org.uk/find- care/code-of-practice.html
Pro18	Welsh Government	Statutory Guidance for service providers (2019)	https://gov.wales/sites/default/files/publications/2019- 04/guidance-for-providers-and-responsible- individuals.pdf
Pro 19	HM Government / Office of the Public Guardian	SD5: Office of the Public Guardian professional deputy standards	https://www.gov.uk/government/publications/office-of- the-public-guardian-deputy-standards/sd5-office-of- the-public-guardian-professional-deputy-standards- web-version

Table 3. Professional participant characteristics

ID	Area*	Role / remit** Organisation type				
P1	Α	Support co-ordinator Charity (national)				
P2	В	Support co-ordinator	Charity (national)			
P3	С	Project co-ordinator	Non-profit (local)			
P4	С	Support officer	Non-profit (local)			
P5	D	Customer support Housing provider				
P6	D	Income officer	Housing provider			
P7	В	Advisor	Charity (national)			
P8	В	Business support	Non-profit (local)			
P9	В	Finance and client support	Non-profit (local)			
P10	С	Manager	Housing provider			
P11	В	Advisor	Housing provider			
P12	С	Manager	Housing provider			
P13	С	Manager	Housing provider			
P14	В	Social worker	Local authority			
P15	Е	Debt & welfare	Local authority			
P16	Е	Debt & welfare Local authority				
P17	В	Programme lead Charity (national)				
P18	G	Company director Home care provider (local)				
P19	Е	Tenancy manager Housing provider				
P20	Е	Debt & welfare Local authority				
P21	F	Information and advice officer Charity (national)				
P22	В	Support worker	Charity (national)			
P23	В	Finance manager	Local authority			
P24	E	Support worker	Charity (national)			
P25	Н	Co-ordinator (community team)	Local authority			
P26	Н	Co-ordinator (community team)	Local authority			
P27	В	Independent advocate	Charity (local)			
P28	G	Debt/consumer advisor (retired)	Charity (national)			
* letter	ndicates	city-region borough				
** role r	nay be de	escribed in terms of broad remit to preserve a	nonymity			
Age (m	edian): 54	4 (IQR 41-57; range 31-82; data provided by 2	25 participants)			
Ethnicit	y: 21 Whi	ite British; 2 Asian/Asian British Chinese; 1 As	sian/Asian British Pakistani; 4 data			

Ethnicity: 21 White British; 2 Asian/Asian British Chinese; 1 Asian/Asian British Pakistani; 4 data not provided

Gender: 19 female; 9 male

Years in current role (median): 4 (IQR 2.75-12; range 1-23; data provided by 24 participants)

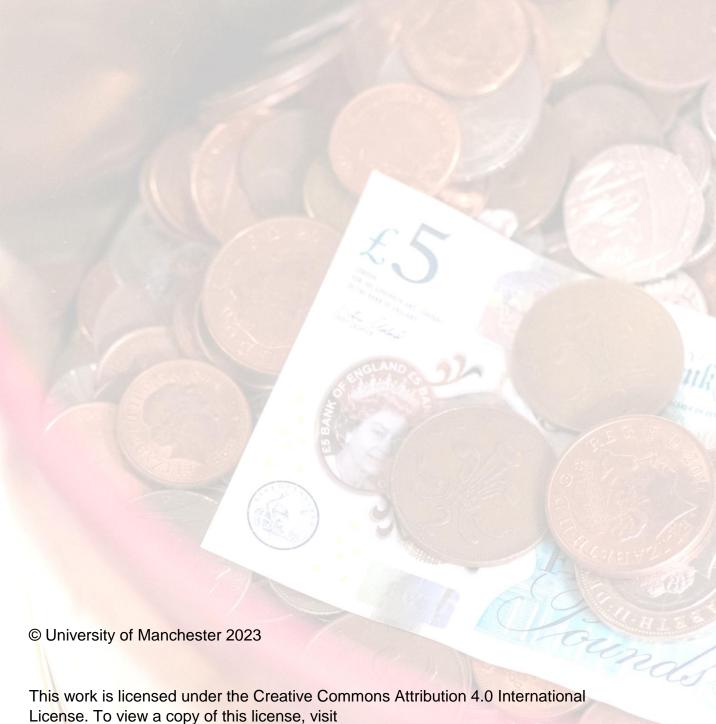
Table 4. Public participant characteristics

ID	Area*	Age	Gender	Ethnicity	Education level	Role/relationship
F1	D	62	Female	White British	Postgraduate	Caring for mother
F2	Н	63	Female	White British	Certificate/Diploma/NVQ	Caring for mother
F3	В	77	Male	White British	Degree	Married couple; planning for future
F4	В	73	Female	White British	GCSE/standard grade	
F5	В	52	Female	Arab	Certificate/Diploma/NVQ	Caring for father
F6	G	59	Female	White British	GCSE/standard grade	Caring for mother
F7	В	72	Male	White British	Postgraduate	Married couple; cared for late
F8	В	70	Female	White British	Certificate/Diploma/NVQ	mother(-in-law)
F9	G	49	Male	White British	Postgraduate	Caring for mother
F10	С	78	Male	White British	No school qualifications	Cared for late wife
F11	I	63	Male	White British	Certificate/Diploma/NVQ	Living with dementia**
F12	В	81	Female	White British	GCSE/standard grade	Married couple; F12 living with
F13	В	71	Male	White British	Degree	dementia

^{*} letter indicates city-region borough

^{**} included although under 65 because of challenges recruiting people living with dementia

Age (median): 70 (IQR 62-73; range 49-81)



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Executive summary:

https://documents.manchester.ac.uk/Doculnfo.aspx?DocID=65802

One-page summary:

https://documents.manchester.ac.uk/Doculnfo.aspx?DocID=65804

Plain English summary:

https://documents.manchester.ac.uk/Doculnfo.aspx?DocID=65807