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Synopsis

'Tired of spinning plates': Synopsis of mixed methods exploration of mental health experiences of adult/older carers of adults with learning disabilities

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Abstract

Background: This research addresses the mental health of family carers of adults with learning disabilities. We investigated participants' perceptions of their mental health and views on the accessibility and quality of support.

Design and methods: The research involved seven work packages which included public involvement, a rapid scoping review of evidence about family carers' mental health and support, an online exhibition, interviews with parent and sibling carers, digital storytelling workshops, key stakeholder discussions and the creation of learning and teaching materials.

Results: Caregiving driven by love is often exploited by health and social care services which deny basic support, information and kindness. Enduring struggle for support and worries about the future are often the cause of mental distress. Participants know what supports mental well-being but have little time to look after themselves due to the lack of support. Social services were described as 'hostile' or absent and participants viewed themselves as exhausted by the lack of support, rather than depressed. Medication can help but can be offered without consideration of their caring role or because there are no alternatives. Participants ask for their statutory entitlements for health and social care support to be met with kindness.

Outputs and dissemination: We delivered: (1) an expansive public engagement model; (2) an innovative and creative participatory approach to generate stories of care; (3) a dissemination strategy to raise awareness of the mental health of family carers and (4) the development of general practitioner resources.

We published journal articles, blogs, magazine articles, an online exhibition, films and presented findings at international conferences.

Public and stakeholder involvement and engagement: Family carers and people with learning disabilities were involved across the study, and in the Study Steering Group.

Limitations: Recruitment was slower than expected. Carers were unable to use care replacement costs because of a lack of alternative care. There were challenges involving marginalised communities. We engaged with fewer respondents through the Exhibition than the planned survey; however, it was important to respond to participants' views.

Conclusions: Health and care services often fail to recognise or adjust support for family carers despite provision under the Equality Act. The role of love in caring relationships, the absence of consideration of this in research, and

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the exploitation of this love by service systems which rely heavily on family carers were highlighted. Provisions in The Care Act and The Equalities Act are not always upheld, family carers struggle to gain support over years and even the 'feeblest' acts of kindness make a difference in health and care delivery. There is a need for policy-makers and practitioners to review and develop robust monitoring of the provision set out in legislation to ensure family carers and people with learning disabilities' entitlements are met. Small acts of kindness on the part of health and social care providers have a big impact on the well-being of family carers.

Future work:

1. Further exploration of care as a relational activity.
2. The development of ways of monitoring compliance and adherence to legal frameworks.
3. Bringing together the perceptions, views and experiences of people with learning disabilities, siblings and parent carers to generate a comprehensive understanding of the support needs of these groups.
4. An exploration of the mental health experiences of LGBTQI+ family carers and family carers of autistic adults without learning disabilities.

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A plain language summary of this synopsis is available on the NIHR Journals Library Website https://doi.org/10.3310/GJKR4724.

Introduction

Rationale for research and background

Our aim was to generate new knowledge and understanding of the mental health experiences of carers of adults with learning disabilities, paying attention to the impact of prolonged caring periods. Despite the call for people to live 'ordinary lives' in their own homes, adults with learning disabilities commonly live with family and friends in caring relationships with them.[1] The mental health experiences of family carers are not always prioritised in research, policy and practice.[2] We wanted to understand how carers perceive the accessibility and quality of health and social care support and generate resources for carers and for those who support them. Research reveals the lasting impacts of coronavirus disease discovered in 2019 (COVID-19) on the mental health of carers of adults with learning disabilities.[3–5] This research sought to ensure the mental health needs of carers of adults with learning disabilities are central to plans to build better health and social care support.[6]

Research aims and objectives

The research aims (RAs) were to:

1. Address the gap in knowledge about how carers of adults with learning disabilities conceptualise and experience mental health across the life course.
2. Address the gap in knowledge about the perceived quality, accessibility and effectiveness of support for carers' mental health.
3. Explore the provision and uptake of support services, including barriers to accessing carers' support services, including marginalised communities and groups.
4. Explore carers' perspectives on the effectiveness of interventions for carers (including respite; medication; social prescribing; passport schemes; employment support; alternative and complementary therapies).
5. Explore the long-term impacts of the COVID-19 pandemic on carers' mental health.
6. Coproduce the project, generate new knowledge and share impactful solutions working with groups of carers as coresearchers, research participants and project advisors.

The RAs were designed to be met through the following research objectives:

1. To convene a 'Tea, Cake and Spinning Plates' Group which will act as the study public engagement group and coresearcher group.
2. To publish a rapid literature review on the mental health of carers of adults with learning disabilities.
3. To co-design and conduct a survey with carers to explore their experiences of mental health and support. (Following coproduced workshops with family carers this became the online exhibition.)
4. To conduct interviews and online storytelling workshops with carers to create new narratives of carer mental health.
5. To synthesise findings and to generate learning and teaching resources for general practitioners (GPs), allied health professionals, social workers, support providers and voluntary organisations, including carer-led organisations and self-advocacy groups of people with learning disabilities, to improve support for carer mental health.
6. To disseminate research findings via an end-of-project event; two round tables; screening of films via healthtalk.org and socialcaretalk.org and through published materials.

FIGURE 1 Research pathway. PPI, patient and public involvement.

Specific research questions were addressed through the research work packages (WPs):

1. How do carers of adults with learning disabilities conceptualise and make sense of their own mental health across the life course?
2. What services, support and interventions do carers access (including: social prescribing; carers' passports; medication; talking therapies; peer support; alternative and complementary therapies) and how effective do they consider them to be?
3. What has been the impact of mental health issues on carers' family lives, ability to care, employment, friendship, and social life?
4. What are the impacts of COVID-19 so far on carers' mental health, and how do carers perceive the medium- and longer-term impacts and necessary support and interventions?

Methods for data collection and analysis

The study took place over 26 months and across 7 research WPs (see *Figure 1*). The academic publications from the project are included in the WP headings below, listed in *Table 1* and referenced throughout the synopsis.

Work package 1: 'Tea, Cake and Spinning Plates' group (RA6) (RO1) (Papers 1, 2, 3, 4 and 6)

The project's public involvement group was made up of six family carers and four people with learning disabilities. The name the 'Tea and Cake Group' seeks to centralise the human lives and experiences of group members beyond the formal and disconnected notion of 'public involvement'. The group provided guidance, feedback and advice across the research and met bimonthly online. In-person meetings with three members with learning disabilities were held bimonthly for the duration of the project. Group demographic data were collected via a Google Form with an Easy Read version available. Age category data comprised: 18–24 years (n2); 25–34 years (n2); 35–44 years (n1); 45–54 years (n1); 55–64 years (n2) and over 65 years (n1). Two group members identified as male and 7 as female. All were White British. With consent, discussions were recorded as coproduced bimonthly blog posts.

In WP1, these blog posts were analysed qualitatively using thematic analysis,[7] a flexible tool which is adaptable and accessible for coresearchers with developing qualitative

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TABLE 1 Publication plan

Paper	Journal	WP
1. Smith M, Runswick-Cole K, Ryan S, Croot L, Hatton C, Kassa C, *et al.*; The Tea and Cake Group (public involvement group who wish to stay anonymous). Tired of spinning plates: a rapid scoping review of the mental health needs and mental health support of carers of adults with learning disabilities in the United Kingdom. *Int J Disabil Soc Justice* 2025;**5**:246–89. https://doi.org/10.13169/intljofdissocjus.5.3.0001	*International Journal of Disability and Social Justice*	WP2
2. Runswick-Cole K, Smith M, Ryan S, Douglas P. Dis/entangling disability, mental health, and the cultural politics of care. *Scand J Disabil Res* 2024;**26**:28–43. https://doi.org/10.16993/sjdr.1101[8]	*Scandinavian Journal of Disability Research*	WP1 WP3
3. Runswick-Cole K, Smith M, Ryan S, Hatton C. 'Should we even have questions?' From survey to exhibition – co-producing research about 'mental health' with carers and adults with learning disabilities. *Int J Care Caring* 2024:1–16. https://doi.org/10.1332/23978821Y2024D000000051[9]	*International Journal of Care and Caring*	WP3
4. Ribenfors F, Smith M, Runswick-Cole K, Ryan S. Kindness and curious kinships in the lives of family carers of adults with learning disabilities. *Int J Care Caring* 2025:1–18.[10]	*International Journal of Care and Caring*	WP4
5. Ryan S, Ribenfors F, Smith M, Runswick-Cole K. 'It's not a sibling relationship, it's an "I help him" relationship'; Unpacking 'caregiving practices' among siblings of adults with learning disabilities. *Scand J Disabil Res* Under review.[11]	*Scandinavian Journal of Disability Studies*	WP4 WP5
6. Runswick-Cole K, Ryan S, Smith M, Ward M, Grosset C. 'Well, I am now looking after this bloody rabbit!' Re-storying care in the lives of people with learning disabilities. *Scand J Disabil Res* 2026;**28**:16–27.[12]	*Scandinavian Journal of Disability Research*	WP5
7. Runswick-Cole,K, Douglas, P, Ryan, S and Smith, M. Moving off script: A/synchronous storytelling with family carers and people with learning disabilities. *J Lit Cult Disabil Stud* 2025:1–20.[13]	*Journal of Literary and Cultural Disability Studies*	WP5

research skills.[14] Our aim was to capture the micro-detail in which people express their experiences while reflecting on what is happening and making sense of their everyday lives. A matrix of themes was produced and discussed at subsequent meetings with the Tea and Cake Group to enable members to contribute to the emerging analysis. We found that family carers disavow dominant global North models which frame responses to mental distress in medicalised and individualistic terms. The group described the way they experience trauma as 'something done to them' in and by service.[10] This work was informed by the UK Standards for Public Involvement, and all participants were remunerated for their time and expertise in line with NIHR guidance.[15]

Work package 2: Rapid Scoping Review of Evidence (RAs 1, 2, 3, 4, 5) (RO2)
(Paper 1)

A rapid scoping review[16] of evidence about family carers of adults with learning disabilities' mental health needs and mental health support available critically explored the following research questions:

1. What are the mental health needs and experiences of adult/older family carers of adults with learning disabilities?
2. What factors influence the mental health of this group of family carers and how?
3. What services, interventions and support systems do this group of family carers engage with and what evidence exists of their perceived effectiveness?
4. How are people with learning disabilities, family carers and mental health experiences conceptually constructed in the evidence?

The review, which used the scoping review framework and Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for scoping reviews, offers an innovative approach to coproduction and was produced collaboratively from conception to synthesis with the Tea and Cake Group.[17] We sought group members' views on included literature, including grey literature. A critical reflexive narrative analysis was conducted using the 19 evidence items included in the scoping review.[17] This thematic synthesis was initiated through undertaking a familiarisation of data, followed by data coding guided by the research questions (see *Appendix 1*). Subsequent themes and subthemes were developed and refined through coproduction with the Tea and Cake Group and research team.

Five key themes were generated: constructing mental health experiences of family carers; unique temporalities of this carer group; economic value of family care, importance of community; and ongoing ableism constructing mental health experiences.[8] The group noted the lack of focus on 'love' in the literature and the need to pay attention to the care people with learning disabilities *give*, as well as receive in discussion of care as a relational activity.

Work package 3: Survey Co-Design Workshops/Exhibition (RAs 1, 2, 3, 4, 5) (RO3) (Papers 2 and 3)

Our initial protocol included two survey co-design workshops with family carers to develop an online structured survey to investigate priority issues for carers in terms of mental health (n = 300). Participants were recruited through organisations that support parent carers and sibling carers and through the project team's social media networks. In the first workshop (n = 6 family carers), it became apparent family carers were not in favour of 'tick box' surveys which they felt could not capture the complexity of their lived experience. They suggested we provide prompt questions for carers to upload photos, pictures, artwork, stories and links to music to an online platform to allow participants to meaningfully represent their experiences.[9] Following a change of protocol and an ethics amendment, participant information and consent forms were translated into six languages: Polish, Punjabi, Roma, Romanian, Urdu and Welsh. Despite these changes, we were able to meet the original study aims and objectives.

This information was shared via the research team networks, social media, family carer and self-advocate groups leading to contributions from 31 participants collected across 9 months (see *Appendix 3* for website informatics). These formed part of an online depository/exhibition hosted by Manchester Metropolitan University. The survey workshop data were analysed qualitatively. This initially involved reading and interrogating notes from the workshop. We were guided, not constrained, by procedural approaches to coding and thematising,[9] paying attention not just to individual stories but to the things in the stories – 'stuff, objects and space – everything':[9] p. 226. The contributions collected for the online depository/exhibition, including text, images and sounds, were analysed using affective analysis paying attention to the affective power of the objects in the exhibition.[19] This involved regularly reviewing deposits in the Tea and Cake meetings, reflecting on how the objects affected us. Group members understood 'affective analysis' as the discussions about experiences and emotions prompted by the objects in the exhibition. Group members understood 'affective analysis' as the discussions about experiences and emotions prompted by the objects in the exhibition.

Work package 4: Qualitative Interview Study (RAs 1, 2, 3, 4, 5) (RO4) (Papers 4 and 5)

Twenty-eight in-depth interviews were conducted (11 family carers; 16 siblings and 1 partner) recruited via social media and research team networks. An open interview guide invited participants to tell their stories of care and mental health; an approach informed by previous experience of interviews to support digital storytelling.[20] The interviews generated data about evidence of the experiences, perspectives and knowledge of participants across the life course. The Tea and Cake Group contributed to the developing analysis and emerging themes, drawing attention to what might be missing or overlooked in the data, particularly in relation to the care people with learning disabilities give.[12]

The data sets (parents and siblings) were analysed separately. Team members individually familiarised themselves with the data, reading and re-reading the transcripts. We annotated the transcripts by noting aspects of data that 'got under our skin', moments of interest or intrigue that fostered further thought.[10] The analysis of the parent carer data set was further developed at a 2-day analysis workshop to share and discuss our notes to generate the focus on kindness.[10] The sibling analysis was conducted at a later stage.[11]

Work package 5: Online Digital Storytelling Workshops (RAs 1, 2, 3, 4, 5) (RO4) (Papers 6 and 7)

Digital storytelling was chosen as an ideal method to capture and mobilise the often-overlooked stories and experiences of carers of adults with learning disabilities to health and social practitioners and policy-makers. The purpose of WP5 was to shed light on and provide depth of insight about this topic. Digital storytelling workshops typically bring together groups around a chosen topic for 4–5 weeks online (synchronous, with 1–1 support provided between weekly group sessions) to make the story participants most want to tell at the time. These short films combine photographs, video, music, voiceovers (a narrated story) and more to express previously excluded experiences. Participants are supported by a skilled facilitation team, which provides tutorials and 1–1 help in using the WeVideo platform (video editing online software), storyboarding and photography, capturing video, taking photos, editing films and narrating voiceovers.

The online digital storytelling format was adapted to meet participant needs. For example, online digital storytelling workshops were planned around participant availability and parent carers joined four online storytelling sessions with flexibility offered for group members to fit in with their lives and responsibilities. Sibling carers preferred not to meet online and were supported in one-to-one sessions with team members.[13]

Seventeen films were produced; nine parent carer films, four sibling carer films, three films made by people with learning disabilities and one film comprising five stories of sibling and parent carers from the Gypsy, Traveller and Roma community who experience stark inequalities in health and social care research.[20]

The films provide rich and new insights within social care research and practice into the experiences of older carers of adults with learning disabilities. These include (1) knowledge about carer strategies for surviving, thriving and hope within an under-resourced and ableist social care system,[8,9,17] (2) intimate knowledge about the meaning of care, difference and living a full life to be shared back with the system,[8,17] (3) insight into the importance of learning to unlearn ableist assumptions in research, especially around time[8] and (4) the importance of coproduction in social care research to reimagine exclusionary systems.[9]

We held two screening events for participants. Following an approach developed by Douglas,[21] the participant film makers and research team collaboratively identified themes and understandings emerging from the films through a process of discussion. This analysis was further developed in a Tea and Cake Group meeting. This open approach to analysis reflected the value we attach to the power of storytelling to illuminate and enrich understandings of lived experience in health and social care research.[13]

Work package 6: Synthesising Findings; Creating resources (RA6) (RO5)

Findings from the survey workshops, the online exhibition, interviews, digital stories and Tea and Cake blogs were synthesised with links and connections drawn across the different data sets. Overarching themes were identified and reviewed with the Tea and Cake Group, prioritising the creation of resources for different audiences (see *Report Supplementary Material 2* and *Report Supplementary Material 3*).

Roundtable discussions were held with GPs/GP commissioners, social prescribers and NHS England to discuss the developing resources. This engagement was crucial to informing our thinking about the content and format of the resources. These discussions were taken back to the Tea and Cake Group to check our sense making.

The synthesis was conducted across the Tea and Cake Group meetings and teams involving KRC, SR and MS. This involved looking at different findings of each WP and drawing links and connections across the data sets. This was an iterative process across 1 month.

Work package 7: Dissemination (RA6) (RO6)

An end-of-project event was held with 37 members of the public and 9 academics/practitioners, while 32 people attended the online and in-person end-of-project events which formed part of the Economic and Social Research Council (ESRC) Festival of Social Science.

Findings have been disseminated via Learning Disability Partnership Boards and Integrated Care Boards, NHS England, the Royal Society of Medicine and the Care Quality Commission. We have published 7 peer-reviewed papers, 1 publication for *Community Living Magazine* and 11 blog posts (see https://sites.google.com/sheffield.ac.uk/tiredofspinningplates/blogs).

Table 1 details the academic journal articles generated during the project. Bi-monthly coproduced blogs with Easy Read summaries and audio versions based on the Tea and Cake Group (public involvement group) meetings were also published: https://sites.google.com/sheffield.ac.uk/tiredofspinningplates/blogs.

Non-academic outputs include *PMLD LINK* (Spring 2024); *Community Living Magazine* (Spring 2025). Please see the *Knowledge exchange and dissemination activities* for further details of this work.

Results summary

The results are summarised with reference to the research questions below.

How do carers of adults with learning disabilities conceptualise and make sense of their own mental health across the life course?

Participants conceptualised care as deeply relational.[8,22] Too often, studies of care are often reduced to a concern with the physical and emotional labour carried out in a dyadic relationship, a clear line drawn between the person perceived to be the 'caregiver' and 'the person who receives care'.[22,23] This terminology fails to capture their entangled relationships between people with the person they care for and others. Participants recognised people with learning disabilities provide care, and it is important this care is recognised in research and in public policy discourse.[9,12,22]

Participants described the love that drove their care, activism and advocacy, and how this love could be exploited by services who denied them basic kindness, information and support.[9,10]

Participants consistently challenged understandings of their mental health based on the idea that caring for a person with a learning disability is always a threat to their mental health.[9] Overwhelmingly, participants explained that their mental distress was caused by the constant struggle for services and support, often over decades. They argued this distress was a 'normal' reaction to the effects of advocating for services.[9] They had unique sets of experiences and understandings about the nature and causes of mental distress and these change over time. Participants also understood care continues to be a deeply gendered activity.[11]

What services, support and interventions do carers access (including: social prescribing; carers' passports; medication; talking therapies; peer support; alternative and complementary therapies) and how effective do they consider them to be?

Participants described their care as unseen labour, misunderstood by services who should support them.[9,10] They argued this lack of understanding has a profoundly negative impact on the support they receive.[8,9] Support services do not recognise how participants' sense of contentment and happiness is inextricably connected to how the person they care for is feeling.[8,17,22] Interactions with multiple services in the education, welfare, health and care system were perceived as part of their caring role. The system itself was seen as a stumbling block to appropriate care and support and as having a negative impact on participants' mental health.[8,9]

Participants identified a sense of threat associated with the power of professionals within health and care service systems.[9,10] They feared they may inadvertently break the rules, and this would result in the removal of care and support. They were frightened the system might take the person they cared for away. One participant described her treatment by the system as a form of 'emotional terrorism'.[10] Participants also described living in fear of being sanctioned by the welfare system and described their interactions with the Department for Work and Pensions as 'traumatic'.[9]

Social care services were widely criticised by participants for failing to offer support and for being hostile. Social services were described as simply absent in some participants' lives, despite the significant needs of the family. Other participants described social services as actively trying to avoid providing statutory support to them. They felt blamed by social workers for asking for help and for not being able to care without support. A lack of continuity of care in social services support was also identified as a cause of stress.[10]

Family carers and people with learning disabilities should expect to be offered flexibility about appointment times/dates and length as well as continuity of care.[24] However, we found that participants did not know if they were flagged as carers with their GP, were often unable to make an appointment with the GP and were not offered reasonable adjustments.

Often participants sought support for mental health as a last resort. In part, this was because they did not believe their experiences would be listened to or understood by professionals. Long waiting lists also deter people from asking for help. Early identification and interventions were not available to them, and so when participants sought mental health support, it was often at a point of high levels of accumulated distress. It was also difficult to access therapy privately for those participants who could afford it. Counselling services also failed to make reasonable adjustments for family carers. Cognitive–behavioural therapy (CBT) was generally described as unhelpful because it did not allow participants time and space to share complex experiences or do 'the homework' that CBT asked of them.

Some participants found medication helpful, but other family carers were reticent about using mental health medications. They did not feel they should be objected to being offered medication for depression when they did not feel they were depressed. Sometimes the offer of medication was seen as a consequence of the wider lack of compassion and time to talk from mental health professionals. Other participants explained that they could not take medication because they needed to stay alert to care effectively.

Support from other family carers was important to participants and described as 'therapy in itself'.[11] However, it was not always easily accessible, and some participants also described how support groups could be places of conflict and exclusion.

What has been the impact of mental health issues on carers' family lives, ability to care, employment, friendship and social life?

Family life is affected by care in multiple ways. Participants expressed distress about the competing demands of caring for different family members. Wider family support networks are sometimes fractured by exclusionary and discriminatory attitudes from family members towards disabled people, and participants could become distanced from friends who they felt did not understand their experiences of care.[8]

Paid employment outside the family home was inaccessible to many participants and those who did worked negotiated jobs and working patterns to enable them to care. This has a significant impact on family income, often leaving families reliant on benefits or on one household income. Family carers are often unable to build a career when in paid employment because they are forced to choose jobs that work around caring responsibilities.

What are the impacts of COVID-19 so far on carers' mental health, and how do carers perceive the medium- and longer-term impacts and necessary support and interventions?

The pandemic has multiple and far-reaching impacts on the lives of people with learning disabilities and family carers.[25] Several participants described how the person they supported lost out on education. Annual health checks were suspended during lockdown and some people with learning disabilities had not had one since. Participants were living with the long-term impacts of heightened anxiety during COVID because of higher levels of care and/or being separated from the person they loved for extended periods.[25]

What do carers believe practitioners, providers and other organisations need to know and do to support carers?

Most caring relationships between family members and with people with learning disabilities are driven by love. Participants asked that this is acknowledged, accepted but not exploited by service systems. They want providers to know mental distress is not an inevitable consequence of caring for a person with learning disabilities. Rather, mental distress is the consequence of inadequate services and support which mean carers experience decades of care work with little support.[8,9]

Carers are a heterogeneous group of people with different understandings of mental health and different requirements for support. They want service providers to challenge their own assumptions about the nature of care, learning disability and mental health and to work with family carers to understand how they make sense of their lives and their experiences of distress.[8,9]

Family carers continue to care for their family members with learning disabilities because they do not feel there are appropriate alternatives. Even when the person with learning disabilities lives outside of the family home, the caring work can continue. Family carers and people with learning disabilities also need and want space from one another to pursue their own hopes and dreams.

Family carers of people with learning disabilities believe their caring experiences are different from those of other carers because they often care for very extended periods of time. Often, they care for a person with learning disabilities from birth and continue to do so in a failing system. People continue to be excluded from education, from work and from equitable access to health and social care with the outcome of significant reduction in life expectancy. The fight against this inequality has a significant impact on carers' mental health over decades.[8,9]

Family carers engage with multiple services in the education, health, and care system.[17] They experience service systems as lacking basic kindness as service systems can be hostile and abusive to them and to the person they care for.[8–10] Family carers described the importance to them of experiencing small acts of kindness in their interactions with practitioners. Kindness is a matter of social justice and family carers want kindness to be practised in health and social care services and systems.[10]

Discussion/interpretation

Principal findings and achievements per project outcome

The discussion of principal findings is organised through a presentation of the key themes generated through the analysis which are referenced back to the RAs.

Love

Love drives family carers' caring relationships. Family carers talk about the love and care they give to *and* the love and care they receive from the person they support.[22] However, this love and care can be exploited, and family carers are denied basic information, support and kindness in service systems[10] (RA1).

Mental health

Many family carers experience mental ill health, although the experiences of, and understanding about, this mental ill health can change over time[8,9] (RA1). Many believe their mental distress is caused by the constant struggle for services and support which can continue over decades[8,9,11] (RA2), and the lack of support and inability to take a break[8,9,11] (RA2).

Gender matters

Care continues to be a deeply gendered practice as mothers and sisters take on most of the care[11] (RA1).

Language

The way language is used matters to family carers who can feel uncomfortable with the word 'carer' and the term 'learning disability'. Indeed, some sibling participants described considerable ambiguity around the carer label.[11] The language feels 'professional' and does not capture the deeply entangled and loving relationships they have with a family member.[9,17]

Fear

Family carers describe living in a state of fear. They can feel threatened by the power health and social care professionals have and fear they will be sanctioned by the welfare system,[17] or their relative may be taken away. The constant fight for support in the present makes families fear for the future, when they are no longer there to advocate.

Lack of understanding and knowledge

Family carers feel that the work they do is unseen and misunderstood by the services who should support them. This lack of understanding is a barrier to family carers seeking timely and appropriate support[11] (RA4).

The isolation

Family life is affected by caring relationships in different ways. Family carers feel pulled in different directions when they face the competing demands of caring for several family members, including ageing parents, children and family members with learning disabilities. Wider family support networks can be lost because of discriminatory attitudes towards disabled people by family members.[8,9] Family carers can become distanced from friends who they feel do not share or understand their experiences. The legacy impacts of the COVID-19 pandemic on care and mental health, including increased isolation and greater mental distress, are still felt in family carers' lives[25] (RA5).

Financial consequences

Paid employment outside the family home can be impossible for family carers because of the lack of support for the person with learning disabilities. Flexible working patterns are needed to fit around caring responsibilities impacting on the type of employment and career progression. Lack of paid work and part-time working reduce family income, often leaving families reliant on benefits and/or one household income which can continue into retirement. Carers allowance (currently £81.90 a week) stops when family carers reach pensionable age[26] (RA4). As a result of their restricted work patterns, family carers are often only entitled to statutory state pension payments in retirement.

Contribution to existing knowledge

This study contributes to the proliferation of debates about the changing nature of care which argue care has often been under theorised in people's lives leaving dominant narratives untroubled.[23] Threads of love, friendship and humanity are woven through care literature, but love appears as an unexpected presence in a literature dominated by sanist and ableist assumptions.[8,9,17] We argue that the temporalities and spaces of care matter and the experiences of carers of adults with learning disabilities are out of step with the 'normative', unilinear models of care across the life course which dominate discourse and policy.[8]

Our analysis contributes to literature which troubles the binary of 'care-giver' and 'care- receiver'[27] and reveals the nested dependencies in the lives of people with learning disabilities and their family carers.[28] It highlights how the term 'carer' does not capture their deeply interwoven caring relationships,[17] and people may not identify as a 'family carer'.[29,30] The study adds to debates about the conceptualisation of 'learning disability' as a category[31] as family carers reject deficit models of learning disability and celebrate diversity without 'othering' or erasing difference.[16] A key finding was that both family carers and people with learning disabilities want wider recognition and acknowledgement of the care people with learning disabilities provide in their families and communities.[8,17,24]

The study contributes to critical disability studies and Mad Studies-informed approaches which share a commitment to troubling biomedical accounts of disability and of mental distress.[32] Family carers reject the assumption that caring for a person with learning disabilities is necessarily associated with poor mental health and see their mental distress as a 'normal' reaction to caring with insufficient breaks, services and support. Mental distress is something that is 'done to them'.[8]

Mental health research continues to use surveys to generate information about people's experiences of mental distress.[33–35] Carers' organisations also use surveys to capture members' experiences and views.[36–38] There is little evidence that filling in a questionnaire causes further distress and that people accept surveys and may find them useful;[35] however, there is some criticism of survey use in mental health services when filling in standardised clinical outcome measures in therapeutic sessions is seen as taking away from therapeutic time.[39] Participants reflected on the administrative burden of caring and the paperwork that this involved[9] regarding survey methods as inadequate tools for capturing complex views and experiences. They considered that using a survey method could be damaging to participants' mental health[16] and suggested a different approach – an online exhibition.[9] These reflections challenge the effectiveness and ethics of the proliferation of the use of surveys by mental health services, the third sector and charities and in research.[9,37,38]

The study contributes to feminist theory[40] and critical disability studies scholarship[41] which emphasises the political significance of emotion and embodied knowledge. It adds to broader debates about practices of kindness in the delivery of health and social care services.[10] Participants shared complex accounts which reveal the presence of kindness, *and its absence*, in their lives.[10] We note the disconnect and lack of recognition of humanity in unkind encounters in service systems and call for kindness practices in health and social service systems beyond that which is currently experienced by family carers.[10]

Take-home messages

These take-home messages were coauthored with the Tea and Cake Group.

What do carers of adults with learning disabilities want people to know?

- We love the person we care for. We do not usually think the person we care for is a burden or a problem. Our mental health issues are usually the result of our difficult fights with education, health and social services.
- As family carers of adults with learning disabilities, we have been carers since the day our child was born. We may have cared for many decades. Our experiences are both the same as and different from the experiences of some other family carers.
- Many adults with learning disabilities continue to live in the family home. Even when they leave home, we family members (parents and siblings) continue to care for them though they do not live with us.

What carers need from other people

- A holistic approach – our experiences of caring are always relevant to discussions about our mental and physical health.
- Continuity of care – it is important for us and for the people with learning disabilities we care for to be able to build relationships with you.
- Flexibility – we sometimes need longer appointments and appointments that fit around our caring roles.
- Kindness – small acts of kindness really matter to us. A phone call, a 'how are you?' matter more than you know.

Strengths and weakness of the study in relation to other studies

The experienced project team brought a critical approach to studies of mental health, disability and care, and was well placed to respond to the opportunities afforded by meaningful collaboration with family carers and people with learning disabilities. The leadership offered by the Tea and Cake Group was crucial to the design, delivery analysis and dissemination of the project.

The use of arts-informed approaches to create digital stories and an online exhibition generated new understandings of family carers' experiences of mental health and care, and encouraged strong public engagement with the project. For example, the call for contributions to the Exhibition on X [formerly known as Twitter (Twitter, Inc., San Francisco, CA, USA)] had 3.1K views and posts from the exhibition were viewed hundreds of times (see *Appendix 3*, *Tables 2* and *3* for online exhibition website analytics). Strong public engagement on social media led to the exhibition being featured in *PMLD Link* and *Community Living Magazine*.

The team have been able to share their networks to open pathways to impact with the Royal Society of Medicine and NHS England.

We faced several challenges in delivering the project.

Participant recruitment

Recruitment was slower than expected despite the team's strong networks and experience of working with family-carer organisations (WP4 and 5). We suggest this reflects the daily challenges that family carers face and a lack of capacity to engage with research given their caring commitments. Participant numbers overall were lower than anticipated; however, in the context of a qualitative research study, the rich and thick data generated have allowed us to demonstrate our contribution to knowledge.

Diversity of the participant group

Most participants were women (91.3%), which is not surprising given the gendered nature of care. Eighteen per cent of participants described themselves as having an ethnic minority background. While this number broadly represents the general population, we hoped to recruit a more ethnically diverse group, as people from ethnic minority communities are often underserved by research. One co-applicant is a trusted member of a minority community, but it was still difficult to win the confidence of potential participants. Our partnership with RosaSenCis Film Productions allowed access to Roma families, but many factors impeded families coming forward and participating fully (WP4 and 5). The terms 'disability' and 'mental health' are seen as taboo words and are fraught with anxiety. One family, while happy to support the project, remained concerned about being identified and potential implications of this within social care services. Despite regular conversations with the elders in the communities, visits to the family and discussion with the 'head' of that family unit, they declined to take part. The families, translators and advocates were surprised to see their voices considered in the project but were not confident enough to come forward. We did not collect information about participants' relationship status; this would have been useful, because some participants stressed the difficulties of being a lone carer.

'Imposter' participants

There is a growing awareness of the rise of 'imposter' participants in qualitative research.[42] Studies which offer remuneration for participants' time and expertise have been approached by people who falsify their identities to take part in research. While not initially prepared for this, we found e-mail communications from 'imposter' participants in WP4 were brief, with little detail. We sought to reduce the risk of imposter participants by recruiting through partner organisations rather than via social media.

Working with the creative team in Canada provided challenges in terms of working across different time zones.

Reflections on the project and what could have been done differently

Attrition of participants from WP4 (interviews) to WP5 (digital storytelling) was expected and some participants were unable to commit the time needed to make a digital story. We planned for flexibility and were prepared to support people at different times to enable participants to join synchronous online workshops. While this was the case for many parent carer film makers, it did not suit sibling carers. The sibling carer films were made asynchronously with support from the Canadian digital storytelling team. This was challenging, in part due to time differences and momentum was sometimes lost with some films not completed. However, this has led to the development of the digital storytelling method.[13]

We did not originally plan to make films with people with learning disabilities (WP4 and 5). As we began to understand the relational nature of care, this became an important addition to the study that should have been considered in the project design stage.[22]

While care replacement costs were budgeted to facilitate participation (WP1, 3, 4, 5, 6), the shortage of support staff nationally meant these could not be used. Participants could not find replacement support and had limited 'free' time. Future research should consider this lack of time to participate in designing studies.

Public involvement funds were used to support the translation of the exhibition invitation into five community languages recognising the importance of engaging with diverse communities in this way (WP3).

Finally, while coproduction was a key strength of the project, it also caused the biggest challenges in pivoting from the planned online survey to creating an online exhibition (WP3) to which carers could contribute. This was complex in terms of working out how to deliver the exhibition, and time consuming, requiring significant ethics amendments and amendments to the protocol (see *Appendix 2*). *Meaningful coproduction* requires considerable time and experience which needs to be reflected in the project timetable and budget.

Engagement with partners and stakeholders

Proposal development

The idea for this proposal came from a small research project funded by internal monies from the University of Sheffield in partnership with Manchester Metropolitan University and funded in part by the Social Sciences and Humanities Research Council, Canada, Insight Grant 435-2019-0129. The project brought together parent-carers of children based in Yorkshire and Humberside with parent-carers in Ontario Canada. Participants shared their experiences of advocating for their children's education in special education systems and the impact this had on their mental health.[43] We worked with parent-carer organisations and Sibs, the charity for siblings of disabled people to develop the proposal in response to the *Health and Social Care Delivery Research* commissioned call. We also sought to recruit diverse project partners with connections to minoritised communities.

Public involvement and engagement/coresearcher group

The Tea and Cake Group was convened at the start of the project and met online regularly. We adopted a flexible approach to working with the group in response to people's access requirements, to support their contributions at each stage and offered a combination of group meetings – one-to-one, in person and online, as well as participation by sending e-mails. The meetings were documented via coproduced blog posts published on the project website. The group played a key role in directing the research and shaping the analysis at each stage, the group have coauthored papers and presented at conferences.

Study Steering Committee

The Study Steering Committee met five times during the project. Chaired by a consultant psychiatrist, it was made up of three parent-carers, one sibling-carer and parent-carer, and two independent academic researchers.

The Study Steering Committee provided vital support during the project and played a key role in advising us when we moved from the survey to online exhibition. They shared their networks and promoted the research, offering us support with participant recruitment and, crucially, with dissemination, offering opportunities to share findings with key beneficiaries.

Individual training and capacity-strengthening activities

Martina Smith has completed the following training and research development activities:

- Easy Read training with photosymbols.com.
- Learning how to carry out a rapid scoping review with support from the University of Sheffield's health science librarian.
- Completing *Daring to Dare* programme for women in research aimed at early career researchers hosted by Tesselle Development.
- The Researcher as Manager programme – an Institute of Leadership and Management recognised award hosted by the University of Sheffield.
- Completing a workshop hosted by ResearchRetold called 'Communicating Research in Engaging and Accessible Ways – Creating a Visual Summary of Research'.
- Martina Smith successfully applied in the competitive process for a Sheffield University Research Experience intern. The intern worked with the team for 8 weeks focusing on the website design for the Exhibition.

Other developments:

- Martina Smith was appointed as the Public Engagement and Involvement Research Associate for the NIHR School for Social Care Research from 1 December 2024.
- Following her work as a research assistant on the project, Martha Ward was awarded an NIHR Three Schools (Dementia Call) PhD scholarship beginning in September 2024.
- Patty Douglas has taken up the Chair in Student Wellness and Success at Queen's University, Ontario, Canada.

Individual digital storytellers have learnt how to use WeVideo to create their own films and are continuing to make films about their experiences and to share them.

Institutional capacity strengthening

During the project, the University of Sheffield became a member of the NIHR School for Social Care Research (IV).

Katherine Runswick-Cole and Liz Croot (Sheffield) continue to develop their careers in applied social care research. Katherine Runswick-Cole is Deputy Director of the School for Social Care Research [equality, diversity and inclusion/public involvement and engagement (EDI/PIE)] and Associate Director of the School for Social Care Sheffield and Croot is Deputy Director of the School for Social Care at Sheffield.

Chris Hatton and Sara Ryan are members of the Social Care Hub for the new NIHR Research Support Service led by the University of Lancaster.

Public involvement and engagement

Section and topic	Item	Reported on page no
1: Aim	The aim was to deliver an expansive model of public involvement by adopting an innovative participatory approach using creative methods to capture stories of care and mental health.	3, 4, 5
2: Methods	Public involvement was woven into every research stage. We worked with family carers, people with learning disabilities and their organisations to develop the research proposal. Following feedback, the proposal was revised to offer separate digital telling workshops for sibling and parent-carers. WP1 involved convening the Tea and Cake Group of family carers (see WP1 summary above).	3, 4, 5, 6, 7, 8, 9, 15
3: Study results	Tea and Cake Group members remained engaged throughout the project. This was achieved by offering members flexibility, establishing, and maintaining good communication and strong relationships with and between group members. Members shaped the analysis in WP4 and 5 and provided crucial sense checking. Their contributions made us pay particular attention to the care that people with learning disabilities give[22] and to the importance of kindness in health and care services.[10,11] In WP6 and 7, the group played a key role in the synthesis of findings and shaping the content and design of the learning and teaching resources for GPs.[11]	9, 10, 11, 12

Section and topic	Item	Reported on page no
4: Discussion and conclusions	The Tea and Cake Group played a highly important role in the research with overwhelmingly positive contributions. The move from a survey to an exhibition was difficult for the research team to manage within the timescales of the project we had not anticipated the possible scale of the changes required to meet the requirements of working in coproduction.[9]	12, 13, 14, 15
5: Reflections/ critical perspective	The contributions of the Tea and Cake Group ensured that the research is accessible and relevant to family carers and to people with learning disabilities. On reflection, we learnt we need to be even more ambitious in our approach to PIE and ensure future projects have sufficient resources, including time, to support expansive models of PIE.	26

For more information, see *Appendix 5*.

Knowledge exchange and dissemination activities

Participants tasked us with sharing their videos as widely as possible to enact change. In addition to sharing films on socialcaretalk.org and restoryingautism.com (and sibling films on sibs.org.uk), the films have also been shared in classrooms, policy contexts (e.g. Autism Alliance Canada future grant planning meetings) and at conferences in England, Canada, Finland and beyond.

We have a commitment from the University of Sheffield and Manchester Metropolitan University for additional funding for public engagement and impact acceleration. We plan to present to an interest group of learning disability specialist GPs and to attend the Royal College of GPs regional and national conferences. We commit to sharing the resource directly with 100 GP practices, focusing on areas of high deprivation and a wide geographical spread.

We have developed a bespoke resource for social care practitioners which we will disseminate via Adult Directors of Social Services, the NIHR School for Social Care Research (SSCR) and via family carer organisations, including Sibs (see *Report Supplementary Material 3*).

We will share the resources via the research team's social media platforms.

These include:

1. Online exhibition hosted by Manchester Metropolitan University at: https://carermhspinningpla.wixsite.com/spinplatesexhibition

Audience: family carers; people with learning disabilities.

2. Digital stories hosted by socialcaretalk.org, restoryingautism.com and sibs.org.uk

Audience: family carers; people with learning disabilities; social care practitioners; health practitioners; members of the public.

3. Learning and teaching materials: Doing Better in Health Care: supporting family carers of people with learning disabilities; Doing Better in Social Care: supporting family carers of people with learning disabilities (see *Report Supplementary Material 2* and *Report Supplementary Material 3*).

Audience: GPs; GP trainees; allied health professionals and support staff

4. Blogs hosted on The University of Sheffield Spinning Plates Google Site: https://sites.google.com/sheffield.ac.uk/tired-of-spinning-plates/home

Audience: family carers; people with learning disabilities; social care practitioners; health practitioners; members of the public.

5. Journal articles linked from The University of Sheffield Spinning Plates Google Site.

Audience: family carers; people with learning disabilities; academics; social care practitioners; health practitioners; members of the public.

6. Magazine articles including *PMLD LINK* and *Community Living Magazine*.

Audience: Family carers; members of the public.

7. Conferences including the Nordic Network on Disability Research (May 2023), the European Congress of Qualitative Inquiry (January 2024); Disability Studies Association Conference in Leeds (September 2024); School for Social Care Research Conference, York (June, 2025); Transforming Care Conference, Helsinki, Finland, (June, 2025).

This synopsis should be referenced as follows:
Runswick-Cole K, Ryan S, Smith M, Hatton C, Douglas P, Kassa C, *et al*. 'Tired of spinning plates': Synopsis of mixed methods exploration of mental health experiences of adult/older carers of adults with learning disabilities. *Health Soc Care Deliv Res* 2026;**14**(6). https://doi.org/10.3310/GJKR4724

Audience: academics.

8. Webinar hosted by the Royal Society of Medicine, 'Hot topics in healthcare in intellectual disability: Challenges and solutions', (19 November 2024).

Audience: Medical practitioners, health and social care practitioners, academics,

9. ESRC Festival of Social Science Online Event, Tired of Spinning Plates (5 November 2024).

Audience: Members of the public, family carers, people with learning disabilities, health and social care practitioners, academics.

10. Invited talks:

    - Melbourne Disability Institute (26 September 2024).
    - Melbourne Social Equity Institute (26 September 2024).
    - Caring Futures Institute, Flinders University, Adelaide (3 October 2024).
    - Australian Society for Intellectual Disability, Adelaide (3 October 2024).
    - Aarhus University, Copenhagen (15 November 2024).
    - York Disability Week, Explore York (4 December 2024).
    - Parliamentary drop-in hosted by John McDonnell, MP at Portcullis House, Westminster, 23 April 2025.
    - Down's Syndrome Scotland (26 August 2025).

Audience: academics, students, members of the public, health and social care professionals

Equality, diversity and inclusion

Language and terminology

Our use of language was guided by the principle that we should ask people with lived experience which language they preferred. On the advice of the Tea and Cake Group, we use the term 'family carer' though we recognise different people may have different understandings and prefer different terminology.[44]

We included plain English summaries, Easy Read summaries and audio recordings of blogs and other published materials. Easy Read summaries were included as supplementary material to published journal articles.

We also sought to remove some barriers to family carers who speak English as an additional language by providing information about the online exhibition in five community languages and by working with a trusted member of the Roma community.

Generalisability and transferability of evidence

It is a mistake to suggest qualitative research lacks generalisability.[45] Feedback from presentations in the UK and in Australia generated conversations about health and care service systems which resonated with family carers and academics. They also recognised the transferability of methods to working in coproduction with marginalised groups.

Participant enrolment, retention and representation

Research team members were already trusted members of participant communities of family carers and people with learning disabilities. We recruited through these networks and via family carers who consented to be contacted about other projects (NIHR 204404). Members of the Tea and Cake Group remained involved throughout the project. This was achieved through offering highly flexible participation and good lines of communication.

Twenty-eight family carers were interviewed but only 13 participants completed digital stories [3 additional digital stories were produced by self-advocates, and 5 members of the Gypsy, Traveller and Roma community compiled 1 film ($N = 17$ films, made by 21 film makers)]. We anticipated it may be difficult to retain participants after the interviews because of their caring responsibilities. Throughout the project no interviewee or digital storyteller took up the offer of payment for care replacement costs. Some participants were put off by the prospect of digital storytelling and worried about their creative and technical skills, despite assurances and support offered.

Inclusion/exclusion criteria

There were some inquiries about participation from family carers of autistic adults who did not also identify as having learning disabilities. We recognise that this group of family carers also experience mental distress in interactions with services and that this is an important area of future research.

Inclusivity of the participant population and participant data

The inclusivity of the participant population varied across protected characteristics (see *Appendix 4* for full details). Ninety-one per cent of the sample identified as women and there were no *trans*, non-binary or other gender identities represented (see *Appendix 4*, *Figure 2*). No data are gathered to capture the number of carers of adults with learning disabilities aged 65+ (see *Appendix 4*, *Figure 3*);[46] however, data show there are half a million people with learning disabilities over 45 years of age[46] so we can reasonably argue that many adults with learning disabilities over 45 are cared for by older family carers.[46] There was a wide spread of the age of the person with learning disabilities and 36.7% lived with family and friends[47] (see *Appendix 4*, *Figure 7*). Of participants, 17.4% identified as other than 'White British' which is roughly equivalent to the 2021 Status data[48] (see *Appendix 4*, *Figure 4*). However, there is evidence to suggest that minority ethnic groups experience higher levels of mental distress.[49] The participant population is dominated by people who identify as heterosexual or straight (see *Appendix 4*, *Figure 5*). The experiences of LGBTQI+ family carers are marginalised within research.[50] This is an area in need of future study. Our sample included only 15.4% of participants who lived in rural areas which is an under-representation in relation to national figures (see *Appendix 4*, *Figure 6*). For example, in 2019, 56.3 million people lived in urban areas (82.9% of England's population) and 9.6 million in rural areas (17.1%).[51]

Reflections on the research team and wider involvement

The research team included three family carers of adults with learning disabilities and a member of the Roma community.

Impact and learning

What difference has been made already?

Participants have described their involvement as empowering, sharing their films with wider family and friends. By sharing these films, they have been able to increase understanding of their lives in their communities. It is also important to them that the research makes wider impacts on policy and practice. To this end, we have met with NHS England to talk about improving service design for family carers of adults with learning disabilities and have coproduced resources (see *Report Supplementary Material 2* and *Report Supplementary Material 3*). The research team were invited to develop personas based on the research findings for the Mind the Gap Board Game, developed by the Centre for Care and Carers UK. The interactive board game promotes learning about the inequalities experienced by unpaid carers.

What longer-term impact might there be? For example, economy, efficiency, effectiveness, equity and environmental impact

Despite provision under the Care Act,[52] evidence suggests social services are not able to support families in the ways that families are entitled to be supported. Family carers experience assessments as unhelpful, or even hostile. Moreover, despite provision under the Equality Act,[53] family carers are often unable to make an appointment with the GP and are not offered reasonable adjustments.

To address issues of inequity in health and social care systems, preliminary discussions with NHS England have focused on:

- Including data about family carers in Health and Care of People with Learning Disabilities, Experimental Statistics 2022–3 – NHS England Digital.
- Building a question about family carers' well-being into the health action plan as part of the annual learning disability health check and including a question about carers' ethnicity.
- Changing the guidance on the Snomed codes to include long-term care and/or codes for carers of people with learning disabilities.

We have developed resources for all those working in General Practice surgeries that will:

- Raise awareness of the specific experiences of carers of adults with learning disabilities.
- Raise awareness of the rights of carers to reasonable adjustments including flexibility about day/time of appointments and appointment length.
- Raise awareness of the kinds of support carers find helpful.
- Challenge deficit discourses of learning disability, mental health and care.
- Promote kindness practice in the delivery of health and social care.

We have coproduced 16 individual films and 1 compilation film made by family carers hosted on socialcaretalk.org and restoryingautism.com. Sibling films are also hosted on sibs.org.uk. We have curated the materials to accompany the films for carers, people with learning disabilities and social care workforce, practitioners and policy-makers as our audiences. We are exploring the potential for also developing this work as a learning and teaching tool for social care practitioners.

Lessons learnt for future research

The experiences of family carers of people with learning disabilities should be prioritised in research, understanding that their lives are deeply entangled with the person they care for and that care is deeply relational.

1. Studies which are committed to high levels of coproduction with members of the public across the research process need to be allocated time and resources to carry out this work. Participatory approaches must include sufficient budgets to support accessibility and, crucially, more time to allow the research team to be able to respond to changes to research design and delivery.
2. All grant applications should include a budget for translation costs – particularly given the high cost of translating into languages where 'there are very limited resources for this language combination, unfortunately the available linguists are very expensive' (quote from e-mail correspondence with translation company). A translator told us that:

> *Many Roma families feel excluded from available services and help due to the lack of understanding and social stigma and by seeing something like this project translated into their language would give them an opportunity to get involved and make them feel empowered and seen.*
>
> *E-mail correspondence*

Coproduction is key to ensuring research is robust and relevant to the communities we serve. Working in collaboration with family carers throughout the research process is time consuming. There needs to be time to engage regularly with people at a time and in a way that works for them and research shaped by coproduction requires imagination and a commitment to searching for different methods. We did not deviate from our coproduced research objectives, aims and questions but our objectives were achieved through flexible and creative methodological approaches. Communication with members of the public needs to be accessible with plain English, Easy-Read documents, information translated into community languages, film, audio and images to support communication.

Flexibility and accessibility in research, including creative research methods and the accessibility of events and of meetings, are crucial. Flexibility was a key part in removing the barriers to participation.

Minoritised people continue to experience multiple barriers to engaging in research. For example, the wider challenges in the social care workforce meant that family carers could not find someone to pay to replace their care to allow them to participate in the study. Furthermore, there is still a lack of representation of diverse communities in research. People from minoritised communities do not see themselves represented in research. It was important for us to use funds for translation of research materials or to support participation.

Related work, for example, things not directly funded by NIHR, but arising from this study

Katherine Runswick-Cole is now Deputy Director of SSCR with responsibility for public involvement and equality diversity and inclusion and is using learning from the Tea and Cake (Public Involvement) Group to develop the SSCR public involvement strategy.

The learning from developing the exhibition is informing work on another project, on which Katherine Runswick-Cole is a co-applicant, to develop an exhibition of the work of disabled artists – Wellcome Anti-ableist Research Culture (A Wellcome Trust Institutional Funding for Research Culture Award).

Following a competitive process, the *Spinning Plates* project was included in the University of Sheffield's ESRC Festival of Social Science programme of events for 2024. We were able to share our films and exhibition exhibits with members of the public

Real-world impact/potential impact

As detailed in *Impact and learning*, pathways to impact focus on health and social care delivery.

Collaborations/further funding/future work

Martina Smith, Katherine Runswick-Cole and Sara Ryan and colleagues at the University of Bristol have secured funding from the School for Social Care Research (£50K) 'What's love got to do with it?' Adult social care, people with learning disabilities and love: what would ethical, empirical enquiry look like? This exploratory study will map existing research into love in adult social care policy and practice, potentially paving the way for a larger project with learning disabled people and family carers.

Katherine Runswick-Cole *et al.* from Manchester Metropolitan University and Bristol have submitted a bid to the School for Social Care Research (£50K). No one wants to talk about it: Exploring transitions in family care for people with learning disabilities. The project will explore the support available to families of people with learning disabilities around care transitions and to assess the feasibility of bringing together the perspectives of all family members to begin to generate new understandings.

Patty Douglas, co-applicant, is submitting a parallel research proposal to the Social Sciences and Humanities Research Council in Canada to deliver a version of the project in Canada. Martina Smith is a co-applicant and Katherine Runswick-Cole and Sara Ryan are advisors.

Katherine Runswick-Cole and Sara Ryan are preparing a Higher Education Innovation Fund application to promote the impact of the work in GP surgeries.

Katherine Runswick-Cole is collaborating on a writing project with Professor Sally Robinson, Flinders University, Adelaide on coproduction.

What are your aspirational/pre-planned dissemination or discussions to ensure the outcomes of the research are taken forward for implementation by your key stakeholders, partners and target audiences/groups?

We plan to:

- raise awareness of the experiences of family carers of people with learning disabilities in order to promote better understanding of their unique challenges by promoting engagement with the teaching and learning resources (see *Report Supplementary Material 2* and *Report Supplementary Material 3*)
- share the teaching and learning materials for GP practices using the films and other data generated during the project to produce training to be delivered to social prescribers in GP practices who will be able to cascade the learning in those practices
- work with NHS England/Digital to introduce a 'long-term carer' flag on patient records to differentiate these carers from short-term carers to ensure timely support
- ask for a question about the carer's health to also be included at the Annual Health Checks: Learning Disability
- conduct further work to find out how NHS England and Care Quality Commission and Integrated Care Boards monitor care for carers.

Implications for decision-makers

- Health and social care service systems need to 'do better' to support the mental health of family carers of adults with learning disabilities.
- There is a lack of interest in the ways in which family carers of adults with learning disabilities, as a specific group of carers, conceptualise and experience mental distress. This translates into the experience of multiple barriers to services and support. The support that is offered to them can be inaccessible and/or inappropriate. There is little recognition of the inaccessibility of this support despite the provision set out in the Care Act[52] and the Equality Act.[54]

- Mental distress among family carers is caused by four major factors:
  - Significant periods of caring, often over many decades, without a break.
  - Struggling for services and support for the person they care over many decades.
  - Fear about the future when family carers can no longer care for their family members has a significant negative impact on mental health.
  - The absence of kindness in their interactions with health and social care systems.

- Provision for family carers set out in the Care Act[52] is not always delivered and that nobody is held accountable. Family carers' love for the person they care for is exploited by service systems.
- The social care system is predicated on the assumption that family carers will continue to care. The question of the impact of providing care on the family carer is not considered nor is the impact on the person with learning disabilities. This has implications for both family carers and for people with learning disabilities both to lead flourishing lives[53,55]
- There is a strong association between love and care, but family carers feel trapped in their caring roles because of a lack of adequate support or alternatives.
- There is a need to review and develop robust monitoring of the provision set out under the Care Act[52] to ensure family carers and people with learning disabilities' entitlements are met.
- Statutory-mandated reasonable adjustments, under the Equality Act[54] in the delivery of health care for carers, are not being met and that lack of adjustments is a significant barrier to family carers accessing mental health support.
- There is a need to raise awareness of the rights to reasonable adjustments among healthcare professionals and carers.
- There is a need to review and develop robust monitoring processes to ensure that family carers are offered reasonable adjustments in health and social care services.
- Small acts of kindness on the part of health and social care providers have a big impact on the well-being of family carers.

Future research recommendations

1. Further exploration of care as a relational activity.
2. The development of ways of monitoring compliance and adherence to legal frameworks.
3. Bringing together the perceptions, views and experiences of people with learning disabilities, siblings and parent carers to generate a comprehensive understanding of the support needs of these groups.
4. An exploration of the mental health experiences of LGBTQI+ family carers and family carers of autistic adults without learning disabilities.

Conclusions

This research has generated new knowledge about the nature and experiences of care and mental health of family carers of people with learning disabilities. The research has highlighted the role of love in caring relationships and the absence of consideration of this in the literature. It has also revealed the ways in which the love family carers have for the person they care for can be exploited by service systems which rely heavily on the care provided by family carers and do not always respect their rights.[52,54] The findings have also generated new knowledge and understanding about the care that people with learning disabilities *give* to their carers. They reveal the important role that people with learning disabilities play in supporting family carers' mental health.

We found the absences of considerations of love in the literature and the marginalisation of family carers of adults with learning disabilities' experiences of care and mental health and a multiplicity of ways that family carers conceptualise and experience mental health and care across the life course. The impact of caring for a person with learning disabilities over many decades, in a context where family carers fight for services and support is substantial. Fear about what will happen to the person they care for in the future has a significant impact on carers' mental health in the present. Crucially, family carers attribute the causes of their mental distress as lack of services and support and struggling in the system, rather than primarily locating the cause of their mental health difficulties in the characteristics of the person they care for.

Family carers question the quality, accessibility and effectiveness of support for their mental health; practitioners often do not understand family carers' experiences of care and of mental health, which means they are offered inappropriate mental health advice and support. Findings suggest that the provisions in The Care Act[52] and the right to reasonable adjustments under The Equalities Act[54] are not always upheld in health and social care service provision and practices. Enhanced monitoring and enforcement of the current statutory provision for family carers of adults with learning disabilities would make a significant impact in their lives.

Family carers know that going for a walk, reading a book or spending time with friends would help their mental health, but without the support they need to take a break from caring, they are unable to do this. They are frustrated by the offer of alternative therapies that they cannot access or that do not work. Psychological therapy is often inaccessible and/or ineffective. CBT does not allow family carers time and space to share complex experiences. Many carers cannot find the time to do the activities required outside of the sessions.

Some family carers find medication helpful. Other family carers are often offered medication when there is no access to talking therapies and without acknowledgement of the long-term exhaustion and stress of fighting for services and support and for caring without a break. Some family carers will not take medication because they fear it will negatively affect their ability to care.

Barriers to accessing support for mental health include simply not having enough time away from caring to be able to take care of their mental health. Healthcare services often fail to recognise or to acknowledge their role as family carers, despite provision under the Equality Act[54] so they are not offered reasonable adjustments to enable them to access support.

The long-term impacts of the COVID-19 pandemic were felt in the lives of people with learning disabilities and family carers. The pandemic impacted on multiple aspects of family life and care and significantly increased family carers' mental distress. Many families continue to live with the legacy of this challenging period in terms of the impact on their mental health and the delayed restart to some provision.

Impactful solutions to improving support for carers' mental health must take a holistic approach. This means supporting family carers by working with them to understand how they conceptualise and experience mental distress in the context of their lives and caring experiences. Family carers have struggled to gain support from services and support over many years without a break. They asked that we highlight their view that even the 'feeblest' acts of kindness make a difference in the delivery of health and care services.

Additional information

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Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.

Ethics statement

Ethical approval was sought, and subsequent amendments submitted for research by the lead university for the WP. Approvals were granted on 1 August 2022 by The University of Sheffield UREC 4058. The following amendments were approved: Amendment approved: 20 May 2024 Amendment approved: 7 December 2023 Amendment approved: 6 November 2023 Amendment approved: 4 May 2023

Ethical approval and subsequent amendments were granted on 17 November 2023 by the Health and Education Research Ethics and Governance Committee at Manchester Metropolitan University (EthOS reference number 58861).

Information governance statement

The University of Sheffield is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, The University of Sheffield is the Data Controller for WPs 1; 2; 4, 5; 6, with collaborating universities being joint Data Controllers of personal data collected for the purposes of this research, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer (dataprotection@sheffield.ac.uk).

Manchester Metropolitan University is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, Manchester Metropolitan University is the Data Controller for WP 3, with collaborating universities being joint Data Controllers of personal data collected for the purposes of this research, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer (dataprotection@mmu.ac.uk).

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/GJKR4724.

Primary conflicts of interest: Katherine Runswick-Cole declares membership of the National Institute for Health and Care Research (NIHR) Research for Social Care (RfSC) Funding Committee (2021–3 and NIHR Research Programme for Social Care (2023–). She is a Trustee of Books Beyond Words, a UK charity publishing picture stories for people with learning disabilities, supporters, family, and professionals. She is Deputy Director of the School for Social Care Research (SSCR) (PIE/EDI) and lead of the SSCR for Sheffield. She is the principal investigator on NIHR135080. She is co-applicant for: NIHR 204107; NIHR 204234; ESRC ES/W003406/1; Wellcome N-8 Research Partnership, 2023).

Sara Ryan declares membership of the National Institute for Health and Care Research (NIHR) Research for Social Care (RfSC) Funding Committee (2021–3) and NIHR Research Programme for Social Care (2023–), is a Patron of My Life My Choice, Trustee of LMCP Care Link and Speak Out Forum, was Principal Investigator on NIHR128616, and is Co-principal investigator on NIHR135080 and NIHR131322, and principal investigator on one project funded by the NIHR School for Social Care Research.

Patty Douglas declares that she is a Co-Investigator on NIHR135080.

Chris Hatton declares previously being deputy and interim chair of the National Institute for Health and Care Research for Social Care (RfSC) Funding Committee (2019–23), membership of the NIHR Incubators Funding Committee (2022 and 2024), and membership of the NIHR School for Social Care Research Phase IV Selection committee. He is currently Deputy Lead of the NIHR Research Support Service Social Care Specialist Centre and an Associate Member of the NIHR Adult Social Care – Policy Research Unit. He is currently the Co-Principal Investigator on NIHR206547, and Co-Investigator on NIHR204416, NIHR151776R/175118, NIHR206563, NIHR204107, on two projects funded by the NIHR School for Social Care Research and on one project funded by the NIHR Three Schools programme.

Liz Croot declares membership of the National Institute for Health and Care Research (NIHR) Pre-Doctoral Local Authority Fellowship (PLAF) competition (2024–) and she is a codirector of the School for Social Care Research (SSCR) in Sheffield. She is Principal Investigator on NIHR151776 and coinvestigator on NIHR135080, NIHR204234 and NIHR160821.

Martina Smith is a Research Associate on NIHR135080. She has no other declarations of interest to disclose.

Clare Kassa is Chief Executive at Sibs, the charity for siblings of disabled children and adults. She has no other declarations of interest to disclose.

Rosemary Cisneros is director of RosaSenCis Film Production Company and has no other declarations of interest to disclose.

Department of Health and Social Care disclaimer

This publication presents independent research commissioned by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by the interviewees in this publication are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, MRC, NIHR Coordinating Centre, the Health and Social Care Delivery Research programme or the Department of Health and Social Care.

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Award publications

This synopsis provided an overview of the research award *Tired of spinning plates: an exploration of the mental health experiences of adults and/or older carers of adults with learning disabilities*.

Other articles published as part of this thread are:

Smith M, Runswick-Cole K, Ryan S, Croot L, Hatton C, Kassa C, *et al*. Tired of spinning plates: a rapid scoping review of the mental health needs and mental health support of carers of adults with learning disabilities in the United Kingdom. *International Journal of Disability and Social Justice* 2025;**5**:246–89. https://doi.org/10.13169/intljofdissocjus.5.3.0001

Runswick-Cole K, Smith M, Ryan S, Douglas P. Dis/entangling disability, mental health, and the cultural politics of care. *Scand J Disabil Res* 2024;**26**:28–43. https://doi.org/10.16993/sjdr.1101

Runswick-Cole K, Smith M, Ryan S, Hatton C. 'Should we even have questions?' From survey to exhibition – co-dis/rupting research about 'mental health' with carers and adults with learning disabilities. *Int J Care Caring* 2024:1–16. https://doi.org/10.1332/23978821Y2024D000000051

Ribenfors F, Smith M, Runswick-Cole K, Ryan S. Kindness and curious kinships in the lives of family carers of adults with learning disabilities. *Int J Care Caring* 2025;**23**:1–8. https://doi.org/10.1332/23978821Y2025D000000128

For more information about this research, please view the award page (www.fundingawards.nihr.ac.uk/award/NIHR135080).

Additional outputs

Runswick-Cole K, Douglas P, Ryan S, Smith M. Going off script: re-storying care through digital storytelling. *J Cult Lit Disabil Stud* 2026;**28**:16–27.

Runswick-Cole,K, Douglas, P, Ryan, S and Smith, M. Moving off script: A/synchronous storytelling with family carers and people with learning disabilities. *J Lit Cult Disabil Stud* 2025:1–20.

Ribenfors F, Smith M, Runswick-Cole K, Ryan S. Kindness and curious kinships in the lives of family carers of adults with learning disabilities. *Int J Care Caring* 2025;**23**:1–8. https://doi.org/10.1332/23978821Y2025D000000128

Under review

Ryan S, Ribenfors F, Smith M, Runswick-Cole K. 'It's not a sibling relationship, it's an "I help him" relationship'; Unpacking 'caregiving practices' among siblings of adults with learning disabilities. *Scand J Disabil Res* Under review.

Conference presentations

Smith M, Runswick-Cole K, Ryan S, Hatton C, Douglas P, Croot L, *et al.*; the Tea and Cake Group. *Tired of Spinning Plates? Understanding the Mental Health and Wellbeing of Carers of Adults with Learning Disabilities*. Nordic Network on Disability Research, Reykjavik, Iceland, 12 May 2023.

Smith M, Runswick-Cole K, Ryan S, Hatton C. *The Co-disruption of Mental Health Surveys: Co-creating an Online Exhibition That Matters in the Lives of Family Carers of Adults with Learning Disabilities*. European Congress of Qualitative Inquiry, University of Helsinki, Finland, 11 January 2024.

Smith M, Runswick-Cole K, Ryan S, Douglas P. *Tired of Spinning Plates: Restorying Care in the Lives of People with Learning Disabilities and Their Family Carers*. Disability Studies Conference, University of Leeds, United Kingdom, 3 September 2024.

Ribenfors S, Smith M, Runswick-Cole K, Ryan S. *Symposium: Transforming Care in the Lives of People with Learning Disabilities and Their Family Carers Through Co Production Research*. Transforming Care Network, Helsinki, Finland, 25–27 July 2025.

Smith M, Runswick-Cole K, Ryan S. *Reflections from the Tired of Spinning Plates Project: Listening and Learning to Co Produce Research with Family Carers of Adults with Learning Disabilities*. Transforming Care Network, Helsinki, Finland, 25–27 July 2025.

Invited talks

Runswick-Cole K. *A Brief History of Co-production*. Melbourne Social Equity Institute, 26 September 2024.

Runswick-Cole K. *Co-production: A Brief History*. Australian Society for Intellectual Disability, Adelaide, 3 October 2024.

Runswick-Cole K, Smith M, Ryan R. *Tired of Spinning Plates: Co-producing Research with Carers of Adults with Learning Disabilities*. Melbourne Disability Institute, 26 September 2024.

Runswick-Cole K, Smith M, Ryan R. *Tired of Spinning Plates? Care Matters*. Caring Futures Institute at the University of Flinders, Adelaide, 3 October 2024.

Runswick-Cole K, Smith M, Ryan S. *Re-storying Care in the Lives of People with Learning Disabilities and Their Family Carers*. Aarhaus University, Copenhagen, 17 November 2024.

Public engagement and knowledge exchange events

Runswick-Cole K, Smith M, Ryan S. *Doing Research Differently*. York Disability Week, York, 4 November 2024.

Smith M, Runswick-Cole K, Ryan S. *Tired of Spinning Plates: An End of Project Celebration*. Manchester Metropolitan University, Manchester, UK, 16 October 2024.

Smith M, Runswick-Cole K, Ryan S. *Tired of Spinning Plates: An End of Project Celebration*. ESRC Festival of Social Science (Webinar), 5 November 2024.

Smith M, Runswick-Cole K, Ryan S. *Tired of Spinning Plates: An Overview of a Project Exploring the Mental Health Experiences of Family Carers of Adults with Learning Disabilities*. Scottish Universities Insight Institute, 'From Competition to Collaboration: The Interface Between Informal and Formal Carers'.

Smith M, Runswick-Cole K, Ryan S. *Tired of Spinning Plates: An Exploration of the Mental Health Experiences of Family Carers of Adults with Learning Disabilities in the Context of Duties of Kindness*. Royal Society of Medicine, Hot Topics in Healthcare in Intellectual Disability: Challenges and Solutions (Webinar), 19 November 2024.

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List of supplementary material

Report Supplementary Material 1 Tired of spinning plates easy read project report summary

Report Supplementary Material 2 Doing better in health care: supporting family carers of people with learning disabilities

Report Supplementary Material 3 Doing better in social care: supporting family carers and people with learning disabilities

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/GJKR4724).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

The supplementary materials (which include but are not limited to related publications, patient information leaflets and questionnaires) are provided to support and contextualise the publication. Every effort has been made to obtain the necessary permissions for reproduction, to credit original sources appropriately, and to respect copyright requirements. However, despite our diligence, we acknowledge the possibility of unintentional omissions or errors and we welcome notifications of any concerns regarding copyright or permissions.

Glossary

Reasonable adjustments A legal requirement to make sure health and care services are accessible to all disabled people.

Reasonable adjustment flag A national record that shows a person needs accommodations and may include details about their impairments and necessary adjustments.

Socialcaretalk.org Provides in-depth information about experiences of social care and helps people feel less alone and better prepared.

SNOMED codes Systematized Nomenclature of Medicine Clinical Terms – a structured clinical vocabulary for use in an electronic health record.

List of abbreviations

CBT	cognitive–behavioural therapy
COVID-19	coronavirus disease discovered in 2019
EDI	equality, diversity and inclusion
ESRC	Economic and Social Research Council
GP	general practitioner
NIHR	National Institute for Health and Care Research
PIE	public involvement and engagement
RA	research aim
SSCR	School for Social Care Research
WP	work package

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Appendix 1 Rapid scoping review literature search information

Database search information:

Date range of searches: November–December 2022

Web of Science

Search conducted 1 December 2022

"learning disabilities" or "learning disability" or "intellectual disability" or "intellectual disabilities" or "profound and multiple disabilities" or "cognitive disability" or "cognitive disabilities" or "learning difficulties" or "developmental disabilities" or "developmental disability" (Topic) and "mental health" or "well-being" or "wellbeing" (Topic) and carer or caregiver or sibling* (Topic) not child* (Topic)

Returned 233 records exported to EndNote (Clarivate Analytics (formerly Thomson Reuters), Philadelphia, PA, USA)

Scopus

Search conducted 22 December 2022

(TITLE-ABS-KEY ("learning disability" OR "learning disabilities" OR "intellectual disability" OR "intellectual disabilities" OR "learning difficulties" OR "cognitive disability" OR "cognitive disabilities" OR "developmental disabilities" OR "developmental disability") AND TITLE-ABS-KEY ("mental health" OR "wellbeing" OR "well-being") AND TITLE-ABS-KEY (carer OR caregiver* OR sibling*) AND NOT TITLE-ABS-KEY (child*)) AND PUBYEAR > 2013 AND (LIMIT-TO (LANGUAGE, "English"))

241 records exported to EndNote

PsycInfo® (American Psychological Association, Washington, DC, USA)

Search conducted 26 November 2022

1 (((“learning disability” or “learning disabilities” or “intellectual disability” or “intellectual disabilities” or “cognitive disability” or “cognitive disabilities” or “learning difficulties” or “developmental disability” or “developmental disabilities”) and “mental health” and carer*) not child*).af.
2 limit 1 to yr=“2014 -Current”
3 limit 2 to english language521

522 records returned

Appendix 2 Protocol amendments

Protocol V5.03 20 February 2024

Amendment no.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made
1	5.03	29 January 2024	Katherine Runswick-Cole Martina Smith Sara Ryan	1. Date 2. Dr Patty Douglas institutional affiliation. p. 7 3. Study design including online depository/exhibition. p. 13 4. Plan size of sample amended. p. 13. 5. Steering group institutional affiliation amended. p. 18. 6. Coapplication institutional affiliation amended. p. 19. 7. Phase 3 survey workshop amended. p. 21. 8. Survey co-design workshop study design amended. p. 28. 9. Phase 3 data analysis amended. p. 29. 10. Phase 3 de-identification amended. p. 30. 11. Phase 3 sample size amended. p. 35. 12. Consent amended. p. 40. 13. Safeguarding lead amended. p. 57. 14. Documentation included amended. p. 61. 15. New data WP3 amended. p. 64. 16. Backup and security of data amended. p. 66. 17. Data and online resources amended. p. 71. 18. Data and online resources availability amended. p. 72. 19. References amended. p. 75.

Protocol V5.04 21 October 2024

Amendment no.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made
2	5.04	21 October 2024	Katherine Runswick-Cole Martina Smith Sara Ryan	1. Date P1 2. Protocol Version Number P1 3. Katherine Runswick-Cole address. p. 5. 4. Katherine Runswick-Cole address. p. 6. 5. Katherine Runswick-Cole address. p. 10. 6. Hereby the Tea and Cake Group (name change). p. 17. 7. Second Tea and Cake Group name change. p. 17. 8. Coauthor diary – added published as blog posts on the Spinning Plates website. p. 17. 9. Phase 5 following discussion with members of the Tea and Cake Group, three members of the group (people with learning disabilities) also made digital stories about care. The total output (total number of films) remains at 24. p. 21. 10. p. 28 Following discussions with the members of the Tea and Cake Group, and following an amendment of the ethics application, three members of the group, all people with learning disabilities, chose to make their own films about care. Film makers were supported by members of the research team in one-to-one sessions to make their films which are also available on the project website and socialcaretalk.org.uk

Amendment no.	Protocol version no.	Date issued	Author(s) of changes	Details of changes made
				11. Deleted healthtalk.org p. 29. 12. Changed Spinning Plates Group to Tea and Cake Group. p. 30. 13. Changed Spinning Plates group to Tea and Cake Group. p. 32. 14. Revised ethical approval. p. 54. 15. Added ‘in person if preferred’. p. 59. 16. Added WP5 deleted ‘and the University secure Kaltura account’. p. 61. 17. Deleted Healthcaretalk.org p. 62.

Appendix 3 Online exhibition analytics

Data gathered 14 November 2024

Total site sessions: 720
Total unique visitors to site: 425
The most popular page visited: Images Gallery

TABLE 2 Traffic by location (countries)

Country	Page views	Site sessions	Unique visitors
GB	2133	617	345
AU	65	35	27
CA	53	16	12
US	17	14	11
NL	13	12	11
GR	9	2	2
DK	8	3	1
DE	8	5	3
NZ	7	1	1
FI	6	6	6
AT	3	3	3
BE	3	3	3
IE	1	1	1
FR	1	1	1
ZA	1	1	1

TABLE 3 Top traffic sources

Traffic category	Traffic source	Site sessions	Unique visitors
Direct	Direct	447	269
Organic social	Twitter	185	113
Organic social	Instagram	23	7
Referral	Google	22	15
Organic social	Facebook	20	18
Organic search	Google	16	13
Organic social	LinkedIn	5	5
Referral	outlook.live.com	1	1
Referral	asid.asn.au	1	1

Appendix 4 Demographic information

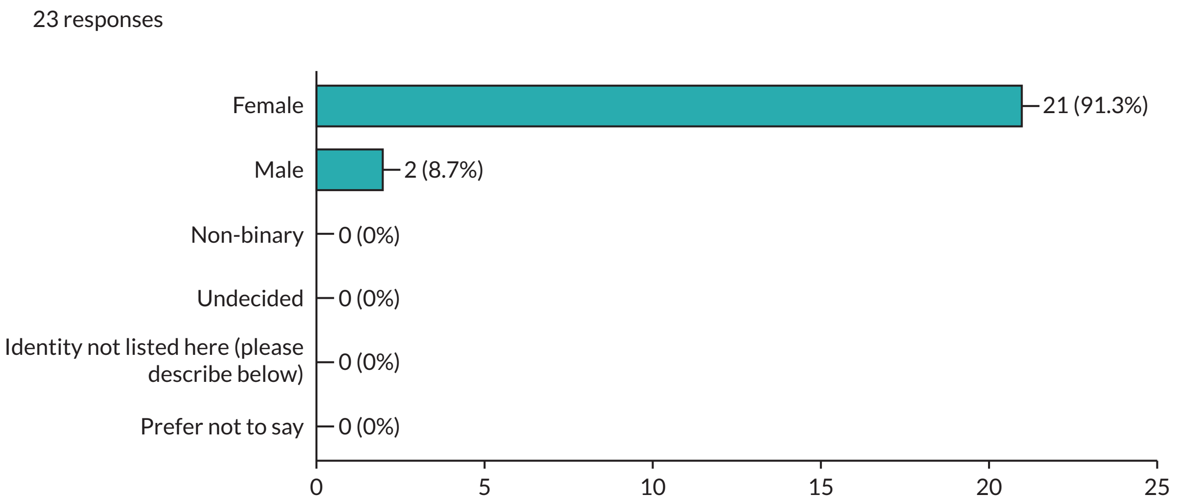

FIGURE 2 Gender.

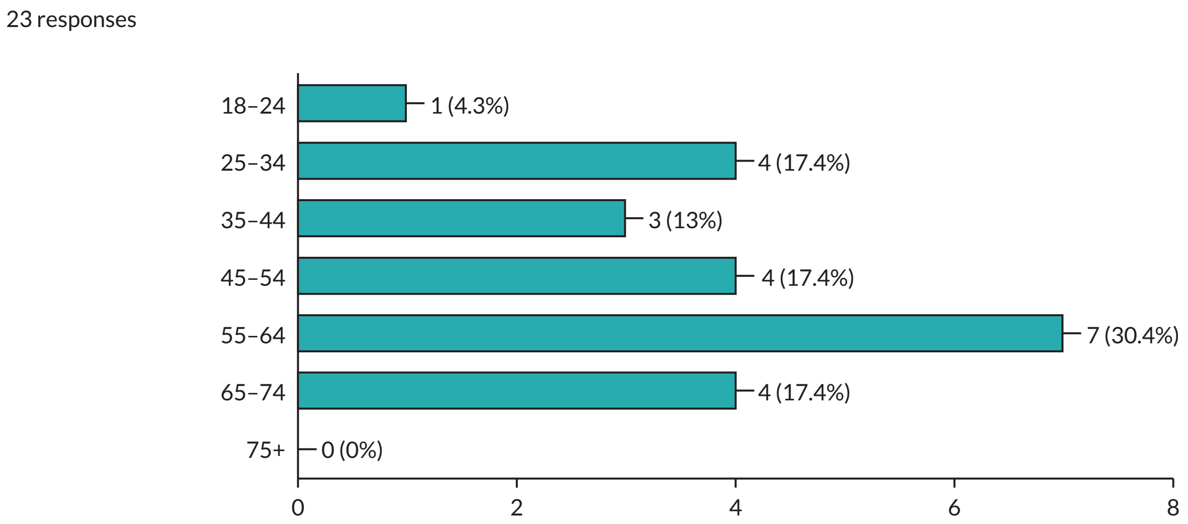

FIGURE 3 Age group.

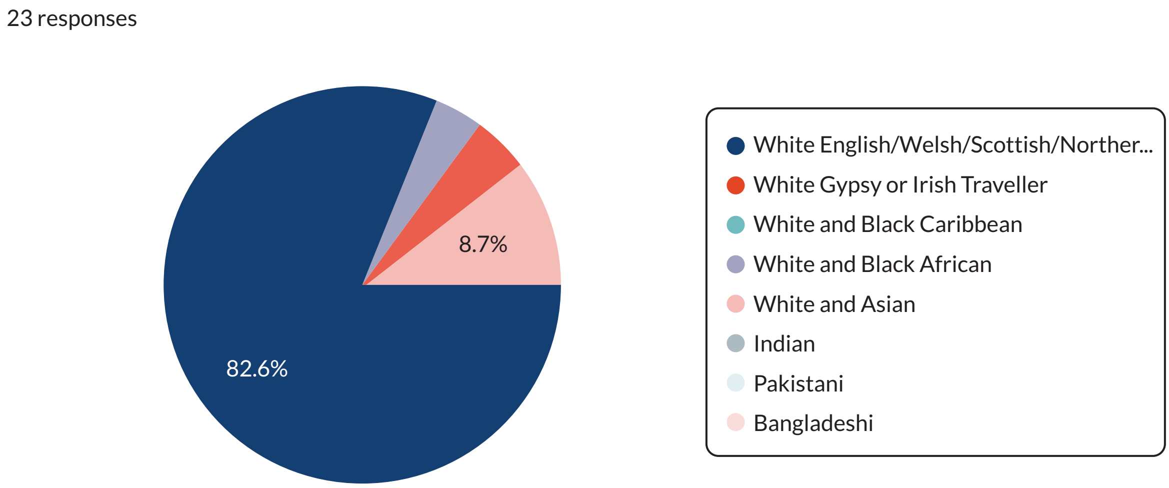

FIGURE 4 Demographic information by ethnic origin. Please note that these categories have been taken from the Office of National Statistics.

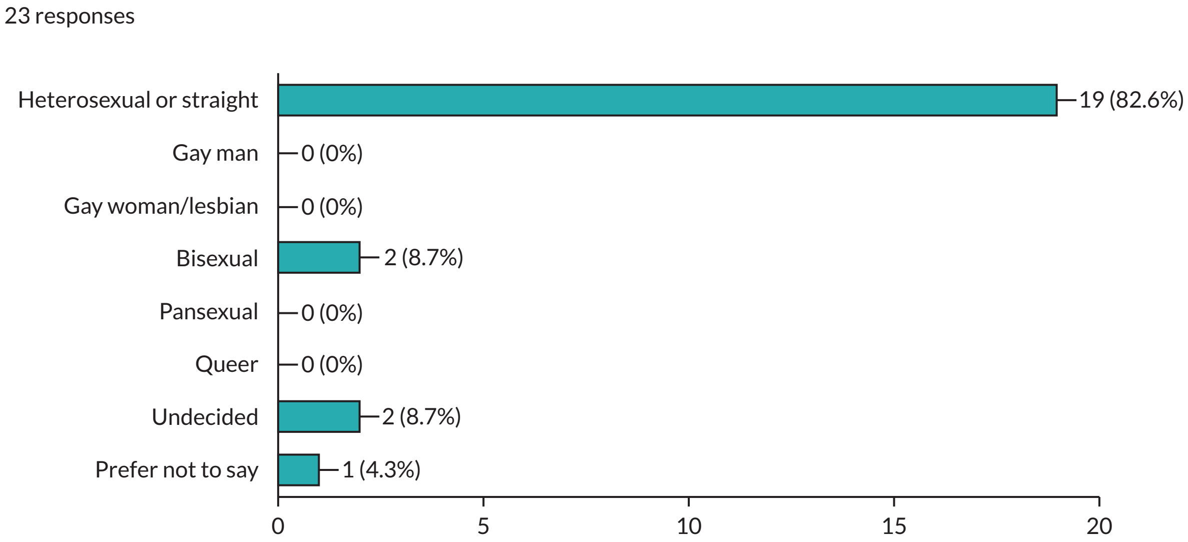

FIGURE 5 Sexual orientation.

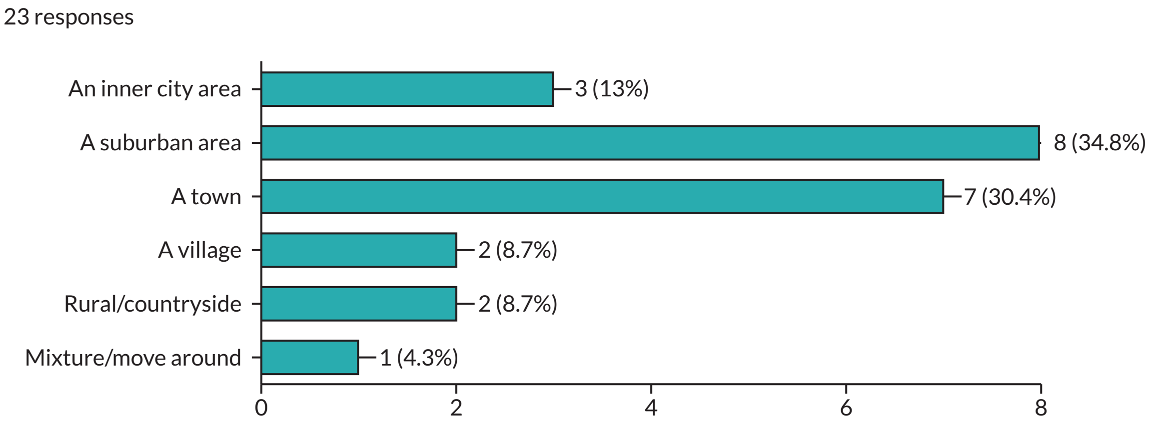

FIGURE 6 Area lived.

This synopsis should be referenced as follows:
Runswick-Cole K, Ryan S, Smith M, Hatton C, Douglas P, Kassa C, *et al.* 'Tired of spinning plates': Synopsis of mixed methods exploration of mental health experiences of adult/older carers of adults with learning disabilities. *Health Soc Care Deliv Res* 2026;**14**(6). https://doi.org/10.3310/GJKR4724

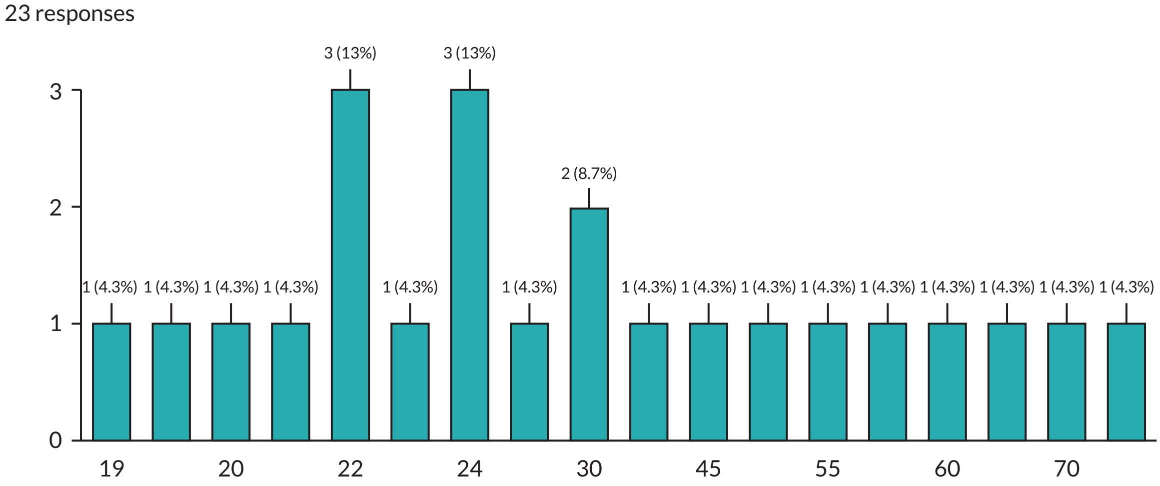

FIGURE 7 Age of adult cared for (years).

Appendix 5 NIHR135080 tired of spinning plates guidance for reporting involvement of patients and the public Guidance for Reporting Involvement of Patients and the Public 2 long form

Section and topic	Item	Reported on page no
Section 1: Abstract of paper		2
1a: Aim	**Report the aim of the study**	1
	This research addresses the mental health of family carers of adults with learning disabilities. We investigated participants' perceptions of their mental health and views on the accessibility and quality of support.	
1b: Methods	**Describe the methods used by which patients and the public were involved**	1
	The research involved seven WPs which included public involvement, a rapid scoping review of evidence about family carers' mental health and support, an online exhibition, interviews with parent and sibling carers, digital storytelling workshops, key stakeholder discussions and the creation of learning and teaching materials.	
1c: Results	**Report the impacts and outcomes of PPI in the study**	1
	Caregiving driven by love is often exploited by health and social care services which deny basic support, information and kindness. Enduring struggle for support and worries about the future are often the cause of mental distress. Participants know what supports mental well-being but have little time to look after themselves due to the lack of support. Social services were described as 'hostile' or absent and participants viewed themselves as exhausted by the lack of support, rather than depressed. Medication can help but can be offered without consideration of their caring role or because there are no alternatives. Participants ask for their statutory entitlements for health and social care support to be met with kindness.	
1d: Conclusions	**Summarise the main conclusions of the study**	1
	Health and care services often fail to recognise or adjust support for family carers despite provision under the Equality Act. The role of love in caring relationships, the absence of consideration of this in research and the exploitation of this love by service systems, which rely heavily on family carers, were highlighted. Provisions in The Care Act and The Equalities Act are not always upheld; family carers struggle to gain support over years and even the 'feeblest' acts of kindness make a difference in health and care delivery. There is a need for policy-makers and practitioners to review and develop robust monitoring of the provision set out in legislation to ensure family carers and people with learning disabilities' entitlements are met. Small acts of kindness on the part of health and social care providers have a big impact on the well-being of family carers.	

Section and topic	Item	Reported on page no
1e: Keywords	**Include PPI, ‘patient and public involvement’, or alternative terms as keywords**	**2**
	Public involvement and engagement; Tea and Cake Group; coproduction	
Section 2: Background to paper		
2a: Definition	**Report the definition of PPI used in the study and how it links to comparable studies**	**12**
	This work was informed by the UK Standards for Public Involvement, and all participants were remunerated for their time and expertise in line with National Institute for Health and Care Research (NIHR) guidance.	**11**
2b: Theoretical underpinnings	**Report the theoretical rationale and any theoretical influences relating to PPI in the study**	**9**
	The study contributes to critical disability studies and Mad Studies-informed approaches which share a commitment to troubling biomedical accounts of disability and of mental distress.	**22**
2c: Concepts and theory development	**Report any conceptual models or influences used in the study**	**9**
	The study is influenced by the fields of critical disability studies, and Mad Studies These approaches share a commitment to troubling biomedical accounts of disability and of mental distress. Mental distress is understood as a ‘normal’ reaction to caring with insufficient breaks, services and support. The study is also shaped by feminist scholarship which emphasises the political significance of emotion and embodied knowledge.	**22**
Section 3: Aims of paper		
3: Aim	**Report the aim of the study**	**2**
	The RAs were to: 1. Address the gap in knowledge about how carers of adults with learning disabilities conceptualise and experience mental health across the life course. 2. Address the gap in knowledge about the perceived quality, accessibility and effectiveness of support for carers’ mental health. 3. Explore the provision and uptake of support services, including barriers to accessing carers’ support services, including marginalised communities and groups. 4. Explore carers’ perspectives on the effectiveness of interventions for carers (including respite; medication; social prescribing; passport schemes; employment support; alternative and complementary therapies). 5. Explore the long-term impacts of the COVID-19 pandemic on carers’ mental health. 6. Coproduce the project, generate new knowledge and share impactful solutions working with groups of carers as coresearchers, research participants and project advisors.	**8**
Section 4: Methods of paper		
4a: Design	**Provide a clear description of methods by which patients and the public were involved**	**3**
	The Tea and Cake Group Public Involvement Group was convened at the start of the project and met online regularly. We adopted a flexible approach to working with the group in response to people’s access requirements, to support their contributions at each stage and offered a combination of group meetings – one-to-one, in person and online, as well as participation by sending e-mails. The meetings were documented via coproduced blog posts published on the project website. The group played a key role in directing the research and shaping the analysis at each stage. Public members were further involved in the two end-of-project events which were held online and in person at Manchester Metropolitan University.	**10** **26**
4b: People involved	**Provide a description of patients, carers and the public involved with the PPI activity in the study**	**3**
	The project’s public involvement group was made up of six family carers and four people with learning disabilities. Group demographic data were collected via a Google Form with an Easy Read version available. Age category data comprised: 18–24 years (*n*2); 25–34 years (*n*2); 35–44 years (*n*1); 45–54 years (*n*1); 55–64 years (*n*2) and over 65 years (*n*1). Two group members identified as male and seven as female.	**10**

Section and topic	Item	Reported on page no
4c: Stages of involvement	**Report on how PPI is used at different stages of the study**	
	In WP1 (Tea and Cake Group), members agreed the terms of reference and group name the group have coauthored papers and presented at conferences.	4
	In WP2 (Rapid Scoping Review of Evidence), the review was produced collaboratively from conception to synthesis with the Tea and Cake Group. We sought group members' views on included literature, including grey literature. This thematic synthesis was initiated through undertaking a familiarisation of data, followed by data coding guided by the research questions. Subsequent themes and subthemes were developed and refined through coproduction with the Tea and Cake Group and research team.	4
	In WP3 (Survey Co-Design Workshops/Exhibition), group members met regularly to review deposits, reflecting on how the objects affected us.	5
	In WP4 (Qualitative Interview Study), the Tea and Cake Group contributed to the developing analysis and emerging themes, drawing attention to what might be missing or overlooked in the data, particularly in relation to the care people with learning disabilities give.	5
	In WP5 (Online Digital Storytelling Workshops), following screening events the analysis was further developed in a Tea and Cake Group meeting.	13
	In WP6 (Synthesising Findings; Creating Resources), overarching themes were identified and reviewed with the Tea and Cake Group, prioritising the creation of resources for different audiences (see *Report Supplementary Material 2* and *Report Supplementary Material 3*). The synthesis was conducted across the Tea and Cake Group meetings and teams involving KRC, SR and MS. This involved looking at different findings of each WP and drawing links and connections across the data sets. This was an iterative process across 1 month.	6
	In WP7 (Dissemination), members of the Tea and Cake Group attended the online and in-person end-of-project event which formed part of the ESRC Festival of Social Science.	6
4d: Level or nature of involvement	**Report the level or nature of PPI used at various stages of the study**	4
	The Tea and Cake Group met bimonthly throughout the project and were involved at every stage of the project, offering advice on study design and on data analysis and dissemination. Parent-carer meetings were online while the members with learning disabilities met in person. We were also in e-mail contact with the group across the project.	10
Section 5: Capture or measurement of PPI impact		
5a: Qualitative evidence of impact	**If applicable, report the methods used to qualitatively explore the impact of PPI in the study**	3
	Bimonthly coproduced blogs with Easy Read summaries and audio versions based on the Tea and Cake Group (public involvement group) meetings were also published, with members' permission: https://sites.google.com/sheffield.ac.uk/tiredofspinningplates/blogs. **Example feedback from group members:** *'What I got from the Tea and Cake group is love, dignity and support.* *I enjoyed getting to know the other people and everyone's backgrounds.* *It made me feel really grown up and more confident and getting to know each other.* *After 2 years of seeing each other on Zoom I gave my Tea and Cake group some feedback and some cuddles and support.* *I am really going to miss seeing everyone.* *I would love to do this again'.* *'I was delighted to have the opportunity of sharing my story with the Tired of Spinning Plates research team who encouraged me to think about making and sharing a short film.* *I hope that by illustrating my experience of supporting a sibling through grief and loss others might be able to identify with some of the challenges that carers and family members with learning disabilities may encounter as they face older age, frailty and loss together'.* *'So you've already heard that one of the best things for the "Tea and Cake" group was the experience of being together with people to whom we did not have to explain ourselves. People who immediately "got it", because they'd been there themselves. If you're not a carer, this may seem odd to you. But. Caring is an isolating experience'.* *'Thank you Staff at Sheffield University and everyone on the project for giving me an opportunity to try to show how stress in caring has affected my Mental Health'.*	15

Section and topic	Item	Reported on page no
5b: Quantitative evidence of impact	**If applicable, report the methods used to quantitatively measure or assess the impact of PPI**	N/A
5c: Robustness of measure	**If applicable, report the rigour of the method used to capture or measure the impact of PPI**	**6**
	The use of coauthored blogs to capture the impact of the PIE in the project stimulated further public engagement with the project and led to invitations to write for *PMLD LINK* (Spring 2024); *Community Living Magazine* (Spring 2025).	**15**
Section 6: Economic assessment		
6: Economic assessment	**If applicable, report the method used for an economic assessment of PPI**	N/A
Section 7: Study results		
7a: Outcomes of PPI	**Report the results of PPI in the study, including both positive and negative outcomes**	**4, 5 ,6 ,7, 10**
	In WP1 (Tea and Cake Group), the Tea and Cake Group shaped the ethical approach to the study offering guidance on the need for a flexible approach to participation for family carers. This impacted on every stage where family carers were given the flexibility to participate in the workshops, interviews and digital storytelling workshops at day of the week and time of day that worked for them. They were not asked to 'fit in' to pre-planned activities. In WP2 (Rapid Scoping Review of Evidence), the impact of the Tea and Cake Group was to ensure that the analysis paid attention to the role of love in caring relationships between people with learning disabilities and family carers. The absence of discussion of love in research literature was noted by the group. In WP3 (Survey Co-Design Workshops/Exhibition), group members supported the decision to move from an online survey to an online exhibition. Reflecting on the learning from the coproduction workshops, they shared the view that an online survey was unacceptable to family carers and that it had the potential to add to their already burdensome levels of paperwork.	**10** **26**
	In WP4 (Qualitative Interview Study), the Tea and Cake Group raised the issues of the care that people with learning disabilities themselves give. They drew attention to the ways in which people with learning disabilities and family carers experience care as relational, rather than as uni-directional.	**10** **11**
	In WP5 (Online Digital Storytelling Workshops), following screening events the analysis was further developed in a Tea and Cake Group meeting. They pointed to the recurrent themes in the films suggesting that mental health is damaged by 'fighting' for services and support.	**12**
	In WP6 (Synthesising Findings; Creating Resources), the Tea and Cake Group coauthored the take-home messages the resources for health and social care practitioners (see *Report Supplementary Material 2* and *Report Supplementary Material 3*).	**13** **14**
	In WP7 (Dissemination), members of the Tea and Cake Group shared the research with their networks. This led to the research team sharing the research at a parliamentary drop-in hosted by John McDonnell, MP at Portcullis House, Westminster, 23 April 2025.	**23**
	Strong public engagement on social media led to the exhibition being featured in *PMLD Link* and *Community Living Magazine*.	**15**
7b: Impacts of PPI	**Report the positive and negative impacts that PPI has had on the research, the individuals involved (including patients and researchers) and wider impacts**	**10, 11**
	The overall impact of PIE on the research was very positive. The Tea and Cake Group supported the development of a highly flexible approach to research. This flexibility was achieved while ensuring that the RAs and questions were met.	**12**
	Example feedback from group members: *'On a personal note, I found the entire experience empowering at a time when I felt voiceless—for that, I will always be grateful'.* However, this approach was also very time consuming. The shift from online survey to online exhibition triggered an extended ethics amendment and protocol review. On reflection, we learnt we need to be more ambitious in our approach to PIE and ensure future projects have sufficient resources, including time, to support expansive models of PIE. The model of PPI used led to the development of strong working relations between the members of the Tea and Cake Group. We were mindful of the project ending and arranged a 'goodbye' event with members.	**25**

Section and topic	Item	Reported on page no
7c: Context of PPI	**Report the influence of any contextual factors that enabled or hindered the process or impact of PPI**	
	Throughout the project, no interviewee or digital storyteller took up the offer of payment for care replacement costs, because of a lack of alternative care. This is an issue which needs considerable thought in future research.	**32**
7d: Process of PPI	**Report the influence of any process factors that enabled or hindered the impact of PPI**	**10, 11, 14**
	The academic team was experienced in working with members of the public in research. This meant that they were able to support the PIE work well.	**23**
	Public involvement funds were used to support the translation of the exhibition invitation into five community languages recognising the importance of engaging with diverse communities in this way (WP3). Although translation costs are high, they are valued by members of the public.	**25**
	'Many Roma families feel excluded from available services and help due to the lack of understanding and social stigma and by seeing something like this project translated into their language would give them an opportunity to get involved and make them feel empowered and seen'. (E-mail correspondence).	**35**
7ei: Theory development	**Report any conceptual or theoretical development in PPI that have emerged**	**15, 16**
	The model of PPI developed which involved setting up a group of public members who contribute to the project at each stage as well as being participants in the research is new, and should make a contribution to considerations of PPI conceptual or theoretical developments going forward.	
7eii: Theory development	**Report evaluation of theoretical models, if any**	N/A
7f: Measurement	**If applicable, report all aspects of instrument development and testing (e.g. validity, reliability, feasibility, acceptability, responsiveness, interpretability, appropriateness, precision)**	N/A
7g: Economic assessment	**Report any information on the costs or benefit of PPI**	N/A
Section 8: Discussion and conclusions		
8a: Outcomes	**Comment on how PPI influenced the study overall. Describe positive and negative effects**	**10, 11**
	As described above, the involvement of the group challenged our thinking across the project, offering different interpretations of developing analysis, highlighting critical absences and offering encouragement throughout. The negative effects were an outcome of us underestimating the time and resources needed to facilitate meaningful engagement.	
8b: Impacts	**Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge**	**10, 11, 14, 15, 16**
	This is covered in 7g and 7ei above. The impacts were substantial, the group's role in the project was consistent and strong, leading to explicit changes in our thinking and working. Members of the research team also have lived experience of being family carers and yet the group made innovative and unexpected contributions to the project.	
8c: Definition	**Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes**	**16**

Section and topic	Item	Reported on page no
	We drew on the UK Standards for Public Involvement which involves six strands: communication, governance, working together, inclusive opportunities, impact and support and learning. These remained relevant throughout the study, although we strongly urge a change to the description of 'public and patient engagement' used on this form. This should be changed to public engagement. An additional consideration is how to overcome enduring barriers which in this project involved being unable to engage fully with Roma community participants and how to support people who are unable to use care replacement costs.	
8d: Theoretical underpinnings	**Comment on any way your study adds to the theoretical development of PPI**	
	As above.	
8e: Context	**Comment on how context factors influenced PPI in the study**	
	As above.	
8f: Process	**Comment on how process factors influenced PPI in the study**	
	As above.	
8g: Measurement and capture of PPI impact	**If applicable, comment on how well PPI impact was evaluated or measured in the study**	N/A
8h: Economic assessment	**If applicable, discuss any aspects of the economic cost or benefit of PPI, particularly any suggestions for future economic modelling.**	N/A
8i: Reflections/ critical perspective	**Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this study**	
	We have commented critically on the public engagement across the study in this form.	

PPI, patient and public involvement.

This synopsis should be referenced as follows:
Runswick-Cole K, Ryan S, Smith M, Hatton C, Douglas P, Kassa C, *et al*. 'Tired of spinning plates': Synopsis of mixed methods exploration of mental health experiences of adult/older carers of adults with learning disabilities. *Health Soc Care Deliv Res* 2026;**14**(6). https://doi.org/10.3310/GJKR4724