RESEARCH PROTOCOL

Full title of project

Improving the support for older people with learning disabilities and behaviours that challenge others, family and professional carers, and end of life care planning for carers

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Ethical approval

Ethics approval for WP2 has been granted by The Open University Human Research Ethics Committee (reference HREC/3639). This protocol precedes ethical approval of WP3 and WP4 for which separate approvals will be sought.

Version control

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V 1.0	Sara Ryan Louise Wallace	n/a	27th July 2020
V 1.1	Sara Ryan Louise Wallace	Change of title Addition of NIHR acknowledgement and disclaimer Removal of Gantt chart	6th Oct 2020

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Summary of research (abstract)

Background: An increase in the life expectancy of people with learning disabilities (PWLD), real reductions in the availability of services, combined with reluctance on the part of their consequently older parent carers to forward plan for transition to independent supported living or care by other family members can lead to an increased risk of crisis placements. Siblings who have taken on caring roles from parents can face multiple caring responsibilities. This is particularly so for people whose behaviour is seen to be challenging to themselves or others. Clear destabilising factors for this group include the family carers[1] themselves growing frailer, deaths of family and friends, and for PWLD the early onset of chronic health conditions including dementia and the loss of the family home. These factors increase vulnerability to distress and deteriorating behaviours in later years. Evidence suggests that older carers worry about what will happen to their adult children when they are no longer able to care for them; however there is a lack of research about how older PWLD feel about what will happen to them at this time. We know little about how older carers plan for their own end of life care (EOLC) while they continue to have responsibility for the wellbeing of their learning disabled adult children with behaviours that challenge.

Aims: To improve support for family (and professional) carers and older PWLD (aged 40+) with behaviours that challenge by producing effective and workable recommendations and resources including EOLC planning for carers. Our multi method research will:

1. Develop an understanding of what is known about the health (physical, mental and social) needs, service interventions and resources for older PWLD with a focus on those with behaviours that challenge, and their family carers.
2. Identify exemplars of good practice in services and support interventions in the UK for older PWLD, and their family and professional carers, with behaviours that challenge towards end of life.
3. Explore service exemplars through ethnographic case studies.
4. Evaluate service support for older PWLD and their families through the co-production and testing of decision aid tools to support future planning and end of life care (EOLC) discussions for carers.
5. Co-produce actionable recommendations with carers, PWLD, providers, social workers and commissioners, resources for older PWLD, family and professional carers and social workers around behaviours that challenge in older age and at the end of life.

Methods: To meet our aims and objectives we will:

- Conduct two rapid scoping reviews focusing on older PWLD with behaviours that challenge and older carers for this group to provide a foundation for the subsequent work packages (WPs).
- Undertake a scoping exercise involving interviews, documentary analysis with key NHS and local authority commissioners, providers and via social media to the wider learning disability community, to identify exemplar services for older PWLD (40+) with behaviours that challenge.
- Conduct a 4 site ethnography of service exemplars involving observations, interviews and documentary analysis.
- Conduct focus groups and interviews with older carers around EOLC planning, develop and test decision aid interventions using experience based co-design methods.

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[1] We define family carer as parent, spouse, partner, sibling or other close relatives who care for PWLD either in their own home or in residential/supported living settings.

- Co-produce implementable recommendations for service improvement and innovative dissemination plans for the uptake of project outputs including decision aid tools, resources and training materials.

Anticipated impact: The main beneficiaries will be PWLD and older family carers. We anticipate that the known lack of forward planning by carers and PWLD with behaviours that challenge, and the lack of attention and limited focus by services on this group, will be addressed by the research findings, outputs and comprehensive dissemination plans. Beneficiaries will also include social workers (the gateway to statutory social services for PWLD) and by extension professional practice. The output, knowledge about needs of PWLD and their carers, can be drawn upon by social workers in their assessments. We anticipate benefits for support workers and frontline staff through the provision of new training and other resources disseminated by the British Association of Social Workers (BASW). In addition, GPs, family members, commissioners, health and social care students and professionals will potentially benefit from the development of engaging and innovative resources covering issues around ageing, EOLC, forward planning and behaviours that challenge. Finally our work is relevant to academics as we demonstrate through video blogs and social media activity across the project how inclusive research can be conducted.

Background and rationale

There are around 900,000 PWLD in England (1), nearly 20% of whom are estimated to engage in behaviours that challenge (2). These behaviours are a product of the interaction between individual and environmental factors (3) varying across the life course. Many PWLD are not known to services until later in their lives having been cared for by family members until they become too frail to do so (4-6). The life expectancy of PWLD is increasing and it is estimated the number of people requiring social care will increase by 68% by 2030 (7). The number of PWLD using adult social services is estimated to double by 2030 (8). Advisory Group member Dame Philippa Russell reported in personal correspondence that her son's consultant recently referred to a '*new generation of survivors'* who are now likely to outlive their parents. Little is known about the needs and experiences of older PWLD (9) yet there are clear destabilising factors for this group which make them particularly vulnerable to distress and deteriorating behaviour. These include reductions in services (10), carers becoming less able to provide care, changing health needs through ageing, a risk of early onset dementia for PWLD (11), a lack of future planning (12,13) which elevates the risk of inappropriate transitioning to more intensive supported care, and a lack of effective EOLC for older carers and PWLD (14). This latter point is particularly important given the government's recent commitment to 'choice in the end of life care (EOLC)' (15). While older PWLD have significant and complex EOLC needs, this project will focus on the EOLC of the carers. 40+ for PWLD has been selected to reflect the early onset of chronic health conditions, such as dementia, for this group (34). Our research will address remit 2ii (Commissioning Brief) by producing rigorous and relevant evidence about how to effectively support PWLD (40 +) and family carers.

Brief literature review

It is well documented that the death of a family member, particularly the main caregiver, can trigger complicated grieving, behaviours that challenge and the need for crisis intervention for PWLD (16). In part because parental loss is often accompanied by further losses including the loss of home (17). This issue is particularly pertinent for ageing family carers living with an older PWLD who may have spent a lifetime worrying about what will happen to their adult children after they die but may not have prepared for this. Primary research on older family carers of PWLD is sparse in the UK and tends to focus on parental carers. Six studies were identified in one review (18) which found fear for the future, lack of trust in services, lack of proactive support to manage crises and transitions, and declining personal support networks in a period when they are most needed. The needs of those caring for people with behaviours that challenge were not identified specifically in these studies. We know that parents are dissatisfied with statutory and private services and have concerns for the future responsibilities of their non-disabled adult children and their own ageing (19, 20). One study found only 28% of participants had made plans for the future residential care of their children and there was strong commitment to maintaining long-term home care for as long as possible (21).

NICE Guidance relevant to PWLD with behaviours that challenge (NG 11,93) advises on the need for transition planning and personalised care but make no recommendations around issues relating to older PWLD. The NICE review for the Guideline (to March 2017) includes seven studies with none particular to older people. A qualitative synthesis of carer experience with services for this group found concerns about times of crisis and availability of services suitable in later life (22). Asking for help from the local community can be particularly difficult for carers from ethnic minorities (23). NICE NG 96 relates to older PWLD in general and does not review evidence related to behaviours that challenge. Projections for increases in life expectancy mean there will be fourfold increases in older PWLD: two thirds living in the parental home with increased risk over time that the care will breakdown, increasing disruption and distress without forward planning. Recommendations are for a multi-agency plan to be in place and reviewed annually or as need arises and for health planning. NICE point to the need for studies of interventions to support families and people developing dementia, with existing UK studies showing a lack of preparedness of families (24). Similarly, NICE identified a gap in evidence on applying advanced care planning in EOL for PWLD despite UK studies showing the prevalent anticipatory anxiety that is apparent (25).

Discrepant views can exist between PWLD, their families and practitioners on EOLC and “bad news” decisions (26). Guidelines exist (27) but issues around behaviours that challenge are not included (28). A study of the experiences of older PWLD in hospitals showed poor care experiences due to the inability of staff to communicate effectively and carers felt behaviours that challenge were likely to precipitate inappropriate early discharge (29). Studies of carer experience of palliative care, cancer and dementia (not specific to those with behaviours that challenge) (30) found concerns about how to access palliative care services and how to communicate the prognosis and treatments required to families and to older PWLD with deteriorating health. Social care staff in palliative care settings with people with Down’s syndrome and dementia experienced dissonance between their enabling role supporting autonomy and their subsequent role of monitoring deteriorating health and diminishing skills (31).

Why this research is needed now

Health need: Family carers of older PWLD report poorer physical health than their peers (32) which can impact on the care they provide. This can inadvertently lead to behaviours that challenge (33). Older PWLD more commonly experience chronic health issues, such as kidney disease, dementia, constipation and diabetes, earlier than their non-disabled peers (34). Recent research highlighted the over-use of antipsychotic medication among older PWLD with 58% of those on antipsychotics reporting problem behaviours (35). Little is known about the experiences of family carers and older PWLD who may develop behaviours that challenge as they grow older, particularly in the context of transitioning to different services in periods of crisis or at the end of life. We also know little about how older family carers manage their own end of life care. Our study will explore the support and health needs of older PWLD and family carers and identify ways of easing transitions to different care settings through forward planning and reducing the development of behaviours that challenge.

Expressed need: A recent Comic Relief funded project *Embolden* led by Oxfordshire Family Support Network (OxFSN) identified 2940 carers of PWLD aged 50 and over in Oxfordshire. A key theme was concern about the future. https://www.youtube.com/watch?v=AMvbrhA2nUk (36). One father (72) said "What keeps you awake at night is not knowing what the future holds for our son" while a mother (92) asked "I just dread that day. What is going to happen? If they decide to uproot her I don't think she will survive". A body of policies and programmes in the UK, including *Valuing People*, *Valuing People Now* and *Transforming Care,* aimed to enable PWLD including those with behaviours that challenge to lead independent supported lives in their communities. However, family carers remain committed to maintaining long-term care in the family home in the absence of support or confidence in existing services.

There is no available data about the number of older PWLD in England although Hatton (37) estimates there are around 81,000 PWLD, aged over 50, many of whom are not in contact with services. We know very little about the lives of PWLD as they age. For example, how health issues or the illness or death of family carers affect people and the potential impact on behaviour. We also know little about the end of life experiences of family carers who are fearful about the future or the ways in which this impacts upon the experiences of PWLD. One study (38) charted what happened when PWLD and behaviours that challenge were effectively supported to continue to live in the family home with nuanced support and forward planning. There is an even more pronounced absence in the academic and grey literature regarding the lives and experiences of older PWLD without family support.

Existing decision aids and services to support people make choices, for example, those produced by Together Matters (39) are not focused on PWLD with behaviours that challenge or at risk of developing behaviours that challenge. Our research will therefore co-produce recommendations, resources for family carers, older PWLD and training materials to help address support and information needs.

Sustained interest and intent: With the increased longevity of PWLD the support needs for this group are likely to increase. Furthermore, the ageing processes for those with Down's syndrome are known to occur earlier (usually 40-50 years old) (40) with ageing progressing at a faster rate than their non-disabled peers. Care planning for these younger adults is within mainstream learning disability services and should include regular re-assessment (41) however, it does not feature in NHS England (NHSE) Transforming Care pathways. This may indicate potential gaps in services as PWLD with dementia develop behaviours that challenge, posing barriers to access to care services later in life. Access to palliative and end of life care planning by older PWLD is known to be problematic but little is known about how behaviours that challenge affect service access and healthcare planning decisions. The results of this rigorous research project will remain pertinent to the needs of the NHS and social care by providing resources and improved guidelines to offer ongoing and relevant support.

Capacity to generate new knowledge: Very little is known about older PWLD, with behaviours that challenge and their family carers. How does the occurrence of behaviours that challenge affect service provision? How do carers manage their caring role as they themselves age? How can forward planning be introduced in an acceptable and reassuring way to family carers and older PWLD? How can health, social care and EOLC services effectively support carers and older

PWLD including where active family involvement is absent? How can commissioners be innovative in developing a service infrastructure that better meets the needs of this group? Our multi method study involving PWLD, older carers, service providers, frontline staff and commissioners will generate in-depth knowledge in this area.

Aims and objectives

Research questions:

1. What are the information, health and social care support needs of family carers and older PWLD with behaviours that challenge that enable effective forward planning around supported living and EOLC for older carers?

2. What are the characteristics of exemplars of good practice in services and support interventions in the UK for older PWLD (and their carers) with behaviours that challenge towards end of life and how are they delivered?

Aim: To improve support for family carers, older PWLD (aged 40+) with behaviours that challenge by producing effective and workable recommendations and resources including end of life care planning for carers.

Objectives:
1. To develop an understanding of existing evidence about the health (physical, mental and social) needs, service interventions and resources for family carers and older PWLD with a focus on those with behaviours that challenge in transition to greater supported care, including EOLC for carers (WP1)

2. Identify exemplars of good practice in services and support interventions in the UK for older PWLD, and their family and professional carers, with behaviours that challenge towards end of life (WP2)

3. To explore how older PWLD with behaviours that challenge and their carers can be better supported in later life by researching the commissioning and delivery of exemplar supported living services using ethnographic case studies (WP3)

4. To coproduce decision aid tools to support future planning and EOLC discussions for carers and future planning for older PWLD and evaluate their initial use (WP4)

5. To coproduce actionable recommendations for commissioners and providers, resources and decision-aids for carers and PWLD with behaviours that challenge, and online training materials about care in later life for social workers and professional carers (WP5)

Research Plan

Design and theoretical/conceptual framework: The theoretical framework underpinning this study is symbolic interactionism as we aim to understand how carers and older PWLD make sense of their lives and ageing. Following Blumer (42) we argue people act towards their environment and others based on the meanings they attribute to it. ‘Joint action’ involves drawing upon pre-existing frameworks of interpretation which remain open to the attribution of different meanings over time. This has particular resonance as our focus is on growing older and carers’ experiences of approaching EOLC. To understand these interpretations and sense making we will use a qualitative approach drawing on ethnographic methods, interviews and focus groups. We will explore with older PWLD and carers what is important to them, their fears, hopes and aspirations, how they can be better informed and supported to plan for their future including transitions to supported living and EOLC decisions for carers. We will also interview service providers, commissioners and Transforming Care Programme NHSE regional leads to produce a comprehensive and robust understanding of what the issues are that currently inhibit forward planning.

The study comprises five work packages (WPs). WP1 and WP2 are both scene setting. WP1 has two rapid reviews focusing on the health needs of older PWLD and carers, practice guidance, interventions and resources. WP2 uses qualitative methods to identify exemplars of supported living services and support interventions across England for older PWLD including those with behaviours that challenge. In WP3 research teams, including including carers or PWLD, will use ethnographic methods of observation, interviewing and documentary analysis to study four exemplar provider sites. Case studies will in part be selected from what emerges from the scoping exercise. WP4 focuses on the EOLC planning experiences of older carers and the use of decision-aid interventions in the associated forward planning for PWLD. The two central strands of facilitating and enabling forward planning for older PWLD and behaviours that challenge, and EOLC for carers come together in WP5 when we co-produce the final project outputs.

WP1

Review literature about the health (physical, mental and social) needs, service interventions and resources for (a) older PWLD and (b) family carers with a focus on those with behaviours in transition to greater supported care

Two ***Rapid Scoping Reviews*** will be conducted using a systematic framework. Recent literature adopting a similar approach (43, 44) found a lack of evidence around research and practice guidance focusing on the health needs, experiences, interventions and resources for **carers** of older PWLD and for **older** PWLD. Whilst the needs of carers are discussed as a general population, primary and secondary evidence for ageing carers of ageing PWLD within the UK is limited (44); a small body of grey literature was identified on future planning but none for interventions available during care crises for PWLD who are cared for by an ageing carer (39). An initial search did not return any peer reviewed papers focused explicitly on care crises for this group (44). One thematic synthesis of qualitative research on the experiences of PWLD and behaviours that challenge and a sister review (45,23) did not focus on ageing or EOLC. To date, literature on carers of older PWLD with behaviours that challenge or older PWLD with behaviours that challenge has not been specifically reviewed. Our reviews will focus on (a) older PWLD and (b) family carers, with a focus on those with behaviours that challenge in transition to greater supported care. Scoping reviews are designed to synthesise knowledge according to an exploratory research question (46), providing an overview of broad research fields and can accommodate a variety of different research methodologies and literature sources. We will adopt the scoping framework proposed by Arksey and Malley (47) and subsequently amended (48), the Joanna Briggs Institute (49) and guidelines by Colquhoun et el (50) in conjunction with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analysis) extension for Scoping Reviews (PRISMA-ScR) to ensure a systematic approach (51).

Inclusion/Exclusion Criteria: Explicit inclusion and exclusion criteria have been developed for each review to be discussed and refined with the Advisory Group. R1: Family carers for PWLD and behaviours that challenge (40+). R2: PWLD and behaviours that challenge (aged 40+) including those with onset of dementia and not excluding those with a secondary diagnosis of ASD. Papers to be inclusive of any design, published since 2001 (publication of *Valuing People* which signalled a new focus on older families in policy and research). Literature must relate to the existing research and practice guidance focusing on the health needs, healthcare experiences, interventions and resources for carers of older PWLD with behaviours that challenge (R1), and older PWLD with behaviours that challenge (R2) in transition to greater supported care or end of life care.

Initial searches: Search strategies will be drafted and undertaken with the support of a subject specialist librarian. An initial limited search will be made of three databases chosen for their varied content and use of subject headings. Using Medical Subject Heading (MeSH) terms and natural language, keyword terms (with synonyms and terminology variations) will be combined using the Boolean operators ‘and/or’ and appropriate truncation and phrase symbols. An initial limited search of two databases will be undertaken; MEDLINE and CINAHL selected for their varied focus and content. It will be peer reviewed using the Peer Review of Electronic Search Strategies (PRESS) tool (51) and a final strategy will be agreed and subsequently used to develop search strategies for the other databases to be included. Indicative search terms for the two reviews include UK, England, Wales, Scotland, NI, social care, learning disability, intellectual disability, challenging behaviour, complex needs, ageing, old, mental and physical health, wellbeing, end of life care, palliative care, carer, caregiver and synonyms and will be combined with Boolean operators. Search terms will be reviewed by the Advisory Group.

Main searches R1 & R2: As for the analysis of initial searches, we will analyse text words contained in the title, abstract and keyword list of all returned articles from initial searches and the index terms used to describe the articles, to identify the full range of words and terms used. These text words and index terms will be used to design the search strategies used for the main searches. Reference lists of included articles derived from the main search will be hand searched and websites of relevant professional, statutory and non-statutory organisations will be reviewed, and follow-up contact initiated where relevant. **Grey literature search R1 & R2:** Modified versions of the strategies will be used to search for grey literature e.g. policy and practice documents, consultations and third sector reports. Given the broad scope and potential for these searches to yield a large number of returns, only the first 100 from each will be extracted. This process will be aided by the relevance ranking algorithms used by the search engines. **Other searching:** We will identify subject experts via the Advisory Group and included articles and ask them to recommend key resources (research papers, reports, other publications).

Study screening and inclusion R1 & R2: Using the PRISMA flowchart we will record the process for screening for full text inclusion. **Data extraction & charting:** A tailored data Excel charting form will be used containing the information extracted for each category for all included articles. **Quality appraisal R1 & R2:** We will use the Mixed Methods Appraisal Tool, Version 20 18 (MMAT-V 2018) (52). Other appraisal frameworks are available for other study designs and nature of evidence e.g. AMSTAR 2 (53) suitable for appraisal of systematic reviews and the Methodological Quality Checklist for Stakeholder Documents and Position Papers (MQC-SP) (54) is suitable to evaluate the quality of grey literature.

Summarising the findings R1 & R2: Given the likely heterogeneity of included evidence, we propose a narrative approach to summarising study findings (43,44) and a narrative synthesis (55). Findings will be integrated by iteratively searching for relationships, allowing us to generate descriptive categories (according to focus) and themes (according to specific issues). In discussion with the wider team and Advisory Group we will identify issues of strategic interest, for example, any notable service models to support older PWLD and behaviours that challenge.

OUTPUTS: A full report and first draft for peer reviewed publication for R1 & R2. The report will contain the description of needs and experiences and a synthesis of evidence on service models and resources; informing WP2-5.

WP2

Identify exemplars of good practice in services and support interventions in the UK for older PWLD (and their family and professional carers) with behaviours that challenge towards end of life

The scoping exercise in WP2 aims to identify the range of service provision for older PWLD in the community and data synthesis (across the interviews and social media) will enable us to produce criteria for the selection of the exemplar case studies to be undertaken in WP3.

NHSE/Improvement have led consultative work in England in a range of services including LD and EOLC to define the principles of good practice (56,57). These do not include older PWLD and behaviours that challenge. WP2 will scope out the range of service support in the community in England for older PWLD including those with behaviours that challenge. Public Health England has published standards relevant to the reasonable adjustments required for this group (58).

Methods: The above standards, and any subsequently issued before the start of WP2, will be considered by the Advisory Group and research team who will meet in a virtual workshop format to develop a working definition (a) of the service users and (b) services in scope for this WP (c) key characteristics of the services (ambitions) most relevant for older PWLD and behaviours that challenge which together are criteria for exemplar services. The Advisory Group will also inform the data collection routes and interview guide described below, and in reviewing the findings and criteria for decisions on case studies for WP3.

In order to scope out the range of service support in the community in England for older PWLD information will be sought using a structured protocol via phone calls with key respondents:

1. We will adopt a pragmatic approach to gaining an overview of the commissioning of services for older PWLD with behaviours that challenge and which are the exemplar providers in England. Service mapping methods adopted in a previous HS&DR study (59) will be used. A similar approach for recruitment will be used to the successful approach adopted in *Building the Right Support* (60) where case studies were at a Transforming Care Partnership (TCP) level. In this scoping exercise we anticipate identifying one or two key strategic level respondents using a cascade approach who are able to identify exemplar services if they exist in their geography for older PWLD. We know from Advisory Group members (see below) that the NHS is undergoing a number of structural changes and there is likely to be geographic variation in the strategic oversight of services over at least the next two years. Who will be approached will be refined with advice from Advisory Group members. Local authority leads will be sourced via the Association of Directors of Adult Social Services (ADASS).

To gather data about commissioning approaches for older PWLD and to identify possible exemplar case study sites for WP3 we will interview NHSE regional leads for LD and/or the lead for EOLC, (up to 14). We aim to conduct at least one formal interview by phone or email per sustainability and transformation partnership (STP) area (currently 44) with key informants. Where possible when provider exemplars are identified an additional phone interview will be conducted with the relevant commissioners and with the specified provider where appropriate to further populate the descriptive service map with details of the exemplar services.

2. Identify exemplars among third sector organisations and providers and innovations in delivery that could be scaled for use more widely. The overall approach, informed by a recent UK study of social care providers (45), will focus on larger providers, although smaller providers may be included. Key respondents will be recruited from larger service providers such as Shared Lives, Dimensions, MacIntryre, United Response, Choice Support, and providers with identifiable specialist provision in their portfolio (L Arche, Style Acre, Home Farm Trust, Leonard Cheshire) identified as registered with the CQC with older PWLD clients. Jackie Fletcher (Executive Director, Quality, Public Affairs and Policy, Dimensions and Advisory Panel member) referred us to their internal quality reviews and views of their Family Consultants as source of insight into exemplars. Macintyre has a Department of Health and Social Care funded LD dementia project whose members would identify good practice service examples. With support from the CQC all providers will be examined for CQC ratings with a particular focus on those with overall “outstanding ratings” or at least outstanding in “Caring and Safe” domains (46). Key respondents will be asked to identify examples of innovations for older PWLD and behaviours that challenge. Third sector networks such Learning Disability England and the Voluntary Organisations Disability Group will also be contacted. Up to 70 phone or email interviews will be conducted for (1) and (2) above, including 2 interviews per potential case study (approximately 8).

3. Reach out via social media to the public and professionals interested in this topic to identify exemplars in service delivery. While this data source will have unknown reach, it provides an additional resource to draw upon and generate wider interest and pathways for dissemination. The protocol for this section of work will be developed in consultation with our Advisory Group and draw upon our networks (see below), Care England and other social care provider trade bodies, RCN Learning Disability Nurses and National Network for Learning Disability Nurses who hold regular twitter chats on particular topics, Facebook groups including the National Network for Learning Disability Nurses, the RCN Learning Disability Nurses forum and the LDDCafe (learning disability and dementia support), British Psychological Society and networks within Royal Colleges.

Analysis: Data will be analysed using rapid qualitative synthesis taking account of service context (61). Service level data will be analysed using a Consensual Qualitative Research approach (CQR) (62) which includes systematic evaluation of thematic representativeness across multiple cases. This method will enable synthesis of data across different sources (interviews and social media) as well as a quantification of the extent of agreement on key themes (63). These themes will be used to form criteria for the selection of case studies for WP3. What is meant by ‘exemplars’ will be refined in the virtual workshop with the Advisory Group with consensus methods using “teamworker” (or similar) software. The data will be used to draw out the key themes of what constitutes an exemplar service, in what context and for whom, for older PWLD and their family carers. This will enable us to draw up a list of candidate exemplars again using consensus methods to agree the criteria.

The existing candidate site (Haringey) will be put to the advisory group in Month 6 approximately along with new potential sites arising from the WP2 data collection. The final decision will rest with the research team, taking into account matters of feasibility and access.

OUTPUTS: Peer reviewed publication, description of services and support interventions for older PWLD and behaviours that challenge from which case studies are selected as exemplars.

WP3

Explore how older PWLD with behaviours that challenge and their carers can be better supported in later life by researching the commissioning and delivery of innovative supported living services using ethnographic case studies

WP3 will involve an ethnographic exploration to understand the delivery and characteristics of exemplary services identified in WP2.

Sampling: Case studies demonstrating a diversity of approaches to the provision of exemplars that support decision-making by families and on-going supported care in the community will be approached and invited to take part in the study. We will negotiate access first at provider level and then with local managers and support workers clearly explaining what participation in the project would involve. Time has been factored into the project timetable for careful initial engagement with the sites as this is important to the success of this WP. Responsiveness to participation in an in-depth ethnographic study is not known although an ethnographic study of the experiences of people with multiple and profound disabilities in Finland (which involved SR as an Advisory Group member) attributed the ease with which they were welcomed into residential settings to the lack of research in that area (64).

Haringey Council Adult Social Care Services will serve as one confirmed site. Haringey has recently agreed to explore the development of specific provision for older PWLD (including autism) and behaviours that challenge in a new facility called Osborne Grove. The Lead Commissioner is in discussion with the Severe and Complex Autism and Learning Disabilities (SCALD) Reference Group to take this new and innovative area of service provision forward. Our ethnographic fieldwork will chart the development of this facility and we anticipate this site will enable us to access the experiences of ethnic minority carers. Local commissioners and parents have agreed to be interviewed.

The ethnographic fieldwork, involving teams from Oxford University, the OU and Manchester Metropolitan University, will include interviews with a sample of people from each site; PWLD, carers and service providers. A sampling framework will be produced to sample for diversity including age, gender, ethnicity, family context and length of time living or working in the provision. The exact number of interviews conducted will depend to some extent on the composition of the setting but we anticipate 5-10 PWLD, 5-8 carers, 4-5 support workers and 1-2 relevant commissioners and service managers at each site. In total the research team will conduct around 80-100 interviews across the four sites.

Setting/context: Four exemplar supported living settings across the UK to include Osborne Grove, Haringey.

Data collection: Research teams will use longitudinal observations, interviews and documentary analysis to understand how people are supported in their everyday lives, to negotiate ageing, how issues like death and dying are discussed and how behaviours that challenge are ameliorated. The research team will spend time with people and staff both within and outside the setting. A total of 20 days divided into two days a week will be spent at each site across Months 5-16 including some weekends and evenings. Research teams will vary depending upon the requirements of specific sites. Some will include at least one co-researcher (either PWLD and/or carers). The case study site led by MC, for example, will draw on the research team from the Greater Manchester Growing Older with Learning Disabilities project (GM GOLD). Funding for training co-researchers has been included in the budget.

The researchers will keep detailed field notes including a description of the setting, interactions between PWLD and staff and with objects and the environment, emotions, impressions and reflections. The research team will debrief after each two-day visit to share developing thoughts and observations. Interviews with PWLD, carers, support workers, provider managers and commissioners will be staggered across the fieldwork period in order to explore developing ideas and test our emerging analysis. Interviews will explore the background context to the PWLD moving away from the family home, what was important to the PWLD and carer (and support workers, providers and commissioners), how decisions were made and negotiated, the relationship between family carers and PWLDs, views about future planning and EOLC. Interviews with family carers will take place in their own homes or at an alternative location if participants prefer. We will be flexible about how we gather information from PWLD about their experiences, views and concerns; for example using pictures, creative methods and vignettes. Interviews will be recorded with permission and transcribed verbatim. Finally, we will conduct a documentary review of the provider policies and guidance at each site.

Data analysis: Analysis will be conducted alongside the fieldwork with the researchers comprehensively familiarising themselves with the different datasets (observation, interviews and documents) using Nvivo qualitative data analysis software as an organisational tool. The observations, field and debrief notes will be coded in Nvivo using a modified framework approach (65). While framework analysis is not aligned to our interactionist theoretical perspective it is a flexible tool which is adaptable and allows the engagement of people without qualitative research experience (see analysis workshop below). A matrix of cases and codes will be produced. Our aim is to capture the micro detail in which people and staff express emotions, both positive and negative, and engage with each other and others, while examining what is happening in (and off) these sites and how people and staff make sense of and act in everyday life.

The interview dataset will be entered into Nvivo and a thematic analysis will be conducted using a modified grounded theory approach and the techniques of constant comparison and memo usage (66). The data will be open coded initially with two researchers independently coding the first two interviews to check that the tags assigned to data extracts are comprehensive. A coding framework will be developed from these open codes and a tree structure produced in Nvivo to facilitate the identification of categories and sub-categories. These categories will be flexible and an iterative approach to this first stage of analysis will incorporate going backwards and forwards between transcripts, codes and categories as new codes are identified in later interviews. When the dataset has been coded a more conceptual analysis will be conducted using a mind map approach (67). This will involve selecting particularly rich and relevant categories and translating the data in each into mind maps to allow us to generate themes, make links, identify patterns and visualise the data in a less linear way. Meaning, action and process will be used as an interpretive analytic lens to understand how participants understand and make sense of their lives, their actions and interactions. The documentary review will again use framework analysis to allow us to identify commonalities and differences across this dataset.

Co-researchers will not be directly involved in the stages of analysis detailed above. Recent research (68) advises that public involvement in qualitative data analysis is better at the beginning of the analysis to advise what the researchers should look out for rather than expect people to read large amounts of text. Strong PPI involvement across the project will capture these initial thoughts and co-researchers will be involved at the stage of emerging findings. An analysis workshop will be held to bring together the different datasets and discuss these findings with co-researchers, applicants, co-researchers and Advisory Group members. Key questions and puzzles about the analysis will be presented (in easy read) for discussion in small groups. Further analysis informed by these workshop discussions will be conducted.

OUTPUTS: A report to inform WP5, a 20 minute film provisionally titled 'The Good Old Life' of interview audio extracts, photographs and other materials for publication on Socialcaretalk.org, a podcast featuring members of the research team and Advisory Group discussing the research process and findings and a peer reviewed paper.

WP4

To co-produce decision aid tools to support future planning and EOLC discussions for carers and evaluate their initial use

WP4 will investigate and test a family based support programme to help families living with older PWLD to prepare for parental loss, transitions in care and EOLC for carers. We will investigate what community-based intervention(s) are welcomed and considered appropriate and helpful by family carers and co-produce and test an intervention that has the potential to be scaled up nationally.

Sample The sample consists of (a) PWLD (aged 40+) who live at home with an elderly parent who have some verbal ability and who are able to give informed consent (stage 3 participants may include PWLD unable to give consent); (b) Parent carers with an adult child with LD (aged 40+) living in the family home; (c) siblings of PWLD (aged 40+) who live with elderly parents; (d) siblings of PWLD (aged 40+) who had to leave the parental home following parental death within the past 3 years. Sampling will be primarily through OxFSN which has committed to support recruitment. In order to widen the sample beyond Oxfordshire an additional sampling method for interviews will be through calls on national forums and networks. The co-applicant team have significant networks of professionals and carers that can be accessed through organisational communication channels and social media (see below). The exemplar sites identified in WP3 will also be approached for potential participant recruitment. Participants who do not live within travel distance of the research team (maximum 3 hours' travel) may be interviewed by telephone, by mutual agreement. All participants with LD will be interviewed face-to-face.

Data collection **Preparation:** The data collection period will be preceded by 3 months of preparations involving staff training, participant recruitment, and refining and trialing data collection methods to elicit the experiences of participants with LD; the co-researcher will take an active part in this. Flexible data collection methods will include the use of: (i) Talking Mats™ (TM), which is a visual framework that helps people with communication difficulties to understand and respond more effectively (69); (ii) Books Beyond Words (BBW) which are wordless stories in picture format, to facilitate discussions with people who struggle with the written or spoken word (70). They are an effective tool for starting conversations about difficult topics.

Stage 1 (month 3-12)**:** Four focus groups (n=6 participants per focus group) and semi-structured interviews (face-to-face or telephone, as mutually agreed) with participants in groups (a), (b), (c) and (d) as described above (n=5 for each category) will be conducted. All will be audio-recorded. There will be a total n=44 (4 focus groups and 20 interviews in total). Focus group and interviews with PWLD will involve a co-researcher with LD, who will be part of a small team of co-researchers and benefit from the support and co-researcher training available at Kingston & St George's University (which has a Centre for Public Engagement). The interview schedules will focus on three areas: (i) Experiences so far: the PWLD living in the parental home, and temporary or permanent moves to live elsewhere (explore positives and negatives); (ii) concerns, worries and hopes about the PWLD's living situation in the future; (iii) what/who has helped with transition planning so far; what else would help.

Stage 2 (month 9-15)**:** Fortnightly 2 hour meeting with parents (n=6) and PWLD (n=6) to work out solutions and develop an intervention, using elements of Experience-Based Co-Design (EBCD) methodology. Parents and daughters/sons may take part together, or separately. We will use creative methods including storytelling and pictures from the Books Beyond Words Series. EBCD uses storytelling to identify opportunities for improvement and focuses on the usability of the intervention for carers and PWLD, as well as for staff. We will use the experiences gathered through stage 1 interviews and focus groups as a basis for group discussions, identifying key 'touch points' (emotionally significant points) and assigning positive or negative feelings. A short edited film will be created from these interviews and discussions (stage 1 participants may be invited to be part of this film). The following will then be invited to watch the film together and explore the findings: families, carers and PWLD (including stage 1 participants); and those that support them in the community (including professionals from the local Community Learning Disability Team, and any other professionals identified by participants as potential contributors to the transition pathway). They will then work in small groups to identify activities that will support the process of preparation for parental loss and transitions in care including EOLC for the carer.

Stage 3 (month 18-25)**:** Introduce and evaluate decision-aid interventions tailored for those at risk of developing behaviours that challenge (including those families where home care is no longer viable, and those with parents or families entering EOLC) on a small scale. Ten family carers and their adult daughter/son with LD will be given the intervention. This may include adults with severe/profound LD. It is not possible, at this stage, to anticipate what this intervention might look like or what resources may be needed to implement it. We hypothesise that resources may be developed that support early discussions about anticipated future transitions and loss (e.g. short films and pictures); and supported decision-making tools (e.g. TM™). The stage 3 intervention will include testing who is best placed to support the intervention, and what resources or training is needed for those. Stage 3 methods may be adapted in light of stage 2 results, but we presently propose the following: Families will keep a diary for 6 months. Observation of the administration/implementation of the intervention (researcher will keep field notes). Structured and semi-structured audio-recorded interviews with the family carer before the intervention (T1), after 2 months (T2) and after 6 months (T3), focusing on the son/daughter's behaviour (including behaviour that challenges), parental anxiety about the future, and advance planning measures. Preparations will begin during stage 2, including obtaining ethical approvals and recruiting participants for this stage.

Final three months: Final data analysis and feeding into the two coproduction events (see WP5), disseminate results.

Data analysis Qualitative data from stage 1 and stage 3 (interviews, focus groups, diaries, field notes) will be analysed using content analysis (using the framework method as described in WP3) supported by Nvivo 12. Stage 2 meetings will not be audio-recorded, but detailed field notes will be kept by the research team to track progress, and coproduced outcomes will be presented to the stage 2 participants for verification.

OUTPUTS: Peer reviewed publication in JARID, stakeholder consultation, a film, resources and decision aids hosted by socialcaretalk.org and OxFSN.

WP5

To co-produce actionable recommendations for commissioners and providers, resources and decision-aids for carers and PWLD with behaviours that challenge, and online training materials about care in later life

Two coproduction events will be held in Manchester and Oxford in collaboration with BASW (Months 26 and 28). These events will bring together a diverse group of carers, older PWLD, self-advocacy groups and other third sector organisations, social care providers, commissioners, social workers, local authority representatives and Advisory Group members. These will be live streamed using Periscope and tweeted to enable engagement beyond attendees. Findings, presented in easy read format to facilitate comprehensive engagement, will be presented followed by discussion around the issues that have arisen, potential barriers to implementation of changes identified, how to ensure effective dissemination and maximise the project pathways to impact. This process will also be cascaded to self-advocacy and carer groups across the UK. An easy read pack with a proposed session plan and feedback form will be circulated via the co-applicant network to generate engagement with the key audiences for our research. The proposed session plan of two hours will include a summary of the research and questions about key areas.

OUTPUTS: Actionable recommendations for commissioners and innovative dissemination plans for the uptake of the project outputs will be produced after these events.

Project management

The co-applicant team bring a strong mix of skills, knowledge and expertise. We have an excellent track record of experience and expertise in developing online training resources and information for health and social care professionals, experience in working within tight budgets and timetables, producing high quality qualitative research and involving the public in our research as well as innovative dissemination approaches. WP1 and 2 will be led by the OU, WP3 and WP5 by the University of Oxford and WP4 by Kingston & St Georges University. Manchester Metropolitan University will support WP3 and WP5 drawing on the expertise of MC, DD and the GM GOLD project.

An Advisory Group will advise on the parameters of the project, sampling and conduct of the interviews and focus groups. They will also be fully involved in the analysis workshop and the co-production events. A separate PPI group will be coordinated by AV who, with a second member of the PPI group, will sit on both groups. The initial meeting will focus on support and training needs to enable members to effectively contribute across the project.

A Study Steering Committee (SSC) with an external chair will be appointed by HS&DR. Professor Ruth Northway, Professor of Learning Disability Nursing, University of South Wales, has confirmed she is willing to fulfil this role. The SSC will meet in Months 3, 14 and 28. Membership will comprise of an older carer and PWLD, social worker, a qualitative researcher with an interest in learning disability and representatives from the voluntary sector. We will not require quantitative input or a separate Data Monitoring and Ethics Committee (DMEC).

Ethics / Regulatory Approvals

A favourable ethical opinion for the separate work packages will be sought from the appropriate Research Ethics Committee between final approval of the grant and the planned start date of September 2020. Focus group and interview topic guides will be included in the application with associated covering letters, information sheets, consent forms and de-brief (including complaint) forms. There are different ethical considerations across the research design including informed consent and power. Researcher-participant power imbalances will be minimised by the researchers spending time in the settings before the interviews are conducted. In the ethnographic fieldwork care will be taken to ensure that people are happy to be observed and 'hang out' with the researcher and co-researcher using 'process consent'. The researcher will constantly pay attention to whether people feel comfortable with the research team presence and, where appropriate, check with support staff or family members. They will take care to sit next to rather than opposite participants and by introducing themselves in more than a cursory way at the start of fieldwork so as to build rapport and trust. Researchers will also take care to notice any distress caused by any questions and any interviewing or focus group activity will be paused/stopped in this case. For those who have communication difficulties, accessible formats will be used to interview including signs and symbols as well as photographs. Natural breaks will be taken according to whether participants become tired or just need a rest from interviewing. We will ensure that we provide signposts to where people might get help if questions arise from the interviews.

Informed consent The research will pay close attention to issues of mental capacity, in particular, how PWLD and behaviours that challenge can be supported to make decisions regarding their changing care needs, including end of life care. Such decisions in England and Wales are governed by the Mental Capacity Act 2005 (MCA), and we will be attentive to the ways in which the law is applied in our fieldwork sites and the decision-making practices that emerge. This will include explorations of how PWLD and behaviours that challenge are supported to be involved in decisions regarding their changing care needs drawing on the MCA Code of Practice. We are particularly interested in efforts made to maximise people's capacity regarding these decisions and how people can be supported to both **understand** the decision at hand and **communicate** their wishes, feelings and preference, where possible. The research will also identify examples in which older PWLD and behaviours that challenge are supported to make advance statements about their future care.

The team will support all potential participants with LD and behaviours that challenge to understand the decision to participate in our research and communicate their wishes, feelings and preferences. The research team comprises researchers with experience and expertise of involving people with complex learning disabilities in research, including projects in which some participants were deemed not to have capacity to make the decision about whether to participate. Informed consent will be obtained using an accessible information sheet and consent form, explained face to face with each participant by the researcher and, where appropriate, with someone the participant knows well.

General Data Protection Regulation (GDPR) legislation will be followed. Consent forms will be stored separately from the data. Transcribed data will be anonymised and all identifiable features removed from the data set. All recordings, transcripts and databases will be password protected, stored at the respective Universities and only available to the research team. Only data specific and relevant to the project will be collected thereby minimising the risk of identifiable data. Archived data will be anonymised (apart from the consent forms which will be stored separately from the data). Information leaflets will stress that participation in the study is voluntary and that consent may be withdrawn by participants at any time up until the data has been anonymously analysed without adverse consequences. Following INVOLVE guidelines, participants will be paid a fee for their time and any expenses incurred.

Patient and Public Involvement

Angeli Vaid will be PPI lead, generating comment and feedback from the PPI advisory group at each stage of the research. Fieldwork and analysis in WP3/4 and the development of resources in WP4 will involve carer and PWLD co-researchers. PPI co-applicants and advisory panel members will be heavily involved in WP5. The project will draw on and further build skills and experiences co-researchers gained from their work on GM GOLD in WP3. We have included funding for the GM GOLD team (15 co-researchers and supporters) to focus on the project from the team members' perspectives as an agenda item at their monthly meetings for 6 months. Relationships with families, the loss of family members, and choice over where people live are important issues arising in the GM GOLD research. We will also organise training at the University of Oxford for co-researchers working on WP3 and WP4.

The Study Steering Committee will include older carers and PWLD, the Advisory Group will include a member from the PPI advisory group as well as Angela Vaid and Daniel Docherty.

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