Improving support and planning ahead for older people with learning disabilities and family carers: a mixed-methods study

Sara Ryan,[1*] Louise Wallace,[2] Elizabeth Tilley,[2] Irene Tuffrey-Wijne,[3] Magdalena Mikulak,[1] Rebecca Anderson,[3] Angeli Vaid,[4] Pam Bebbington,[5] Richard Keagan-Bull,[3] Emmie Morrissey[1] and Angela Martin[6]

[1]Department of Social Care and Social Work, Manchester Metropolitan University, Manchester, UK
[2]School of Health, Wellbeing and Social Care, Open University, Milton Keynes, UK
[3]Centre for Health, Science, Social Care and Education, Kingston University London, London, UK
[4]Oxfordshire Family Support Network, Oxford, UK
[5]My Life My Choice, Oxford, UK
[6]Nuffield Department of Primary Care Health Sciences, University of Oxford, Oxford, UK

[*]Corresponding author sara.ryan@mmu.ac.uk

Published June 2024
DOI: 10.3310/MTHW2644

Scientific summary

Improving support and planning ahead for older people with learning disabilities and family carers: a mixed-methods study

Health and Social Care Delivery Research 2024; Vol. 12: No. 16
DOI: 10.3310/MTHW2644

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

While a significant age gap remains in mortality between people with learning disabilities (PWLD) and the general population, more PWLD are growing older. Research shows that parents of PWLD are dissatisfied with social care services and concerned about the future of their adult child. Various policies aim to enable PWLD to live independently with support; however, family carers often maintain long-term care. This can generate a crisis for the PWLD, who may be moved to an alternative home that may not be appropriate for them. Our research focuses on PWLD aged ≥ 40 years in line with evidence that people may experience early onset of long-term conditions such as neurological, cardiovascular, respiratory and gastrointestinal disorders.

Aim

The aim was to improve support for family carers, older PWLD (aged ≥ 40 years) and 'behaviours that challenge others' ('BTCO') by producing effective recommendations and resources to support planning ahead for a good older age.

Objectives

1. Develop an understanding of what is known about the health needs, service interventions and resources for older PWLD, with a focus on those labelled with 'BTCO', and family carers [work package 1 (WP1)].
2. Identify exemplars of good practice in services in the UK for older PWLD, and their family and professional carers towards the end of life (WP2).
3. Explore service exemplars through ethnographic case studies (WP3).
4. Evaluate support for older PWLD and their families through the co-production and testing of decision aid tools to support future planning (WP4).
5. Co-produce recommendations with PWLD, carers, providers, social workers and commissioners, and resources for older PWLD, family and support workers and social workers (WP5).

Methods

Work package 1: systematic scoping reviews

Three rapid scoping reviews (RRs) focused on the health and social care needs of older PWLD and 'BTCO' (RR1), the health and social care needs of family carers of older PWLD and 'BTCO' (RR2), and how care can be best co-ordinated for older PWLD and 'BTCO' (RR3). Literature including research articles, reports, policy and practice guidance was included. RR1 and RR2 included UK-related evidence from 2001, and RR3 had no date restriction and was international in scope. Older PWLD were defined as those aged ≥ 40 years. 'Family carers' included parents and siblings. Care contexts encompassed any community living. We focused our search strategy on 'challenging behaviour', 'ageing' and 'learning disability'. Data were extracted into a form and considered alongside non-research information and guidance relevant to older PWLD and 'BTCO', and their family carers. A narrative approach was combined with insights from the research team and Project Advisory Groups. A three-stage inductive process was applied: development of a coding framework; development of descriptive themes and subthemes; and development of analytical themes and subthemes.

Database searches yielded 261 returns, and a subsequent extended search for RR1 yielded 355 returns; 9 papers were included. RR2 searches yielded 157 returns; 7 items were included. RR3 searches yielded 1449 returns, with 9 included.

Work package 2: scoping and mapping exemplars of good practice in living arrangements in the community for older people with learning disabilities and 'behaviour that challenges others'

Published service standards and grey literature of WP1 were analysed into themes supporting criteria to judge the excellence of services. Data from the mapping of services were subject to rapid analysis to refine the criteria, and further criteria were generated about participants' relationships with services.

A mapping exercise aimed to identify if services met the criteria for excellence. Multiple routes were used to identify the commissioning and provision of exemplar services and to find out key information about services using interviews (n = 30), an online survey (n = 9), websites and other documentary sources, including a search of Care Quality Commission (CQC) reports.

Data generation produced descriptions of services and critiques of the criteria of excellence. Analysis involved coding and summarising information into a template including how the service met the criteria, the service model and who the services were provided to. The templates were presented to the research team and Advisory Groups for a final decision on the list of excellent services for WP3.

Work package 3: ethnography of exemplar community living models

Nine case studies of four models of provision: independent supported living (n = 4), residential nursing home (n = 2), living with family and using day activities (n = 1) and Shared Lives (n = 2). Shared Lives is a national scheme in which PWLD live as part of a family usually funded by the local authority (LA). Ethnographic fieldwork was conducted by academics and co-researchers with lived experience. Sites were dispersed across England.

Researchers spent approximately 20 days within each model of care. Interviews were conducted with 95 PWLD including people who would be described by services as having severe learning disabilities and/or complex needs, family carers, support workers and managers, and commissioners.

A thematic data analysis of observation notes, interview transcripts and policy documents was undertaken. Coding categories evolved iteratively. Mind maps and more conceptual analysis of meaning, action and process were used, capturing the micro-detail of participants' lives. Co-researchers were involved in a section of analysis using audio and written extracts of data.

The opening of a second residential nursing site selected during proposal development was delayed. Modified ethnographic data collection methods, including documentary analysis of planning meetings, interviews with the service development project manager, lead commissioner, a LA councillor, the chairperson of a parent carer group, and the co-design process, were considered in interviews and by observation.

Work package 4: co-production and testing of resources for older people with learning disabilities and their families

Co-design methods explored what approaches are considered appropriate by PWLD and family carers, and a set of resources for PWLD and families was co-produced. The team included a research assistant with learning disabilities. Thirty-six people (9 PWLD, 11 parents, 16 siblings) took part in interviews and focus groups using communication aids Books Beyond Words and Talking Mats™. Data were analysed using a Framework approach. An experience-based co-design approach was used to produce a decision-making resource. Twelve online sessions were held with 11 participants, including a core group of 4 PWLD and 4 parents, to develop the resources. A small-scale evaluation tested these with eight families across a 2-month period. This focused on the usefulness of the resource, the impact of planning actions and feedback for improvement. Data were collected twice using a questionnaire.

Work package 5: methods

This WP aimed to co-produce recommendations for commissioners and providers, resources for carers and PWLD, and online training materials for social workers and support staff. Participants in two co-design workshops (*n* = 45 and *n* = 30) shared initial findings and discussed developing recommendations. A third workshop (*n* = 22) focused on the developing recommendations, and research priority setting in the north of England. Participants included a wide range of stakeholders: PWLD and family carers, NHS England, NHS, the CQC, LA delegates, disability charity organisations, service providers, commissioners and academics.

Findings

Work package 1

Rapid review 1 generated four themes: transition over time, including proactive planning for circumstances in which PWLD are no longer able to remain in their home; avoiding the need for inappropriate transitions; making transition work; and an absence of targeted resources to support this. There is limited planning by ageing family carers and PWLD, and a need for professional involvement in supporting the family before ageing-related problems become manifest. Commissioners have a responsibility to proactively plan for the delivery of appropriate housing and support, requiring robust databases of ageing family carers and older PWLD.

Rapid review 2 generated four themes: a lack of accessible advice, information and support for families to plan ahead; challenges facing family members with their own needs; the lack of availability of suitable housing and support; and lack of targeted resources to guide PWLD, family carers or professionals in planning ahead.

Rapid review 3 identified three layers to co-ordinating care for older PWLD. For individuals this is communicating effectively and co-ordinating care to pre-empt the effects of ageing, delivered by skilled staff. At service level this is co-ordination across teams and services including housing, drawing on those with expertise in learning disabilities. At local/regional level, this is commissioning services taking account of current and future age-related needs.

The reviews confirmed an inadequate evidence base concerning the experiences, needs and support of family carers of older PWLD, who are being supported when their family member's preference is to remain at home and/or to achieve a potential move where appropriate and desired. WP1 also highlighted the conceptual limitations of the term 'BTCO'.

Work package 2

The final criteria of excellence were:

- personalisation, with goals, daily plans and activities shared and updated
- matching staff to people being supported
- personalised living space and choice around who this is shared with
- proactive, preventative health care involving primary care, and involvement of NHS multidisciplinary learning disability teams
- staff recruitment underpinned with the right values and skills
- high staff retention to provide continuity of care
- inclusive communication methods
- family involvement
- community engagement and inclusion

- trauma-informed services where appropriate
- good practices such as end-of-life care planning, dementia assessment and management embedded as routine
- commissioner endorsement of provider quality and resilience
- commissioners working with providers, PWLD and families in building capacity for future services.

The mapping involved review of 330 potentially relevant locations, which was reduced to 74 after consideration of the relevance of the service to older PWLD. There was contact with around 260 people across England, which led to 89 contacts who provided information in formal interviews and informal discussions, via online meetings and by e-mail about at least one specific service, with around 3–6 provider and commissioner perspectives on the same services.

A shortlist of 15 services was agreed for consideration in WP3.

Work package 3

Findings were organised around environmental, organisational and social factors. Environmental factors supporting independence, and choice over who people interact with, were maximised for those living on their own or with people they chose to live with. Organisational factors related to systems that support good and consistent relationships with support staff, staff matching, aspirational support and adapting to changing needs as people age. Commissioners that actively plan for adapting care packages and contingency provision were seen to avoid crises. Planning for end-of-life care was not well supported by policies and practices except in the nursing home and one supported living provider. Shared Lives provision actively supported people who were developing dementia. Social factors included maintaining family and community relationships and being supported to do a range of activities. The label of ‘BTCO’ could be removed with consistently good support and environment.

Poor practices of institutionalisation were observed, where staff schedules over-rode choice and/or duration of activities. Small providers that had strong values and management engagement with support workers were more able to offer consistently good support than larger organisations where excellent support can exist alongside examples of poor support. Observation of planning for a new nursing home offered useful insights into the challenges involved in growing capacity for local services for PWLD as they age, while adhering to models of excellent care. The research showed the extent to which independence, choice in relationships, support for healthy ageing, and meaningful activity including work was evidenced in different ways across providers, with some failing to achieve this despite the rhetoric and aspirations of providers and commissioners.

Work package 4

Families were acutely aware of the need to plan ahead and were worried about the future, unaware of and unsupported to explore options. Co-design sessions stimulated ideas and discussion and the content and format of a decision-making resource was produced based on what worked for family carers and PWLD. This comprised a set of 102 ‘Planning Ahead’ cards and a ‘Me and my plans’ booklet in which families could record their discussions and plans. What participants wanted in their home reflected WP3 findings about the factors that enable excellence in care. They wanted to choose who they lived with; to be supported by people who know them well and care for them; to live in a location that suits their lives; and to have control over what they do and when. The lack of awareness of alternatives and absence of social work support was striking. In some cases, the lack of options led to parents ignoring the future, denying PWLD the opportunities to have lives that their peers without learning disabilities can have.

Work package 5

Formative discussion across three stakeholder workshops informed the development of recommendations about how to raise awareness and improve access to information about planning and options. The workshops involved a range of stakeholders, and short films were used to present developing project analysis and raise key questions. Discussion focused on improved needs assessment data including for those not known to services; improved peer learning by providers and commissioners, and funding of self-advocacy groups to support people's local decision-making; and improved individual support by matching staff to people and enabling staff to celebrate their successes. To support dissemination, a session plan was created in standard and Easy Read versions to enable self-advocacy groups to contribute to the development of practical recommendations for providers and commissioners.

Resources

Project outputs include two OpenLearn courses, one for practitioners and one for family carers; a training resource to support researchers, PWLD and family carers to work together as ethnographers; a resource for social workers hosted by the British Association of Social Workers; a carers' forum hosted on Facebook; a short film; a podcast about the experience of taking part in the project; blogs; and a range of publications for non-academic audiences and academic papers.

Limitations

While a systematic approach was taken to reviews and mapping services, it is possible that some evidence was missed in WP1 and WP2. The COVID-19 pandemic created challenges for participant recruitment, and workarounds were needed. One 'excellent' site withdrew early in WP3 due to staffing issues caused by the pandemic. Reliance on providers for recruitment in WP3 resulted in a sample limited to White British participants.

Participation may have influenced providers to present excellence and hide less good practice, but, given the mix of provision observed, this was a low risk. The discussion cards produced in WP4 may be in formats and have content that exclude some people. This needs to be tested further. Attempts to plan by families may be frustrated by insufficient resources and options to achieve what people want, raising expectations that cannot be met.

Conclusions

There is little research on older PWLD and family carers. Some participants were leading good lives in their own homes with excellent support from staff who knew them well. Even largely excellent services vary in their proactive approach to planning for older age support and end-of-life care. Families are often unsupported to plan ahead, and PWLD are by default left without choices about their future lives. The label 'BCTO' was found to be an unhelpful term that did not stimulate discussion of personalised care and rights to autonomy. It had little practical utility in the ethnographic research and was absent in the reviews.

Research recommendations

The over-riding recommendation is the urgent need for a new strategy for older PWLD and family carers that encompasses commissioning practices (including the sharing of best practice); professional input (roles and responsibilities, the role of social workers, support staff skills and training); proactive support to live and age well; and excellent service design (appropriate, sustainable, local and adaptable housing that enables people to age and die in place). Recommendations are made for improved proactive health care, organisational learning, matching and support for staff, and 'try before you buy' options to support choice and personalisation.

Future work

Given the lack of focus in this area, there is a range of future work to consider: experiences of older PWLD from diverse ethnic backgrounds; supporting people to age and die ‘in place’; best practice regarding designing/commissioning services, including housing; the role of social workers; access to nature and pet ownership; access to mainstream support; and evaluation of the ‘Planning Ahead’ cards.

Trial registration

This trial is registered as ISRCTN74264887.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Health and Social Care Delivery Research programme (NIHR award ref: NIHR129491) and is published in full in *Health and Social Care Delivery Research*; Vol. 12, No. 16. See the NIHR Funding and Awards website for further award information.

Health and Social Care Delivery Research

ISSN 2755-0079 (Online)

A list of Journals Library editors can be found on the NIHR Journals Library website

Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb™ (ProQuest LLC, Ann Arbor, MI, USA), NCBI Bookshelf, Scopus and MEDLINE.

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr.

Criteria for inclusion in the *Health and Social Care Delivery Research* journal

Manuscripts are published in *Health and Social Care Delivery Research* (HSDR) if (1) they have resulted from work for the HSDR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HSDR programme

The HSDR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HSDR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm

This article

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as award number NIHR129491. The contractual start date was in September 2020. The draft manuscript began editorial review in March 2023 and was accepted for publication in November 2023. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR editors and production house have tried to ensure the accuracy of the authors' manuscript and would like to thank the reviewers for their constructive comments on the draft document. However, they do not accept liability for damages or losses arising from material published in this article.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Newgen Digitalworks Pvt Ltd, Chennai, India (www.newgen.co).