

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 Morrissey¹ and
Angela Martin⁶

¹Department of Social Care and Social Work, Manchester Metropolitan University, Manchester, UK

²School of Health, Wellbeing and Social Care, Open University, Milton Keynes, UK

³Centre for Health, Science, Social Care and Education, Kingston University London, London, UK

⁴Oxfordshire Family Support Network, Oxford, UK

⁵My Life My Choice, Oxford, UK

⁶Nuffield 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

Plain language 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

Plain language summary

People with learning disabilities are living longer, but most live with their families, who are also getting older. This is because there are not enough suitable places for people with learning disabilities to live, and family carers worry that the person will not get the right support and have a good life. Our research aimed to improve support for people with learning disabilities and their family carers to plan ahead for a good life.

We focused on people who are labelled with 'behaviours that challenge others'. We read what has been written about this area. We looked for and found examples of excellent support for older people with learning disabilities. Researchers and people with learning disabilities and family carers spent time hanging out with people where they live or spend their days to see what support they get. Then we had three meetings with everyone involved and discussed our research findings with people with learning disabilities, family carers, and professionals. We found that people can be supported to live good lives as they grow older. This can be living alone or with people they choose, and it means having staff they like and who like them and being supported to be active.

However, we found that ageing of people with learning disabilities is often ignored, and some people were not living good lives. We also found that the label of 'behaviours that challenge others' is unhelpful. We worked with people with learning disabilities and family carers to make a set of cards with pictures and questions to help people plan ahead for a good life. We produced resources and made recommendations to create a new plan for older people with learning disabilities to support people to lead good lives. This is very important because there is a lack of attention to and support for people with learning disabilities as they age.

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.

This article presents independent research funded by the National Institute for Health and Care Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, the HSDR programme or the Department of Health and Social Care.

This article was published based on current knowledge at the time and date of publication. NIHR is committed to being inclusive and will continually monitor best practice and guidance in relation to terminology and language to ensure that we remain relevant to our stakeholders.

Copyright © 2024 Ryan *et al.* This work was produced by Ryan *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaptation in any medium and for any purpose provided that it is properly attributed. See: <https://creativecommons.org/licenses/by/4.0/>. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

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

