

Improving the support for older people with learning disabilities and behaviours that challenge, family and professional carers, and end of life care planning for carers: Mapping health and care services in England

Information Sheet

A research team at the Open University lead by Professor Louise Wallace, and at the University of Oxford lead by Doctor Sara Ryan, are conducting a study funded by the National Institute for Health Research (NIHR). We are inviting you to take part in the strand of our study that aims to find out what services work well for older people with learning disabilities and behaviours that challenge, and their families. In particular, we want to find examples of services that support people to live well in family, supported living or residential care settings, including at points of transition.

Whilst little is known about the needs and experiences of older people with learning disabilities, it is clear that a number of factors make them vulnerable to distress and deteriorating behaviour. A key example is the transition that occurs in their lives when their families are no longer able to care for them at home. This study seeks to find good examples of services that help with this transition. We are particularly interested in people with learning disabilities and behaviour that challenges others, as they are at greatest risk of crises and of placement in unsuitable and expensive restrictive care.

Before you decide whether or not to take part, it is important for you to understand what it will involve. Please take time to read the following information carefully.

Who are we looking to recruit?

We would like to talk to senior leaders and commissioners of NHS services in England that provide care for adults with learning disabilities, end of life care, and adult social care. We would also like to talk to senior directors of services that provide supported living and residential care for older adults with learning disabilities, including those whose behaviour challenges others. We also would like to talk to members of professions and the public who are interested in this topic. Your participation will not affect your employment, as none of the information you share with us will be attributed either to you personally, or to the organisation you work for.

What we are planning to with this research

The aim is to find out about the best services in the England and understand why they work and for whom. This research will be followed by more in depth study by other researchers in the team who will visit these services over several months in 2021-2022.

The research has been approved by the Open University's Human Research Ethics Committee (No. XXXX) and recorded by the Health Research Authority.

What will participation involve?

If you decide to take part in the study, participation will involve sharing with us your professional or personal knowledge of services for older adults with learning disabilities and behaviour that challenges others. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw without giving a reason and to have your data removed at any time up to the end of this study (end of March 2021) by sending an e mail to Louise.Wallace@open.ac.uk.

The interview will last for a maximum of 30 minutes, will be semi-structured and recorded. You can choose when and how you wish to be interviewed: examples include by telephone, by Skype or by Microsoft Teams.

If the topic of the research raises issues which are sensitive to you, for example as a carer, you may find it beneficial to discuss these with a neutral person but if you feel uncomfortable or emotionally overwhelmed, we can take a break and/or stop the interview whenever you like. You can refuse to answer any questions that you find too distressing and withdraw from the study at any time, without giving a reason. If you are answering the questions by an emailed survey, you do not have to complete the questions unless you want to for any reason. If you decide not to take part or to withdraw this will not have any effects for you on the services you receive now or in the future. We are able to offer information on sources of support: louise.wallace@open.ac.uk

What are the possible benefits and risks of taking part?

There are no risks to taking part in the study. The only disadvantage is that it will take up some of your time. The benefit of taking part is that you will help us to find out how information that may inform the commissioning and provision of services for older people with learning disabilities and behaviour that challenges others in the UK.

How will the data I provide be used?

The information from the interviews will only be shared within the research team. Quotations will be entirely de-identified, so that neither the specific person nor organisation can be identified, although you alone may recognise the words you have spoken. If you wish, you can agree a pseudonym with the researcher so you can identify any words of yours we use in the results of the study, but this is up to you. No personally identifying information or information about named organisations will be used in any results. Personal information such as e mail addressees for contacting participants will be stored in a secure database on University servers and destroyed at the end of the study. Consent forms will be stored apart from any information you provide. All data from the study will be stored on secure servers in the Open University and destroyed after 10 years. Data storage of e mails and responses to an on line survey uses software approved by the Open University and is compliant with UK/EU data protection regulations.

The de-identified results and quotations will be used in academic publications and public reports. They will also be publicised via social media, with a short summary on the project website. The research team and Advisory Group and Study Steering Committee will use the results to inform decisions about the selection of services for more in depth study.

Interested?

If you are interested in taking part in the study, please complete the attached consent form and return to louise.wallace@open.ac.uk. You will be contacted to arrange a phone, Skype or Microsoft Teams, or be sent a link to a survey which will ask the same questions. If you consent to being interviewed, we will talk with you in order to find out your wishes regarding audio-recording the interview and how your interview transcript should be anonymised when it is edited for dissemination purposes.

If you need more information or would like to ask some questions before deciding on whether to take part in the project you can contact Louise Wallace at louise.wallace@open.ac.uk;

If you have any concerns about the project, you can talk to **Professor Regine Hampel** about this. Regine oversees all research in the Faculty of Wellbeing, Education and Language Studies at the Open University: Regine.Hampel@open.ac.uk

Thank you for taking time to read this information sheet.

Data Protection

The Open University is the Data Controller for the personal data that you provide.

The lawful reason for processing your data will be that conducting academic research is part of the Open University's public task. (The consent we request from you relates to ethical considerations.)

We share the information you have given to us with the researchers in the Universities involved in this research and with a contractor to transcribe interviews. The lawful reason for these transfers is that it is part of our public task to conduct academic research, and where we use a third party to provide a service, it is in our legitimate interest to manage our operations effectively. They will only be given personal data in order to carry out a specific activity, and we have contractual arrangements to safeguard their use of your personal data.

You have a number of rights as a data subject:

- To request a copy of the personal data we have about you
- To rectify any personal data which is inaccurate or incomplete
- To restrict the processing of your data
- To receive a copy of your data in an easily transferrable format (if relevant)

- To erase your data
- To object to us processing your data

If you are concerned about the way we have processed your personal information, you can contact the [Information Commissioner's Office](#) (ICO). Please visit the ICO's website for further details.