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Promoting personhood in social care

Submission date
09/07/2025

Recruitment status
No longer recruiting

Registration date
22/07/2025

Overall study status
Completed

Last Edited
08/10/2025

Condition category
Other

[X] Prospectively registered
[_] Protocol
[_] Statistical analysis plan
[_] Results
[_] Individual participant data
[_] Record updated in last year

Plain English summary of protocol

Background and study aims
The delivery of person-centred health and social care remains a strategic priority for NHS Scotland and the Scottish Government. The question of what it means to be a person has been at the heart of philosophical debate for hundreds of years. But whilst all human beings may be classed as people, some people with disabilities are considered to be less human than others. This raises a fundamental question as to how person-centredness meaningfully translates into health and social care practice. Whilst the concept of 'personhood' has been prevalent in the context of dementia care little attention has been given to it in the context of services that support people with learning disabilities. This study will therefore use an experience-based co-design (EBCD) approach to explore how personhood is understood and experienced by people with learning disabilities and by staff who provide support in a social care context, in order to identify and co-design service improvements. As a type of participatory action research, EBDC focusses on the experiences of people using services, of carers and of staff. In this study, I will be inviting people to share their stories about their personhood and about support. Through identifying 'emotional touchpoints' in the stories shared, participants will come together and agree areas for service improvement in relation to person-centred support, using the co-design process to achieve this.

Who can participate?
Adults who have a learning disability, or are the carer of an adult with a learning disability or who provide support in social care are eligible to participate in the study.

What does the study involve?
The study will involve undertaking conversational interviews with participants (people with learning disabilities, carers, staff). The data from the interviews will be analysed and the key themes and emotional touchpoints created into a film; this will be initially shared with people with learning disabilities and carers for discussion and to identify any gaps in the information shared. There will also be a workshop for staff to validate the feedback from their interviews. Ideas for service improvements will be discussed and agreed at each workshop. All participants will then come together for an initial joint co-design workshop, where the film will be shown to spark discussion about the service improvements discussed at the previous workshops. The whole group will agree and prioritise service improvements to take to the 3 co-design

workshops. Outputs from these workshops will be piloted and evaluated depending on what they are and what the participants decide. A celebratory event will mark the end of the research and will provide a platform to showcase outcomes to key stakeholders.

What are the possible risks and benefits?
It is hoped that participation will be a positive and empowering experience and will allow views to be heard and will lead to improvements to within social care support for people with learning disabilities. Due to the nature of the questions in the conversational interviews, it is not anticipated that distress will be caused. Participation in the conversational interview or workshops constitutes low level involvement. However, I will ensure there is a safe place for people to have time out and a debrief if required, which will utilise my skills and experience as a therapist. Participants will have the option to bring someone with them to the conversational interview for support if required, although it will be made clear that this person will not be able to contribute to the conversation. A trusted health professional from the Learning Disability Service will be identified should any participant require follow-up support at any point in the research.

Where will study be run from?
The study is taking place in the Learning Disability Service in NHS Borders (UK). The main sponsor and supervisory arrangements are through Queen Margaret University as part of a professional doctorate.

When is the study starting and when is it expected to end?
October 2024 to June 2026.

Who is funding the study?
Queen Margaret University (UK)

Who is the main contact?
Clare Gillespie, clare.gillespie@nhs.scot

Contact information

Type(s)
Public, Scientific, Principal investigator

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Additional identifiers

Integrated Research Application System (IRAS)
342858

Study information

Scientific Title
Exploring personhood in person-centred support: an experience based co-design approach with people with learning disabilities and social care staff

Acronym
EBCDPCS

Study objectives
The principle aim of the research is to co-design service improvements with people with learning disabilities, carers and staff that promote personhood in social care. The key objectives are:
1. To understand how personhood (“all about me”) is understood and experienced by people with learning disabilities who receive support
2. To understand how personhood is understood and experienced by social care staff who provide support to people with learning disabilities
3. To bring people with learning disabilities and staff together to reflect on findings from the above objectives and establish improvements to services in relation to promoting personhood in practice
4. To co-design service improvements that promote personhood in social care support

Ethics approval required
Ethics approval required

Ethics approval(s)
1. Approved 03/10/2025, Divisional Ethics - Occupational and Arts Therapy (Queen Margaret University, Musselburgh, EH21 6UU, United Kingdom; +44 131 474 0000; OTATethics@qmu.ac.uk), ref: Ref 2024/13

2. Approved 02/10/2025, South East Scotland Research Ethics Service - Scotland B Research Ethics Committee (Mainpoint 102 West Port , Edinburgh, EH3 9DN, United Kingdom; -; Sriparna.Pal@nhs.scot), ref: 25/SS/0074

Primary study design
Observational

Study design
Single-centre qualitative participatory study using experience-based co-design methodology

Study type(s)
Other, Quality of life, Efficacy

Health condition(s) or problem(s) studied
Person-centred support and people with learning disabilities

Interventions
1-1 hour long interviews with people with learning disabilities, carers and staff

Workshops x 5:
1 = 135 mins (Feedback/validation of interview themes: 1 x people with learning disabilities & 1 x staff)
2 = 180 mins (Co-design)
3-5= 120 mins each (Co-design)

Intervention Type
Other

Primary outcome(s)
People's experiences (people with learning disabilities, carers, social care staff) of personhood captured using conversational interviews and analysed using Reflexive Thematic Analysis

Key secondary outcome(s)
There are no secondary outcome measures

Completion date
01/06/2026

Eligibility

Key inclusion criteria
1. A person who:
1.1. has a learning disability and attends a Local Citizen's Panel (LCP) or is supported by the Local Area Co-ordinator (LAC) service within a specified geographical area
1.2. is a carer/guardian of a person with a learning disability within the specified geographical area
1.3. can give informed consent

2. A person who:
2.1. is currently working as a social care worker within an identified 3rd Sector Service Provider (within a specific geographical area) commissioned by Scottish Borders Learning Disability Service (LDS)
2.2. can give informed consent
2.3. is over the age of 18 years

Participant type(s)
Carer, Employee, Service user

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 Years

Upper age limit
99 Years

Sex
All

Key exclusion criteria
1. A person who:
1.1. is under the age of 18 years
1.2. has a learning disability and cannot give informed consent
1.3. is a carer/guardian and cannot give informed consent
1.4. is currently attending music therapy with me
1.5. is not the carer/guardian of a person with a learning disability

2. A person who:
2.1. does not currently work as a social care worker within the identified 3rd Sector Service Provider
2.2. cannot give informed consent
2.3. is under the age of 18 years

Date of first enrolment
06/10/2025

Date of final enrolment
01/06/2026

Locations

Countries of recruitment
United Kingdom

Scotland

Study participating centre
NHS Borders
Newstead
Melrose
United Kingdom
TD6 9DB

Sponsor information

Organisation
Queen Margaret University

ROR
https://ror.org/002g3cb31

Funder(s)

Funder type
University/education

Funder Name
Queen Margaret University

Alternative Name(s)
Queen Margaret University, Edinburgh, QMU

Funding Body Type
Private sector organisation

Funding Body Subtype
Universities (academic only)

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated and/or analysed during the current study are not expected to be made available due to the research being undertaken as part of a professional doctorate. Data collected will be through interviews and co-design workshops. Full consent will be sought for each stage of data collection. Some of the data will be incorporated in the thesis and future publications in anonymised form.

IPD sharing plan summary
Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet			21/07/2025	No	Yes