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Improving the health, wellbeing and social networks by of older adults with intellectual disability: The Matilda Study

Submission date
02/12/2022

Recruitment status
No longer recruiting

Registration date
20/12/2022

Overall study status
Completed

Last Edited
20/02/2026

Condition category
Mental and Behavioural Disorders

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

Plain English summary of protocol

Background and study aims
Like the general population, the average age of people with intellectual disabilities is rising. However old age for people with intellectual disabilities is different. It starts earlier and has more impact on their physical and mental health. Most older adults with intellectual disabilities feel isolated and cut off from friends and local communities. But joining a local community group (such as men's sheds, dance, sports, and knitting groups) can help them feel less lonely or depressed and more included in society, and improves their quality of life.
A team of Australian researchers developed a social intervention called Transition to Retirement (TTR), a peer-led project. They trained 2-3 retired adults without disabilities who were part of a local community group to act as volunteers or mentors and to support an older person with an intellectual disability to take part in the group a few times a week for at least six months. The project helped older adults with intellectual disabilities to develop new social networks and friendships by working with peers who did not have a disability. They became more connected with their local communities and felt less lonely and isolated. The adults with intellectual disabilities liked the project and the mentors continued providing support even after its funding ended.
Recently, our team in Northern Ireland met with stakeholders to see if we could adapt the TTR project for the UK. There was less emphasis on retirement and more on supporting older adults with intellectual disabilities to become involved in their local communities. We changed the name to Matilda (Managing Activities Together, to involve older people with intellectual disabilities in their local community) and we're now ready to test if this can be delivered and is acceptable in the UK. The study aims to test whether Matilda can help older adults with intellectual disabilities participate in local community groups with the support of mentors without disabilities, to improve their health, well-being and social networks.

Who can participate?
Adults aged 45 years old and over with mild/moderate intellectual disability

What does the study involve?
This 30-month study will run in Northern Ireland and London. If an older adult with intellectual

disabilities and their carers agree to take part they will answer some questions about their health, well-being, social networks and the services they receive before being randomly (by chance) allocated to either the 6-month Matilda intervention or usual care (to provide a control group). Those allocated to the control arm will receive usual care and 3 recreational activities with their intellectual disability peers over the course of the study (cinema, bowling, meal). The adults with intellectual disabilities in both arms will complete the same questionnaires at baseline, and 6 and 12 months later. The mentors will also be asked to provide information at the same time points on their health, well-being and attitudes towards people with disabilities. Volunteer Now in Northern Ireland and the Camden & Islington Foundation Trust in London will help us to recruit mentors. In both places, we will appoint a volunteer coordinator who will identify community groups, and train and supervise the mentors to support the older adults with intellectual disabilities. We have worked with older adults with intellectual disabilities, their carers, social care staff, and older people without disabilities in designing this study. They will continue to be involved if the research is funded. Everyone in the research team will play a part in sharing the findings with a variety of audiences. As we have done in the past, we will also prepare easy-read summaries.

What are the possible benefits and risks of participating?
The potential benefits are that the adults with a learning disability could extend their social networks and be more socailly included in their local communities. There are no perceived risks in participating in this study.

Where is the study run from?
Ulster University (UK)

When is the study starting and how long is it expected to run for?
February 2022 to April 2025

Who is funding the study?
National Institute for Health and Care Research (NIHR) Public Health Research Programme (PHR) 129125 (UK)

Who is the main contact?
Prof Laurence Taggart, l.taggart@ulster.ac.uk (UK)

Contact information

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Principal investigator

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
279668

Protocol serial number
19/0066, IRAS 279668

Study information

Scientific Title
A feasibility study of the clinical and cost-effectiveness of the MATILDA intervention to support older adults with intellectual disability to their improve health, wellbeing and social networks compared to usual care

Acronym
MATILDA

Study objectives
Older adults with intellectual disability who access and engage in a local community group over a 6-month period will improve their health, wellbeing, and social networks

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 14/06/2022, Office for Research Ethics Committees Northern Ireland (ORECNI) (Customer Care & Performance Directorate, Unit 4, Lissue Industrial Estate West, Rathdown Walk, Moira Road, Lisburn, BT28 2RF, UK; +44 (0)28 95361400; recb@hscni.net), ref: ORECNI 22 /NI/0067

Study design
Phase II 2-arm single-blind randomized feasibility study with 1:1 allocation study

Primary study design
Interventional

Study type(s)
Quality of life

Health condition(s) or problem(s) studied
Older adults with intellectual disability

Interventions
Following informed consent, older adults with an intellectual disability will be randomised using a 1:1 ratio to the intervention group (Matilda) or control group, stratified by site. The randomisation will be generated by a member of staff based at the Northern Ireland Clinical Trials Unit not connected to the study. The research assistants at Ulster University and UCL will inform the adults with an intellectual disability which arm they have been allocated to. At the time of randomisation, each participant will be allocated a unique Participant Study Number, which will be used throughout the study for participant identification.

The Matilda intervention uses active mentoring to support older adults with an intellectual disability (aged 45 years or more) to engage in mainstream local community groups. Using 2 or 3 retired adults without an intellectual disability from local community groups to act as volunteers or ‘mentors’, they then will support 1-2 older persons with an intellectual disability to join the group. The person with the intellectual disability will attend the group 1 to 3 times a week for six months. The focus of the Matilda intervention is to help older adults with an intellectual

disability develop new social networks and friendships, with peers without an intellectual disability.

Process evaluation
The process evaluation intervention interviews will examine four key aspects of the feasibility of conducting a definitive trial of the Matilda intervention:
1. Intervention recruitment, adherence and reach
2. Intervention implementation
3. Intervention mechanisms, including receipt and acceptability and
4. The feasibility of implementing Matilda within a definitive randomised trial. These interviews will be undertaken with a sample of the older adults with an intellectual disability, mentors, and carers across both sites as part of the process evaluation that will take place post-intervention (1-2 months after the participants finished the intervention). These will be conducted by the RAs, digitally recorded and last approximately 40-60 mins.

Intervention fidelity and adherence
A checklist will be further developed to explore the fidelity of the Matilda intervention in greater detail in the process evaluation. In assessing the external validity, the extent of true collaboration in each local community group initiative will be assessed with the adults with an intellectual disability, carers, and mentors. To determine whether the Matilda intervention will be delivered as intended (adherence), each mentor will be asked to complete their own weekly paper checklist which details attendance, frequency, activities, adverse events, etc.

Intervention Type
Behavioural

Primary outcome(s)
Feasibility is assessed using the following outcome variables:
1. Recruitment measured using data collected in the case report form (CRF) at baseline
2. Consent measured using data collected in the CRF at baseline
3. Matching measured using data collected in the CRF after randomisation has taken place and during the process-evaluation interviews
4. Retention measured using data collected in the CRF at the end of the intervention at 6-months

Key secondary outcome(s))
Secondary feasibility is assessed using the following outcome variables:
1. Eligibility measured using data collected in the CRF at baseline
2. Recruitment rates and pathways measured using data collected in the CRF at baseline
3. Consenting rate measured using data collected in the CRF at baseline
4. Randomisation process measured using data collected in the CRF at baseline
5. Matching of mentors (and local community groups) and older adults with an intellectual disability measured using data collected in the CRF after randomisation has taken place, and during the process-evaluation interviews
6. Training and supervision measured using the process-evaluation interviews
7. Attendance levels measured using data collected in the CRF at 6-months post-randomisation
8. Drop-out rates measured using data collected in the CRF at 6-months post-randomisation
9. Retention of participants measured using data collected in the CRF at 6-months post-randomisation

Completion date
30/04/2025

Eligibility

Key inclusion criteria
1. Mild/moderate intellectual disability
2. Living in the community with a family member(s) or in any type of community accommodation (residential/supported/shared lives)
3. 45 years old and over
4. Able to communicate verbally
5. Able to provide informed consent

Healthy volunteers allowed
No

Age group
Mixed

Sex
All

Total final enrolment
0

Key exclusion criteria
1. Severe/profound intellectual disability
2. Severe challenging behaviour
3. Unable to communicate verbally or in English Unable to provide consent
4. Already accessing mainstream community groups.

Date of first enrolment
01/02/2023

Date of final enrolment
31/05/2023

Locations

Countries of recruitment
United Kingdom

England

Northern Ireland

Study participating centre
Northern Health and Social Care Trust
Trust Headquarters
Bretten Hall
Bush Road

Antrim
Northern Ireland
BT41 2RL

Study participating centre
Camden and Islington Mental Health (north Camden Site)
St. Pancras Hospital
4 St. Pancras Way
London
England
NW1 0PE

Sponsor information

Organisation
Ulster University

Funder(s)

Funder type
Government

Funder Name
NIHR PHR 129125

Alternative Name(s)
NIHR Public Health Research Programme, The Public Health Research (PHR), PHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

Individual participant data (IPD) sharing plan

IPD sharing plan summary

Data sharing statement to be made available at a later date

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article		18/02/2026	20/02/2026	Yes	No
HRA research summary			28/06/2023	No	No
Participant information sheet	version 2.0	16/05/2022	13/12/2022	No	Yes