

Here to Stay: People with learning disabilities from new migrant communities

Submission date 31/01/2012	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
Registration date 31/01/2012	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
Last Edited 06/12/2016	Condition category Other	<input type="checkbox"/> Individual participant data <input type="checkbox"/> Record updated in last year

Plain English summary of protocol

Background and study aims

Research evidence shows that while progress is being made, people with learning disabilities from ethnic minority communities, including new migrant communities, find it hard to get advocacy and support. The Here to Stay project is in response to the need to increase our knowledge base about this population including their understanding of the condition, their access to support and the extent of demand they place upon learning disability services. We believe that better information about them and their needs will result in providing better services. The study aims are:

To determine the current numbers of people from new migrant communities in England requiring support from learning disability services (through analysing information from health, social care and education sectors based on service uptake by people with learning disabilities)

To gain greater knowledge about what happens to people with a learning disability from new migrant communities who are not using the learning disability services

To find out how the public, private and third sector can work with people with learning disabilities from the new migrant communities to promote their well-being and improve their prospects

Who can participate

People with learning disabilities from ethnic minority communities and new migrant communities

Carers of people with learning disabilities from ethnic minority communities and new migrants

Professionals supporting people with learning disabilities across health, social care and education services in public, private and third sectors

What does the study involve?

The study involves 1) collecting prevalence information on people with learning disabilities from health, social care and education services, 2) collecting information from study participants about their needs and service requirements, 3) producing, implementing and evaluating a set of guidelines developed in collaboration with all stakeholders of this research to make learning disability services more visible and available to people with learning disabilities from ethnic minority communities and new migrants. The study will involve:

Focus Groups, interviews, surveys: we are going to recruit key stakeholders (including equality

leads, equality and human rights commission leads, advocacy groups, regional charities, voluntary sector community groups, service users, and carers) to ask them to share their knowledge, experiences and comments on providing services.

A consultation process: following analysis of data from surveys, interviews and focus groups we will work with key stakeholders to develop a set of practice improvement guidelines. These guidelines will then be implemented in selected sites and their relevance and effectiveness evaluated.

What are the possible benefits and risks of participating?

Participants may experience a positive change in the quality and utilisation of services as a result of our interventions. There are no notable risks involved with participating.

Where is the study run from?

The Study is run from the Centre for Health and Social Care Improvement, School of Health and Wellbeing, University of Wolverhampton (UK)

When is the study starting and how long is it expected to run for?

August 2010 to August 2015.

Who is funding the study?

The Big Lottery Fund (UK)

Who is the main contact?

Dr Olga Kozłowska

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Contact information

Type(s)

Scientific

Contact name

Dr Olga Kozłowska

Contact details

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Additional identifiers

EudraCT/CTIS number

IRAS number

ClinicalTrials.gov number

Secondary identifying numbers

10818

Study information

Scientific Title

Here to Stay: People with learning disabilities from new migrant communities - A non-randomised study

Acronym

Here to Stay

Study objectives

'Here to Stay,' a five year project, explores the numbers and needs of people with learning disabilities from ethnic minority communities including new migrants.

Research questions:

1. What are the current numbers of people from established and new migrant communities in England requiring support from learning disability services?
2. How can the learning disability service providers, voluntary sector and wider community engage with the ethnic minority communities to promote their well-being and improve their prospects?

The aim of this study is to gain knowledge of how to promote better ways of engaging with new migrants and ethnic minorities with learning disabilities to help meet their future needs and to improve the quality of life for this population as a result.

Ethics approval required

Old ethics approval format

Ethics approval(s)

The Black Country NHS REC, 24/06/2011, ref: 11/H1202/14

Study design

Non-randomised; Interventional and Observational; Design type: Process of Care, Not specified

Primary study design

Interventional

Secondary study design

Non randomised study

Study setting(s)

Hospital

Study type(s)

Screening

Participant information sheet

Not available in web format, please use the contact details below to request a patient information sheet

Health condition(s) or problem(s) studied

Topic: Primary Care Research Network for England; Subtopic: Not Assigned; Disease: All Diseases

Interventions

The aim is to develop a set of guidelines on how to make the learning disability services more visible and available to new migrants in cooperation with the policy makers, service commissioners, service providers and service users.

Four pilot sites will be used to implement the guidelines and to examine the extent to which the guidelines have an impact upon the increase in numbers of migrants using LD services and how this impacts upon the migrants' lives.

First, the uptake in learning disability services within our pilot site areas will be measured.

Second, 80 individuals and their families will be asked to complete a questionnaire about their experiences and opinions during their journey of using learning disability services.

Intervention Type

Other

Phase

Not Applicable

Primary outcome measure

Estimated prevalence numbers; Timepoint(s): Number of people with LD in ethnic minority communities

Secondary outcome measures

No secondary outcome measures

Overall study start date

01/12/2011

Completion date

31/12/2014

Eligibility

Key inclusion criteria

Geographical area of inclusion: England with focus on the West Midlands and the Black Country in particular

Stage 1:

1. Primary care trusts (PCTs)
2. Local Authorities
3. 3rd sector organisations targeting migrants and people with learning disabilities (LD)

Stage 2:

1. People with LD as follows: ethnic minority communities, new migrants
2. Health and Social Care Practitioners - qualified as health and social care practitioners and experienced in caring for the target group
3. Families and carers - experienced in caring for people with learning disabilities
4. PCTs
5. Local Authorities
6. 3rd sector service providers for people with learning disabilities; Target Gender: Male & Female; Upper Age Limit 65 ; Lower Age Limit 0

Participant type(s)

Patient

Age group

Adult

Sex

Both

Target number of participants

Planned Sample Size: 416; UK Sample Size: 416; Description: Focus groups: 216 Delphi Study: 80 Interviews/case studies: 120

Key exclusion criteria

Interviews and case studies of people with LD in Stage 2

People who are not:

1. From ethnic minority communities

OR

2. From new migrant communities

Date of first enrolment

01/12/2011

Date of final enrolment

31/12/2014

Locations

Countries of recruitment

England

United Kingdom

Study participating centre

School of Health and Wellbeing

Wolverhampton

United Kingdom

WV1 1DT

Sponsor information

Organisation

University of Wolverhampton (UK)

Sponsor details

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MA Building
Wulfruna Street
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WV1 1LY

Sponsor type

University/education

ROR

<https://ror.org/01k2y1055>

Funder(s)

Funder type

Government

Funder Name

Big Lottery Fund (UK)

Alternative Name(s)

BIG

Funding Body Type

Private sector organisation

Funding Body Subtype

Other non-profit organizations

Location

United Kingdom

Results and Publications

Publication and dissemination plan

Not provided at time of registration

Intention to publish date**Individual participant data (IPD) sharing plan****IPD sharing plan summary**

Not provided at time of registration