

Mapping and Evaluating Services for Children with Learning Disabilities and Behaviours that Challenge in England

Submission date 26/07/2021	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered <input checked="" type="checkbox"/> Protocol
Registration date 05/08/2021	Overall study status Completed	<input checked="" type="checkbox"/> Statistical analysis plan <input checked="" type="checkbox"/> Results
Last Edited 16/01/2024	Condition category Mental and Behavioural Disorders	<input type="checkbox"/> Individual participant data

Plain English summary of protocol

Background and study aims

1 in every 5 children with a learning disability in the UK display behaviours that challenge. These are not a medical diagnosis, but are behaviours (like aggression or self-injury) that may cause harm to the child or other people or prevent the child being included in the community. Children with learning disability and behaviours that challenge are at risk of negative outcomes (like abusive care), their families are more likely to experience stress, and these children's care is costly for services. When the National Institute of Health and Care Excellence (NICE) reviewed the evidence, they found little research about how best to design and deliver health and care services to these children.

This research is about community based services across England that support children with a learning disability and behaviours that challenge, and their families. We want to find out how these services are structured and organised (known as "service models").

Who can participate?

Staff from eligible services can take part in the study. To be eligible to take part in the study, community-based services will need to be providing supports for children with learning disabilities and behaviours that challenge who are 0-17 years of age, or providing supports to this group of children as a clearly distinct care pathway (whilst also providing other services). Services will not be excluded if they also provide services to individuals 18+ years of age as well as within the 0-17 age range.

What does the study involve?

We aim to find all the community NHS/local authority services in England supporting children with learning disabilities and behaviours that challenge. We will contact service managers/lead clinicians at each service who will identify suitable staff members to complete an online survey and interview to collect information about the service. We will then use a combination of statistical methods and the expert views of family carers and professionals to describe groups of similar services. These similar groups will be our "service models".

What are the possible benefits and risks of participating?

There are no direct and immediate benefits to taking part in this study, but data from services will enable us to describe the current service models for children with learning disabilities and behaviours that challenge in England. This will contribute to the evidence base about community-based service provision for these children, which may inform developments in service provision across England.

We are not aware of any risks related to taking part in this study.

Where is the study run from?

University of Warwick (UK)

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

From February 2021 to December 2021

Who is funding the study?

National Institute for Health Research Health Services and Delivery Research (UK)

Who is the main contact?

Trial manager, meldstudy@warwick.ac.uk

Study website

<https://warwick.ac.uk/fac/soc/cedar/meldstudy/>

Contact information

Type(s)

Scientific

Contact name

Dr Samantha Flynn

ORCID ID

<http://orcid.org/0000-0003-3466-9506>

Contact details

CEDAR
New Education Building
Westwood Campus
University of Warwick
Coventry
United Kingdom
CV4 7AL
+44 (0)7823 362152
S.Flynn.1@warwick.ac.uk

Type(s)

Scientific

Contact name

Prof Richard Hastings

ORCID ID

<http://orcid.org/0000-0002-0495-8270>

Contact details

CEDAR
New Education Building
Westwood Campus
University of Warwick
Coventry
United Kingdom
CV4 7AL
+44 (0)2476 522197
R.Hastings@warwick.ac.uk

Type(s)

Public

Contact name

Mr Nicholas Manktelow

Contact details

Room WE 1.41, New Education Building
Westwood Campus
University of Warwick
Coventry
United Kingdom
CV4 7AL
-
meldstudy@warwick.ac.uk

Additional identifiers**EudraCT/CTIS number**

Nil known

IRAS number**ClinicalTrials.gov number**

Nil known

Secondary identifying numbers

CPMS 49890

Study information**Scientific Title**

Mapping Services for Children with Learning Disabilities and Behaviours that Challenge (MELD)

Acronym

MELD

Study objectives

There will be at least two distinct service models for children and young people with intellectual disability and behaviours that challenge.

Ethics approval required

Old ethics approval format

Ethics approval(s)

Approved 16/03/2021, University of Warwick Humanities and Social Science Research Ethics Committee (HSSREC)(University House, University of Warwick, Coventry, CV4 7AL; +44 (0)24 765 73123; hssrec@warwick.ac.uk)

Study design

Observational cross-sectional study

Primary study design

Observational

Secondary study design

Cross sectional study

Study setting(s)

Community

Study type(s)

Treatment

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

Health services research, mental health, children with learning disabilities and behaviours that challenge

Interventions

This is a descriptive services-mapping study and does not include any specific intervention. The study team will contact service managers/lead clinicians at each service who will identify suitable staff members to complete an online survey and interview to collect information about the service. A combination of statistical methods and the expert views of family, carers, and professionals will be used to describe groups of similar services.

Intervention Type

Other

Primary outcome measure

Key characteristics of services including size, staffing compliment, referral methods, and caseloads collected via online survey and interviews with staff members working in each service at a single timepoint

Secondary outcome measures

There are no secondary outcome measures

Overall study start date

01/02/2021

Completion date

31/12/2021

Eligibility

Key inclusion criteria

Services:

1. NHS, local authority or another (e.g. private or charity) service commissioned by a CCG/local authority or another commissioner, or service where individual places are purchased by CCG /local authority or other commissioners
2. Providing supports for children with learning disabilities and behaviours that challenge who are aged 0-17 years, or providing supports to this group of children as a clearly distinct care pathway (whilst also providing other services). Services will not be excluded if they also provide services to individuals 18+ years of age as well as within the 0-17 age range.

Staff:

Employed at an eligible service.

Participant type(s)

Health professional

Age group

Adult

Lower age limit

18 Years

Sex

Both

Target number of participants

Planned Sample Size: 400; UK Sample Size: 400

Total final enrolment

161

Key exclusion criteria

Services:

1. Inpatient service

2. Service commissioned by non-CCG or local authority commissioner (e.g. solely a special school service)
3. Service that is not yet operational (has received no referrals at the time of data collection)

Staff:

Does not meet inclusion criteria

Date of first enrolment

10/06/2021

Date of final enrolment

03/12/2021

Locations

Countries of recruitment

England

United Kingdom

Study participating centre

University of Warwick

Coventry

United Kingdom

CV4 7AL

Sponsor information

Organisation

University of Warwick

Sponsor details

Research & Impact Services

University House

Coventry

England

United Kingdom

CV4 8UW

+44 (0)24 765 75732

sponsorship@warwick.ac.uk

Sponsor type

University/education

Website

<https://warwick.ac.uk/>

ROR

<https://ror.org/01a77tt86>

Funder(s)

Funder type

Government

Funder Name

National Institute for Health Research

Alternative Name(s)

National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type

Government organisation

Funding Body Subtype

National government

Location

United Kingdom

Results and Publications

Publication and dissemination plan

Planned outputs from the MELD study will include open-access peer-reviewed journal articles in international academic journals, presentations at national and international academic conferences, and at public engagement/dissemination events.

Intention to publish date

31/12/2023

Individual participant data (IPD) sharing plan

The data sharing plans for the current study are unknown and will be made available at a later date.

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 file	version 1.2	21/05/2021	04/08/2021	No	No
Protocol file	version 1.3	22/09/2021	22/09/2021	No	No
Protocol file	version 1.4	10/11/2021	29/11/2021	No	No
Statistical Analysis Plan	version 1.1	16/12/2021	16/12/2022	No	No
Results article		04/12/2023	16/01/2024	Yes	No