

## PROSPERO

### International prospective register of systematic reviews

Barriers and facilitators to primary health care services for physical and / or mental health issues experienced by adolescents and adults either with intellectual disabilities (only), with intellectual disabilities and autism, or with autism (only): an integrative review  
 Alison Doherty, Richard Hastings, Christopher Hatton, Kerry Hood, Lynn James-Jenkinson, Ralph Leavey, Elizabeth Randell, Janet Reed, Laurence Taggart, Neil Wilson, Umesh Chauhan

### Citation

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### Review question

What are the barriers and facilitators that adolescents and adults with intellectual disabilities and / or autism experience to accessing and / or using primary health care services for physical and / or mental health issues?

### Searches

Electronic searches of e-databases: Cochrane database of Systematic Reviews, MEDLINE, EMBASE, CINAHL, PsycINFO. Hand searching of grey literature (publications, policy documents, guidance, reports, news articles, and social media articles). Citation searches and checking the reference lists of all included studies. All languages (to the extent that a translation is available and / or the data is understandable). Time limit: 1980 to date.

Subject index terms:

MeSH terms and word terms:

1. (TI ( learning N1 (disab\* or difficult\* or handicap\* ) OR TI ( mental\* N1 (retard\* or disab\* or deficien\* or handicap\* ) OR TI ( intellectual\* N1 (disab\* or impair\* or handicap\* ) OR TI development\* N1 disab\* OR TI ( multipl\* N1 (handicap\* or disab\* ) OR TI "Down\* syndrome" OR (MH "Developmental Disabilities") OR (MH "Intellectual Disability&#43;") OR (MH "mentally disabled persons")) OR (AB ( learning N1 (disab\* or difficult\* or handicap\* ) OR AB ( mental\* N1 (retard\* or disab\* or deficien\* or handicap\* ) OR AB ( intellectual\* N1 (disab\* or impair\* or handicap\* ) OR AB development\* N1 disab\* OR AB ( multipl\* N1 (handicap\* or disab\* ) OR AB"Down\* syndrome");

2. OR autism; OR autistic disorder, OR autism spectrum disorder; OR ASD; OR autistic spectrum condition; OR ASC; OR Asperger's; OR ADHD; OR Attention Deficit Hyperactivity Disorder; OR APD; OR Auditory Processing Disorder; OR OCD; OR Obsessive Compulsive Disorder; OR SPD; OR Sensory Processing Disorder.

3. AND adolescent; OR young adult; OR young people; OR teenagers; OR adult; 4. AND access; OR health services; OR referral and consultation; OR utilise; OR utilisation; OR utilization; OR facility design and construction; OR building; OR waiting room; OR family practice; OR primary health care; OR health status; OR physical health; OR mental health; OR social adjustment; OR adjustment; OR aid; OR modification; OR adaptation; OR intervention; OR apps; OR devices; OR monitors; OR delivery of health care; OR health services accessibility; OR innovation; OR toolkit; OR technology; OR self-help devices; OR informatics; OR communication aids for disabled; OR telemedicine; OR telehealth; OR support; OR patient advocacy; OR peer group; OR social support.

## Types of study to be included

Inclusion criteria: Qualitative studies. Interviews. Focus Groups. Surveys. Formal case studies e.g. case studies of primary health care services. Cohort studies. Panel studies. Ethnographies. Case reports. Quantitative studies. Randomised Controlled Trials. Quasi-experimental pre and post intervention testing. Mixed methods studies. Trials. Feasibility studies. Intervention studies (primary health care and secondary health care interventions). Studies published in peer-reviewed journals. Grey literature. Policy documents. Guidelines. Newspaper articles, commentaries and editorials. Social media: blogs / tweets / commentaries written by and for people with intellectual disabilities and / or autism. (N.B., The social media search will be limited to the previous 5 years for the purposes of practicalities of hand searching such media i.e. 2013 - 2018).

Exclusion criteria: Individual clinical case studies (unpublished). Individual case studies (published).

## Condition or domain being studied

Physical health conditions. Mental health conditions. Health care access. Health care utilisation. Primary health care.

## Participants/population

Adolescents and adults aged 14 years and over who either have: a) An intellectual disability (only); b) An intellectual disability and autism; c) Autism (only); d) Asperger's syndrome.

Inclusion criteria: Studies involving participants who have been formally identified by health care / education providers as having an intellectual disability (mild, moderate, severe or profound) and / or an autism condition. Studies involving participants who self-identify as having an intellectual disability and / or an autism condition. Adolescents and / or young people with either or: intellectual disability (only); intellectual disability and autism; with autism only; or Asperger's syndrome only (14 – 18 years). Adults (18 years and over) with either or: intellectual disability (only); intellectual disability and autism; autism only; or Asperger's syndrome only. Family members, paid or unpaid carers or support workers of people with intellectual disabilities and / or autism. Wider studies if adolescents and adults with intellectual disabilities and / or autism are reported on separately and / or where over 70% of the study's sample has individuals with intellectual disabilities and / or autism (aged 14 years and over). Wider studies which include children under the age of 14 years, if the sample includes over 70% adolescents and or adults with intellectual disabilities and / or autism (aged 14 years and over). Primary health care settings (NHS provided services and NHS commissioned services - which may be in the NHS or which may be in the independent sector i.e. third sector / voluntary / private sector providers of primary health care services). General Practitioner's practices, walk-in clinics, pharmacies, dentists, audiologists, optometrists. Annual Health Checks. Screening services (breast, cervical, bowel screening services). Vaccination and other preventative health services. Secondary health care settings (hospitals, Accident and Emergency services, hospital wards or clinics) because there may be relevant transferable knowledge, interventions and / or practice in secondary care for primary health care services. Mental health service provision in primary and secondary health care service settings.

Exclusion criteria: Studies which include only a sample of children aged  $\geq$ 14 years with intellectual disabilities and / or autism.

## Intervention(s), exposure(s)

Information on barriers and facilitators to accessing and / or using primary health care services for physical and / or mental health issues which are experienced by adolescents and adults with intellectual disabilities and / or autism (and their carers or support workers).

## Comparator(s)/control

Not applicable.

## Context

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### International prospective register of systematic reviews

The review will be international. Primary health care services in the UK and in other international countries with similarly structured, funded and resourced primary health care services will be included. However, studies involving other countries with differently structured, funded and resourced primary health care services may also be informative and these will also be included.

#### Main outcome(s)

The views and experiences of adolescents and adults with intellectual disability and / or autism (and their carers / other sources) in relation to barriers and facilitators to accessing and / or utilisation of primary health care services for physical and / or mental health issues which are experienced by adolescents and adults with intellectual disabilities and / or autism.

#### *Timing and effect measures*

#### Additional outcome(s)

The types of interventions, aids, adjustments, modifications which may facilitate access to, and utilisation of, primary health care services by adolescents and / or adults with intellectual disability and / or autism.

The types of physical and mental health conditions experienced by this target population.

The views and experiences of GPs and other primary health care practitioners involved in the provision and delivery of primary health care services for physical and / or mental health issues which are experienced by adolescents and adults with intellectual disabilities and / or autism.

#### *Timing and effect measures*

#### Data extraction (selection and coding)

Author(s) name(s), year, journal name, publication title, study aims or hypotheses, theoretical standpoints, study design, setting(s), country or countries, participant information (age, gender, ethnicity, type and level of disability), sample size, measures, interventions, analysis, findings and conclusions.

#### Risk of bias (quality) assessment

Critical appraisal of studies using Mixed Methods Analysis Tools: MMAT:  
<http://mixedmethodsappraisaltoolpublic.pbworks.com>

Cochrane risk of bias: <http://methods.cochrane.org/bias/assessing-risk-bias-included-studies>.

CASP: <https://casp-uk.net/casp-tools-checklists/> CONSORT: <http://www.consort-statement.org>

#### Strategy for data synthesis

Thematic analysis and narrative description of qualitative and quantitative studies' findings.

#### Analysis of subgroups or subsets

Not applicable.

#### Contact details for further information

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#### Organisational affiliation of the review

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### International prospective register of systematic reviews

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#### Anticipated or actual start date

06 July 2018

#### Anticipated completion date

30 April 2019

#### Funding sources/sponsors

Lancashire Research Institute for Global Health & Wellbeing, University of Central Lancashire

#### Conflicts of interest

None known

#### Language

English

#### Country

England, Northern Ireland, Wales

#### Stage of review

Review\_Ongoing

#### Subject index terms status

Subject indexing assigned by CRD

#### Subject index terms

Adolescent; Adult; Autistic Disorder; Health Services; Humans; Intellectual Disability; Mental Health; Physical Examination; Primary Health Care

#### Date of registration in PROSPERO

17 July 2018

#### Date of publication of this version

17 July 2018

#### Details of any existing review of the same topic by the same authors

#### Stage of review at time of this submission

The review has not started

<b>Stage</b>	<b>Started</b>	<b>Completed</b>
Preliminary searches	No	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	No	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

**Versions**

17 July 2018

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