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Appendix A: Scope for the development of the clinical guideline

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

SCOPE

A.1 Guideline title

Mental health problems in people with learning disabilities: prevention, assessment and management of mental health problems in people with learning disabilities

A.1.1 Short title

Mental health problems in people with learning disabilities

A.2 The remit

The Department of Health has asked NICE to prepare a clinical guideline on 'mental health problems in people with learning disabilities'.

A.3 Need for the guideline

A.3.1 Epidemiology

- a. Learning disabilities are defined by 3 core criteria: low intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning, and onset in childhood. There are many causes of learning disabilities and the cause is often unknown. People with learning disabilities have a diverse range of skills and needs.
- b. 'Learning disabilities' is the term that is widely used and accepted in the UK. It is a term that has been used in Department of Health documents such as Valuing People (2001) and is well understood by health and social care practitioners in the UK. It will therefore be used in this guideline. It equates to the terms 'intellectual disabilities' which is widely accepted internationally. The World Health Organization's revision of the International statistical classification of diseases and related health problems (ICD-11), due to be published in 2017, has proposed the term 'disorders of intellectual development'. DSM-5, published in May 2013, uses the term 'intellectual disability (intellectual developmental disorder)'.
- c. Learning disabilities are different from specific learning difficulties such as dyslexia, which do not affect overall intellectual ability, and are not included in this guideline.
- d. People with milder learning disabilities will need support in some areas (for example, budgeting, planning, time management, and understanding complex information). Their needs may be less apparent to people who do not know them well. The more severe a person's learning disabilities, the more likely they are to have limited verbal

- communication skills and understanding of others, and a reduced ability to learn new skills. Likewise, the more severe the person's learning disabilities, the more likely they are to need support with daily activities such as dressing, washing, eating, and mobility. People with learning disabilities may also have physical and sensory disabilities and health or mental health problems that further affect the levels of support they need.
- e. It is important to respect each person as an individual, with their own specific skills and needs. It is recognised that a broad and detailed assessment of skills and needs is essential. This typically calls for a multidisciplinary, and person-centred approach.
 - f. People with learning disabilities often experience mental health problems alongside other conditions such as epilepsy, physical health problems and sensory impairments. It is important to take these other problems into account when assessing, diagnosing and managing any mental health problems.
 - g. The prevalence of mental health problems among people with learning disabilities varies depending on the populations sampled and the definitions used. Population-based estimates suggest that 40% of adults with learning disabilities experience mental health problems (28% if problem behaviours are excluded). An estimated 36% of children and young people with learning disabilities experience mental health problems (24% if conduct disorders are excluded). These rates are much higher than for people who do not have learning disabilities. Psychosis, dementia, autism, attention deficit hyperactivity disorder, problem behaviours and conduct disorders are all more common than in the general population. Emotional disorders are at least as common as in the general population. Within learning disabilities some diagnoses are associated with particularly high levels of mental health problems (for example, Down's Syndrome) or particular presentations of symptoms (for example, obsessive compulsive symptoms in Prader-Willi syndrome and attentional problems in Fragile X Syndrome).
 - h. There are many underlying factors that may contribute to people with learning disabilities developing mental health problems, including the severity of their learning disabilities; the cause of their learning disabilities (including behavioural phenotypes); other biological factors such as pain, physical ill health and taking multiple types of medication (polypharmacy); psychological factors such as attachment difficulties and trauma; social factors such as abuse and neglect, poverty, multiple co-occurring life events, poverty of social environment and social networks, stigma and hate crimes; developmental factors such as affect dysregulation and attentional control; and cultural and identity factors.
 - i. Mental health problems are often overlooked in people with learning disabilities for a variety of reasons. For example, they may be unable to complain of or describe their distress; their carers may not recognise that their behaviour has changed (this depends on how long carers have known the person and how well information is communicated within and across care teams); their symptoms may inadvertently be attributed to their learning disabilities; the more severe the learning disabilities, the more likely the person is to have unusual presentations of symptoms; symptoms may be attributed to side effects of medications or to other disorders such as complex partial epilepsy; and primary care services are typically designed to provide reactive rather than proactive health care. Diagnostic delay can compound problems over time, and influence outcomes.
 - j. Mental health problems can cause significant distress for a person with learning disabilities, and restrict their opportunities for community participation and further development. They can also affect their family and paid carers, and place a stress on organisations and services.

- k. Race, ethnicity, gender, sexuality, social, cultural and religious factors and age may also influence the patterning of mental health problems and equity of access to services and supports.

A.3.2 Current practice

- a. The under recognition and/or misattribution of mental health problems in people with learning disabilities is a key issue, and can result in the person not being provided with effective interventions, or worse being given ineffective or harmful interventions.
- b. A further issue relates to access to services that offer prevention, treatment or support. Barriers can be present in accessing primary care services, secondary care, and social services. Variability in service provision across England and Wales may also contribute to access problems in some areas. Good practice in helping people access services often needs to take a 'whole system' approach including the person with learning disabilities, their family and paid carers and other key people in the person's life, as well as primary care, secondary care, specialist learning disabilities health and social services. This needs good coordination and communication.
- c. Psychotropic medication is commonly prescribed for people with learning disabilities. About 50% of adults with learning disabilities are prescribed psychotropic drugs with 20–25% taking antipsychotics, and 12% antidepressants. A large proportion (about 25%) take mood stabilising drugs, although these are usually prescribed to manage epilepsy rather than mood disorders.
- d. The next most commonly used interventions for mental health problems in people with learning disabilities are psychosocial interventions. However, despite national guidance highlighting the importance of psychological therapies, many such therapies developed for the general population remain inaccessible for people with learning disabilities.
- e. Other approaches are also used, such as educational, occupational and developmental approaches, and promotion of healthy lifestyles.
- f. Families are an important source of help for many people with learning disabilities, so supporting them in their caring role is vital. Paid carer support is usually funded by social services (for example, support for self-care, daily living, daytime activities and respite care, specialist equipment and adaptations). This is frequently commissioned from independent agencies. Increasingly, support is provided through personal budgets. People with learning disabilities may also receive education support (such as support to meet special educational needs in mainstream schools and colleges, support in special schools or classes in further education colleges). There is a statutory duty to provide support in education to children with disabilities under the Children Act, 1989.
- g. People with learning disabilities and mental health problems may use general mental health services, and also additional specialist health services, which tend to be provided and organised by community teams. For children and young people these services are usually embedded in child and adolescent mental health services (CAMHS) teams, although many families report that services from these teams are variable. For adults, the specialist services are usually provided by Community Learning Disabilities Teams. Transitions – for example from child to adult services or to services for older people – are often problematic, and need close coordination between services. Services are sometimes lacking for adults with mild learning disabilities who may have significant mental health problems but are otherwise relatively able. This is because they may fall outside of both local eligibility criteria established by social services and the criteria established by the local specialist health services.
- h. People with learning disabilities who have mental health problems live in a diverse range of environments. They may live at home with their families. They may hold their

own individual or shared tenancy with paid carer support, or live in residential services of various kinds (including residential special schools, residential services for adults, or secure settings). Severe mental health problems are sometimes a reason for placement in residential special schools, or specialist services run by independent providers or the NHS, which may be located outside the person's area, sometimes hundreds of miles away, contrary to recent guidance.

- i. There is a statutory duty on services to make reasonable adjustments to accommodate the needs of people with disabilities (Equality Act, 2010). This may involve offering people with learning disabilities longer appointments and information written in an accessible way, and using different approaches to improve communication. The Mental Capacity Act, (2005), stipulates that people should get the support they need to make decisions, and that best interest decisions should be made in circumstances where a person does not have capacity to decide for themselves.

A.4 The guideline

The guideline development process is described in detail on the NICE website (see section 6, 'Further information').

This scope defines what the guideline will (and will not) examine, and what the guideline developers will consider. The scope is based on the referral from the Department of Health.

The areas that will be addressed by the guideline are described in the following sections.

A.4.1 Population

A.4.1.1 Groups that will be covered

- a. Children, young people, and adults with mild, moderate, severe or profound learning disabilities and mental health problems, and their families and carers.
- b. People with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs may differ from those of people with other learning disabilities (for example, Down's syndrome, Prader-Willi syndrome, Fragile X syndrome).
- c. Special consideration will be given to groups affected by equality issues, such as black, Asian and minority ethnic groups and older adults.

A.4.2 Care setting

- a. The guideline will cover all settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.

A.4.3 Management and support

A.4.3.1 Key issues that will be covered

- a. Identifying people with learning disabilities who are at risk of developing mental health problems.
- b. Recognising mental health problems in people with learning disabilities.
- c. Diagnosing and assessing mental health problems in people with learning disabilities, including identifying contributory factors.

- d. Interventions to prevent, reduce and manage mental health problems, including:
 - psychological interventions
 - social and environmental interventions
 - personal and support strategies in community and residential settings
 - pharmacological interventions
 - dietary interventions
 - other multidisciplinary therapies
 - combined interventions
 - occupational interventions
 - community interventions (for example to reduce stigma or hate crimes).
- e. Accessibility of services for people with learning disabilities.
- f. Transitions between services.
- g. Coordination and communication with key people and services in the life of the person with learning disabilities.
- h. Strategies to engage, train and support family carers and paid carers in designing, implementing and monitoring interventions for the person with learning disabilities.
- i. Service structures, training and supervision to support practitioners in the effective delivery of interventions.
- j. Interventions, training, and support for family carers and paid carers that aim to improve their own health and wellbeing as well as that of the person with learning disabilities.
- k. The experience of care for service users and their carers.

A.4.3.2 Issues that will not be covered

- a. The specific care and management of behaviour that challenges in people with learning disabilities. This will be covered by another NICE guideline (see section 5, 'Related NICE guidance').

A.4.4 Main outcomes

- a. Mental health.
- b. Problem behaviours.
- c. Adaptive functioning.
- d. Quality of life.
- e. Service user and carer satisfaction.
- f. Carer health and quality of life.
- g. Adverse effects of interventions.
- h. Rates of placement breakdown.
- i. Psychiatric admissions.
- j. Out-of-area placements.
- k. Rates of seclusion.
- l. Rates of manual restraint.
- m. Use of psychoactive medication.
- n. Community participation.

A.4.5 Economic aspects

Developers will take into account both clinical and cost effectiveness when making recommendations involving a choice between alternative interventions. A review of the economic evidence will be conducted and analyses will be carried out as appropriate. The preferred unit of effectiveness is the quality-adjusted life year (QALY) but a different unit of effectiveness may be used depending on the availability of appropriate clinical and utility data for people with learning disabilities and mental health problems. The costs considered will usually be only from an NHS and personal social services (PSS) perspective, although economic analyses will attempt to incorporate wider costs associated with the care of people with learning disabilities and mental health problems if appropriate cost data are available. Further detail on the methods can be found in The guidelines manual (see 'Further information').

A.4.6 Status

A.4.6.1 Scope

This is the final scope.

A.4.6.2 Timing

The development of the guideline recommendations will begin in October 2014.

A.5 Related NICE guidance

Related NICE guidelines include all those published on specific types of mental health problems for children and adults who do not have learning disabilities, such as:

- Autism diagnosis in children and young people NICE clinical guideline 128 (2011)
- Autism: the management and support of children and young people on the autism spectrum NICE clinical guideline 170 (2013)
- Autism in adults NICE clinical guideline 142 (2012)
- The epilepsies NICE clinical guideline 137 (2012)
- Service user experience in adult mental health NICE clinical guidance 136 (2011)
- Self-harm NICE clinical guideline 16 (2004)
- Self-harm: longer-term management NICE clinical guideline 133 (2011)
- Dementia NICE clinical guideline 42 (2006)

A.5.1 Guidance under development

NICE is currently developing the following related guidance (details available from the NICE website):

- Challenging behaviour and learning disabilities NICE clinical guideline. Publication expected May 2015.
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs NICE clinical guideline. Publication expected November 2015.
- Transition from children's to adult services NICE clinical guideline. Publication expected February 2016.

- Transition between inpatient mental health settings and community and care home settings for people with social care needs NICE clinical guideline. Publication expected August 2016.
- Mental health of people in prison NICE clinical guideline. Publication expected November 2016.

A.6 Further information

Information on the guideline development process is provided in the following documents, available from the NICE website:

- How NICE clinical guidelines are developed: an overview for stakeholders the public and the NHS
- The guidelines manual.

Information on the progress of the guideline will also be available from the NICE website.

Appendix B: Declarations of interests by Guideline Committee members

With a range of practical experience relevant to learning disabilities in the GC, members were appointed because of their understanding and expertise in healthcare for mental health problems in people with learning disabilities and support for their families/carers, including: scientific issues; health research; the delivery and receipt of healthcare, along with the work of the healthcare industry; and the role of professional organisations and organisations for people with mental health problems and learning disabilities and their families/carers.

To minimise and manage any potential conflicts of interest, and to avoid any public concern that commercial or other financial interests have affected the work of the GC and influenced guidance, members of the GC must declare as a matter of public record any interests held by themselves or their families which fall under specified categories (see below). These categories include any relationships they have with the healthcare industries, professional organisations and organisations for people with learning disabilities and their families/carers.

Individuals invited to join the GC were asked to declare their interests before being appointed. To allow the management of any potential conflicts of interest that might arise during the development of the guideline, GC members were also asked to declare their interests at each GC meeting throughout the guideline development process. The interests of all the members of the GC are listed below, including interests declared prior to appointment and during the guideline development process.

B.1 Categories of interest

- Paid employment
- Personal pecuniary interest: financial payments or other benefits from either the manufacturer or the owner of the product or service under consideration in this guideline, or the industry or sector from which the product or service comes. This includes holding a directorship or other paid position; carrying out consultancy or fee paid work; having shareholdings or other beneficial interests; receiving expenses and hospitality over and above what would be reasonably expected to attend meetings and conferences.
- Personal family interest: financial payments or other benefits from the healthcare industry that were received by a member of your family.
- Non-personal pecuniary interest: financial payments or other benefits received by the GC member's organisation or department, but where the GC member has not personally received payment, including fellowships and other support provided by the healthcare industry. This includes a grant or fellowship or other payment to sponsor a post, or contribute to the running costs of the department; commissioning of research or other work; contracts with, or grants from, NICE.
- Personal non-pecuniary interest: these include, but are not limited to, clear opinions or public statements you have made about individuals with mental health problems and learning disabilities, holding office in a professional organisation or advocacy group with a direct interest in mental health problems and learning disabilities, other reputational risks relevant to mental health problems and learning disabilities.

Guideline Committee – declarations of interest

Professor Sally-Ann Cooper

Mental health problems in people with learning disabilities
 Appendix B: Declarations of interests by Guideline Committee members

Guideline Committee – declarations of interest	
Employment	Professor of Learning Disabilities and Honorary Consultant Psychiatrist, University of Glasgow
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Non-personal non-pecuniary interest	None
Action taken	None
Professor Steve Pilling	
Employment	Director, National Collaborating Centre for Mental Health/Director, Centre for Outcomes Research and Effectiveness, University College London
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Non-personal non-pecuniary interest	None
Action taken	None
Dr Regi Tharian Alexander	
Employment	Consultant Psychiatrist, PiC LD Services, Diss, Norfolk Lead Research Consultant, Leicestershire Partnership NHS Trust Honorary Senior Lecturer, Department of Health Sciences, University of Leicester
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action taken	None
Ms Stella Ayetey	
Employment	Carer Representative
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action taken	None
Mrs Alison Baker	
Employment	Carer Representative
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None

Mental health problems in people with learning disabilities
Appendix B: Declarations of interests by Guideline Committee members

Guideline Committee – declarations of interest	
Action taken	None
Professor Sabyasachi Bhaumik	
Employment	Consultant Psychiatrist and Senior Medical Advisor, Leicestershire Partnership NHS Trust
Personal pecuniary interest	Director, RAPID Healthcare (UK) Ltd. which provides advice and training to NHS and non-NHS services providing Mental Health and LD services. Medical member of First Tier Mental Health Review Tribunal of Judiciary Department.
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	An Editor for the third edition of the Frith Prescribing Guidelines for Adults with Intellectual Disability (Publisher—Wiley). The Royalty income will be paid directly to Leicestershire Partnership NHS Trust. Member of HS&DR researcher led panel of NIHR
Action taken	None
Dr Umesh Chauhan	
Employment	GP, CVD and Research Lead East Lancashire CCG Division 5 Clinical Lead NWC CRN and Honorary Senior Lecturer, University of Central Lancashire.
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	Chair of the Special Interest Group for LD at the SAPC Member of the RCGP ID group
Personal non-pecuniary interest	Member of the Advisory Group for Learning Disabilities Mortality Review Programme (LeDeR) Member of the Advisory for ANDREA-LD trial
Action Taken	None
Ms Lindsey Gagan	
Employment	Speech and Language Therapist, Salford Royal Foundation Trust
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action taken	None
Professor Angela Hassiotis	
Employment	Professor in the Psychiatry of Intellectual Disability, UCL Division of Psychiatry
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None

Mental health problems in people with learning disabilities
Appendix B: Declarations of interests by Guideline Committee members

Guideline Committee – declarations of interest	
Action taken	None
Professor Richard Hastings	
Employment	Professor of Education and Psychology Centre for Educational Development Appraisal and Research, University of Warwick
Personal pecuniary interest	None
Personal family interest	My wife is a cognitive behaviour therapist in a CAMHS service and she is employed by the NHS in Wales.
Non-personal pecuniary interest	University of Warwick has is receiving funds under a research grant from NIHR (HTA) to evaluate a psychological therapeutic intervention for adults with learning disability and depression, and from NISCHR (Wales) to evaluate mindfulness based intervention for adults with LD with anger problems.
Personal non-pecuniary interest	Trustee of the Royal Mencap Society (until May 2015)
Action taken	None
Professor Chris Hatton	
Employment	Professor of Psychology Health & Social Care, Lancaster University Co-Director, Public Health England Learning Disabilities Observatory
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	Prof Hatton is a co-applicant on an NIHR HTA research grant to evaluate a psychological therapeutic intervention for adults with learning disabilities and depression. Lancaster University (including Prof Hatton) is contracted to Public Health England to jointly run their Learning Disabilities Observatory.
Personal non-pecuniary interest	None
Action taken	None
Ms Sharon Jeffreys	
Employment	Head of Commissioning; Learning Disabilities and Autism, South West Lincolnshire Clinical Commissioning Group Previous Nurse Consultant Children and Young Peoples Mental Health, Learning Disabilities and Autism, Rotherham, Doncaster and South Humber NHS Foundation Trust Registered mental health nurse and learning disability nurse
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action taken	None

Mental health problems in people with learning disabilities
Appendix B: Declarations of interests by Guideline Committee members

Guideline Committee – declarations of interest	
Action Taken	None
Dr Anne Livesey	
Employment	Consultant Community Paediatrician, Sussex Community Foundation Trust
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action taken	None
Dr Julie O’Sullivan	
Employment	Educational Consultant and Former Head Teacher, Nightingale School, Wandsworth
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action taken	None
Mr Ian Rogers	
Employment	Carer Representative
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action taken	None
Ms Zandra Stewart	
Employment	National Autism Lead Advisor (ADASS) National Principal Adviser Winterbourne, Joint Improvement Programme & Transforming Care (until July 2015) Health and social care manager/Social Care professional
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	Director of a Health and Social care service improvement and transformation consultancy business including Learning Disability, Autism and Mental Health
Action taken	None
Professor John L Taylor	
Employment	Professor of Clinical Psychology and Consultant Clinical Psychologist, Northumbria University and Northumberland, Tyne & Wear NHS Foundation Trust
Personal pecuniary interest	
Personal family interest	None

Mental health problems in people with learning disabilities
Appendix B: Declarations of interests by Guideline Committee members

Guideline Committee – declarations of interest	
Non-personal pecuniary interest	None
Personal non-pecuniary interest	Past President and Board member of the British Association for Behavioural and Cognitive Psychotherapies (BABCP), a charitable organisation that promotes the theory and practice of cognitive and behavioural psychotherapies. Member of the BABCP's Scientific Committee Active researcher in the field of cognitive behavioural therapy and its applications to people with learning disabilities who experience mental health and emotional difficulties.
Action taken	None
Ms Liz Whitaker	
Employment	Lead Physiotherapist, Bradford District Care Foundation NHS Trust
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action taken	None
NCCMH/NGA staff	
Ms Clare Taylor	
Employment	Senior Editor
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Nuala Ernest	
Employment	Assistant Editor
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Ifigeneia Mavranezouli	
Employment	Senior Health Economist
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Heather Stegenga	

Mental health problems in people with learning disabilities
 Appendix B: Declarations of interests by Guideline Committee members

Guideline Committee – declarations of interest	
Employment	Systematic Reviewer
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Emma Seymour	
Employment	Research Assistant
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Jo Wolfreys	
Employment	Project Manager
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Mrs Katherine Andrea	
Employment	Senior Project Manager
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Eva Gautam Aitken	
Employment	Project Manager
Personal pecuniary interest	None
Personal Family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Tina Johnson	
Employment	Project Manager

Mental health problems in people with learning disabilities
Appendix B: Declarations of interests by Guideline Committee members

Guideline Committee – declarations of interest	
Personal pecuniary interest	None
Personal Family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None

Appendix C: Special advisors to the Guideline Committee

Those who acted as advisors on specialist topics or have contributed to the process by meeting the Guideline Development Group:

Professor Andrew Jahoda

Professor Dave Dagnan

Dr Jacqui Rodgers

Dr Vicki Grahame

Appendix D: Stakeholders who submitted comments in response to the consultation draft of the guideline

5 Boroughs Partnership NHS Foundation Trust
Action on Hearing Loss
Bradford District care NHS Foundation Trust
British Academy of Childhood Disability
British Association of Art Therapists
British Association of Dramatherapy
British Association of Music Therapy
British Institute of Learning Disabilities
British Psychological Society
College of Mental Health Pharmacy
Home Farm Trust (HFT)
Home Group
HQT Diagnostics
Humber NHS Foundation Trust
IND
Islington Learning Disability Partnership, Camden & Islington NHS Foundation trust
London Fire & Emergency Planning Authority
Mencap
Mental Health Foundation

Mental health problems in people with learning disabilities
Appendix D: Stakeholders who submitted comments in response to the consultation draft of the guideline

The National Development Team for Inclusion (NDTi)
Norfolk and Suffolk NHS Foundation Trust
Nottinghamshire Healthcare NHS foundation trust
Partnerships In Care
Public Health England Learning Disabilities Observatory
Royal College of General Practitioners
Royal College of Nursing
Royal College of Paediatrics and Child Health
Royal College of Psychiatrists
Shared Lives Plus
South Staffordshire and Shropshire NHS Foundation Trust
Southern Health NHS Foundation Trust
Tees Esk and Wear Valleys NHS Foundation Trust

Appendix E: Researchers contacted to request information about unpublished or soon-to-be published studies

Prof. Nigel Beail
Dr Betsey Benson
Prof. Dave Dagnan
Prof. Petri Embregts
Dr Anna Esbensen
Dr Kylie Gray
Dr Sigan Hartley
Prof. Andrew Jahoda
Dr Biza Kroese
Prof. Bill Lindsay
Dr Bill Maclean
Prof. Jane McGillivray Prof. John Rose
Prof. Carlo Schuengel
Nirbhay Singh
Dr Jonathan Weiss

Appendix F: Review questions and final review protocols

F.1 Review questions

RQ	Review question
1.1	What is the incidence and prevalence of mental health disorders in people (children, young people and adults) with learning disabilities?
1.2	What are the most appropriate methods/instruments for case identification of mental health problems in people (children, young people and adults) with learning disabilities?
1.3	<p>In people (children, young people and adults) with learning disabilities, what are the key components of, and the most appropriate structure for, an assessment of mental health problems?</p> <p>To answer this question, consideration should be given to:</p> <ul style="list-style-type: none"> - the nature and content of the interview and observation - formal diagnostic methods/psychological instruments for the assessment of mental health problems - the setting(s) in which the assessment takes place - the role of the any informants - severity of LD - diagnostic overshadowing - genetic syndromes.
2.1	In people (children, young people and adults) with learning disabilities, do psychological interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.2	In people (children, young people and adults) with learning disabilities, do social and environmental interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.3	In people (children, young people and adults) with learning disabilities, do personal and support strategies in community and residential settings which are aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.4	In people (children, young people and adults) with learning disabilities, do pharmacological interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.5	In people (children, young people and adults) with learning disabilities, do dietary interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?

RQ	Review question
2.6	In people (children, young people and adults) with learning disabilities, do other multidisciplinary therapies aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.7	In people (children, young people and adults) with learning disabilities, do combined interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.8	In people (children, young people and adults) with learning disabilities, do occupational interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.9	In people (children, young people and adults) with learning disabilities, do community interventions (for example, to reduce stigma or hate crimes) aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.10	In people (children, young people and adults) with learning disabilities, does psychoeducation aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.11	In people (children, young people and adults) with learning disabilities, do annual health checks aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.12	In people (children, young people and adults) with learning disabilities, does family carer or staff training aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
2.13	In people (children, young people and adults) with learning disabilities, do exercise interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.1	In people (children, young people and adults) with learning disabilities and mental health problems, do psychological interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.2	In people (children, young people and adults) with learning disabilities and mental health problems, do social and physical environmental interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.3	In people (children, young people and adults) with learning disabilities and mental health problems, do personal and support strategies in community and residential settings which are aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.4	In people (children, young people and adults) with learning disabilities and mental health problems, do pharmacological interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.5	In people (children, young people and adults) with learning disabilities and mental health problems, do dietary interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?

RQ	Review question
3.6	In people (children, young people and adults) with learning disabilities and mental health problems, do other multidisciplinary therapies aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.7	In people (children, young people and adults) with learning disabilities and mental health problems, do combined interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.8	In people (children, young people and adults) with learning disabilities and mental health problems, do occupational interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.9	In people (children, young people and adults) with learning disabilities and mental health problems, do community interventions (for example, to reduce stigma or hate crimes) aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.10	In people (children, young people and adults) with learning disabilities and mental health problems, does psychoeducation aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
3.11	In people (children, young people and adults) with learning disabilities and mental health problems, do exercise interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?
4.1	In people (children, young people and adults) with learning disabilities and mental health problems, do interventions aimed at improving accessibility of services (e.g., by removing barriers) produce benefits that outweigh possible harms when compared to an alternative approach?
4.2	In people (children, young people and adults) with learning disabilities and mental health problems, what are the effective models or support for transition between services (for example, young person to adult, adult to older adult, NHS to social care/residential)?
4.3	What is the best approach with regard to the coordination and communication with key persons and services in the life of the person with learning disabilities and mental health problems?
4.4	What are the most appropriate strategies to engaging the family and staff/advocate of people with learning disabilities in the design, implementation and monitoring of interventions for that person's mental health problems?
4.5	What are the most appropriate strategies to engage and empower service users with learning disabilities in the design, implementation and monitoring of interventions for that person's mental health problems?
4.6	What are the most appropriate service structures, training and supervision to support practitioners in the effective delivery of interventions for people (children, young people and adults) with learning disabilities and mental health problems?

RQ	Review question
5.1	In family carers and staff caring for people (children, young people and adults) with learning disabilities and mental health problems, which interventions, training and support improve the health and well-being of the family and staff as well as that of the person with learning disabilities when compared to an alternative approach?

F.2 Review protocols

F.2.1 Case identification (RQ1.1)

Item No.	Item	Details
Guideline details		
1.	Guideline*	Mental health problems in people with learning disabilities guideline
2.	Guideline chapter*	Chapter 4: Identification and assessment of mental health problems
3.	Objective of review*	To determine which mental health problems are more common in people with learning disabilities and in which populations (that is, different severities of learning disabilities, children and young people or adults, underlying phenotypes) in order to aid early identification.
Review methods		
4.	Review question(s) *	RQ1.1: What is the incidence and prevalence of mental health disorders in people (children, young people and adults) with learning disabilities?
5.	Sub-question(s)	n/a
6.	Searches*	<p>Search 1 Embase (inception to December 2016), Medline (inception to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (inception to December 2016)</p> <p>Search 2 and 3: updates Buckles, J. et al (2013) and Enfield, J. et al (2013) Embase (2010 to December 2016), Medline (2010 to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (2010 to December 2016)</p> <p>Other sources of evidence:</p>

		<ul style="list-style-type: none"> • Reference lists of included studies • Calls for evidence from registered stakeholders • PROSPERO (http://www.crd.york.ac.uk/Prospero/) • Conference abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Dissertation titles/abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full <p>Non-English language papers (with English abstracts) will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in an English language journal. Note. Unpublished data will only be included where a full trial report is available with sufficient detail to properly assess the risk of bias. Authors of unpublished evidence will be asked for permission to use such data, and will be informed that summary data from the study and the study's characteristics will be published in the full guideline.</p>
7.	Condition or domain being studied*	<p>Learning disabilities and mental health problems</p> <p>Definitions:</p> <ul style="list-style-type: none"> • Learning disabilities: <ul style="list-style-type: none"> ○ Heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood. This corresponds to 'intellectual disability' as described in the major taxonomy DSM-5 (American Psychiatric Association, 2013) and 'mental retardation' in ICD-10 (WHO, 1992). • Mental health problems (as defined in the guideline).

8.	Participants/ population*	<p>Included:</p> <p>People (children, young people and adults) with or without learning disabilities</p> <p>Excluded:</p> <ul style="list-style-type: none"> • studies which also include patients with borderline intelligence (IQ between 71 and 84), where results for those with and without learning disabilities have not been presented separately, and when less than 80% of the patients included have learning disabilities (or using IQ of 70 as a cut-off for learning disabilities, if the study does not describe the proportion with learning disabilities) <p>If possible, results will be stratified by the following:</p> <ul style="list-style-type: none"> • Age: adults (18 years or older), children and young people (under 18 years), all ages combined. • Underlying cause of learning disability, such as: Down’s syndrome, Fragile X syndrome, Prader-Willi syndrome, Learning disabilities (not otherwise specified). • Severity of learning disabilities: <ul style="list-style-type: none"> ○ Adults: mild = IQ 50-69, moderate = IQ 35-49, severe = IQ 20-34, or profound = IQ <20 (or as categorised by the studies). ○ Children: categorised by IQ above or severity as categorised by the studies. • Source of study sample: population-based or from other sources (that is, registry, school).
	Exposure(s)*	Presence of a learning disability
9.	Comparator(s)/ control*	<p>Included:</p> <p>People (children, young people and adults) without learning disabilities</p> <p>Excluded: None</p>
10.	Types of study to be included initially*	<p>Included:</p> <ul style="list-style-type: none"> • Reviews conducted for existing guidelines and published systematic reviews. • If no existing systematic reviews address the review question, individual prospective or retrospective cohorts and cross-sectional studies may be considered. A stepped approach will be made for each area, depending on the availability of evidence.

		<ul style="list-style-type: none"> Excluded: Case series or case reports, studies with N <100 (the study size exclusion was added after the protocol was initially set as it was felt that studies with sample sizes than 100 people were unlikely to be able to adequately estimate incidence or prevalence). <p>[post-hoc note: the group later decided to exclude studies where the risk or the incidence and prevalence were determined from specific populations (such as, inpatient only settings), unless it was for a specific genetic phenotype (such as, databases of all people with a particular genotype in a geographical area); population-based studies and administrative studies were included but presented separately.]</p>
11.	Context*	<p>Included: All settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.</p> <p>Excluded: none</p>
12.	Primary/Critical outcomes*	<p>Difference in risk of mental health problems (relative risk preferred but odds ratio also extracted if only outcome provided)</p> <p>Incidence or prevalence of mental health problems</p>
13.	Secondary/Important, but not critical outcomes*	n/a
14.	Data extraction (selection and coding)*	<p>Citations from each search will be downloaded into EndNote and duplicates removed. Records will then be screened independently by two reviewers against the eligibility criteria of the review (if there is disagreement, resolution will be by discussion or a third reviewer). However, if search results are large (greater than 1000), all records will be screened by one reviewer and another reviewer will screen 10% of all references; inter-rater reliability will be assessed and reported in the guideline. The unfiltered search results will be saved and retained for future potential re-analysis. All primary-level studies included after the first scan of citations will be acquired in full and re-evaluated for eligibility at the time they are being entered into a study database (standardised template created in Microsoft Excel). Eligibility will be confirmed by at least one member of the Guideline Committee (GC). The GC are experts in the topic and/or research methodology. Two researchers will extract data into the study database, comparing a sample of each other's work for reliability. Discrepancies or difficulties with coding will be resolved through discussion with members of the GC.</p>

		<p>Data to be extracted:</p> <p>Study characteristics (Study ID, Year, Study design, Context [locality, rural/urban, country], recruitment [recruitment location, approached N, completed screening N, exclusion rate, screening format, screening admin, diagnostic system, diagnostic method/method used to define population as having a learning disability], inclusion/exclusion criteria, demographics of both groups [age, sex, race, IQ, etc], funding, publication type, references, risk of bias)</p> <p>Outcomes (outcome type, outcome name, data type, rater, outcome data).</p>
15.	Risk of bias (quality) assessment*	The quality of individual studies will be assessed using the appropriate NICE quality assessment checklist. The quality of evidence will be assessed by individual study, using the approach recommended in the NICE manual.
16.	Strategy for data synthesis*	<p>If existing reviews are found, the review team with advice from the Guideline Committee (GC) will assess their quality, completeness, and applicability and relevance to the scope of the guideline. If the GC agree that a systematic review appropriately addresses a review question, the GC will consider searching for studies conducted or published since the review was conducted, and the GC will assess if any additional studies would likely affect the conclusions of the existing review. If new studies are likely to change the conclusions, we will update the review and conduct a new analysis. If new studies could not change the conclusions of an existing review, the GC will use the existing review to inform their recommendations.</p> <p>Results will be presented as a narrative synthesis. If possible, results will be summarised appropriately (such as a median and range of prevalence from included studies).</p> <p>For areas with no evidence or limited evidence, formal consensus methods will be considered.</p>
17.	Analysis of subgroups or subsets (including sensitivity analyses)	<p>The following sensitivity analyses will be explored to test the robustness of the findings:</p> <ul style="list-style-type: none"> • Exclude studies which include some people without learning disabilities (<20%) were included and where results have not been presented separately for those who do and do not have a learning disability.
18.	Type of review	Epidemiological

Further information		
	Existing reviews utilised in this review:	
19.	<ul style="list-style-type: none"> • Updated 	None.
20.	<ul style="list-style-type: none"> • Not updated 	<p>The following systematic reviews on general psychopathology will be used to identify the published literature up until the search date within the reviews and a search for primary studies which have been published after the reviews' search dates will be conducted. Each primary study included within these reviews will be obtained and examined individually against inclusion criteria and, if the study is subsequently included, data will be extracted from the primary study.</p> <p>Adults: Buckles JR, Luckasson R, Keefe E. A systematic review of the prevalence of psychiatric disorders in adults with intellectual disability, 2003-2010. <i>Journal of Mental Health Research in Intellectual Disabilities</i>. 2013;6:181-207 (search completed in 2010)</p> <p>This review excluded all papers included in the following two reviews so the primary papers from these reviews were also obtained for application against inclusion criteria:</p> <ul style="list-style-type: none"> • Kerker BD, Owens LO, Zigler E, Horwitz SM. Mental health disorders among individuals with mental retardation: challenges to accurate prevalence estimates. <i>Public Health Reports</i>. 2004;119:409-17. • Whitaker S, Read S. The prevalence of psychiatric disorders among people with intellectual disabilities: an analysis of the literature. <i>Journal of Applied Research in Intellectual Disabilities</i>. 2006;19:330-45. <p>Children: Einfeld SL, Ellis LA, Emerson E. Comorbidity of intellectual disability and mental disorder in children and adolescents: a systematic review. <i>Journal of Intellectual & Developmental Disability</i>. 2011;36:137-43 (search completed 2008)</p>

F.2.2 Case identification methods and instruments (RQ1.2)

Item No.	Item	Details
Guideline details		
1.	Guideline*	Mental health problems in people with learning disabilities guideline
2.	Guideline chapter*	Chapter 4: Identification and assessment of mental health problems
3.	Objective of review*	To determine the most appropriate methods or instruments to use to identify people with learning disabilities who may have a mental health problem and would benefit from further assessment. These methods or instruments would normally be of short duration, would not require specific training to administer, and those who are identified as possibly having a mental health problem would likely go on to further, more detailed assessment (see RQ1.3 for the full assessment).
Review methods		
4.	Review question(s) *	RQ1.2: What are the most appropriate methods/instruments for case identification of mental health problems in people (children, young people and adults) with learning disabilities?
5.	Sub-question(s)	n/a
6.	Searches*	<p>Embase (inception to December 2016), Medline (inception to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (inception to December 2016)</p> <p>Other sources of evidence:</p> <ul style="list-style-type: none"> • Reference lists of included studies • Calls for evidence from registered stakeholders • PROSPERO (http://www.crd.york.ac.uk/Prospero/)

		<ul style="list-style-type: none"> • Conference abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Dissertation titles/abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Non-English language papers (with English abstracts) will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in an English-language journal. <p>Note. Unpublished data will only be included where a full trial report is available with sufficient detail to properly assess the risk of bias. Authors of unpublished evidence will be asked for permission to use such data, and will be informed that summary data from the study and the study’s characteristics will be published in the full guideline.</p>
7.	Condition or domain being studied*	<p>Learning disabilities and mental health problems</p> <p>Definitions:</p> <ul style="list-style-type: none"> • Learning disabilities: <ul style="list-style-type: none"> ○ Heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood. This corresponds to ‘intellectual disability’ as described in the major taxonomy DSM-5 (American Psychiatric Association, 2013) and ‘mental in ICD-10 (WHO, 1992). • Mental health problems (as defined in the guideline).
8.	Participants/ population*	<p>Included:</p> <p>People (children, young people and adults) with learning disabilities</p> <p>Excluded:</p> <ul style="list-style-type: none"> • studies which also include patients with borderline intelligence (IQ between 71 and 84), where results for those with and without learning disabilities have not been presented separately, and when less than 80% of the patients included have learning disabilities (or using IQ of 70 as a cut-off for learning disabilities, if the study does not describe the proportion with learning disabilities) • people who are suspected of having a mental health problem and who require more detailed assessment to confirm the presence of a mental health problem with a diagnosis (see RQ1.3)

		<p>If possible, results will be stratified by the following:</p> <ul style="list-style-type: none"> • Age: Adults (18 years or older), children and young people (under 18 years), all ages combined. • Underlying cause of learning disability, such as: Down's syndrome, Fragile X syndrome, Prader-Willi syndrome, learning disabilities (not otherwise specified). • Severity of learning disabilities: <ul style="list-style-type: none"> ○ Adults: mild = IQ 50-69, moderate = IQ 35-49, severe = IQ 20-34 or profound = IQ <20 (or as categorised by the studies) ○ Children: severity is likely to be categorised by the studies, not by IQ; use as described in studies
9.	Index test	<p>Included: brief methods/instruments for case identification (for example, with no more than 3 items or lasting no longer than 10 minutes)</p> <p>Excluded: methods or instruments that are more comprehensive and require more time to administer (see RQ1.3 below).</p>
10.	Comparator(s)/control /reference standard	<p>Included:</p> <p>Diagnosis from full psychiatric or psychological assessment</p> <p>Excluded: None</p>
11.	Target condition	<p>Mental health problems (as defined in the guideline).</p> <p>Results will be stratified by different mental health problems, if possible.</p>

12.	Types of study to be included initially*	<p>Included:</p> <p>Reviews conducted for existing guidelines and published systematic reviews</p> <p>If no existing systematic reviews address the review question, individual cross-sectional studies may be considered. Studies considering individual symptoms may also be considered in areas where no tools have been found. A stepped approach will be made for each area, depending on the availability of evidence.</p> <p>The range of included studies may be expanded to case-control studies if evidence from cross-sectional studies is limited such as in numbers of included participants.</p> <p>Excluded: Other study designs including case series or case reports</p>
13.	Context*	<p>Included: All settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.</p> <p>Excluded: none</p>
14.	Primary/Critical outcomes*	<p>Sensitivity and specificity</p> <p>Validity and reliability (while sensitivity and specificity are usually the most valuable for case identification instruments, validity and reliability were felt to be particularly important in the learning disabilities population where it is difficult to administer tests and where tools used in the general population may not be appropriate)</p>
15.	Secondary/Important, but not critical outcomes*	n/a
16.	Data extraction (selection and coding)*	<p>Citations from each search will be downloaded into EndNote and duplicates removed. Records will then be screened independently by two reviewers against the eligibility criteria of the review (if there is disagreement, resolution will be by discussion or a third reviewer). However, if search results are large (that is, greater than 1000), all records will be screened by one reviewer and another reviewer will screen 10% of all references; inter-rater reliability will be assessed and reported in the guideline. The unfiltered search results will be saved and retained for future potential re-analysis.</p>

		<p>All primary-level studies included after the first scan of citations will be acquired in full and re-evaluated for eligibility at the time they are being entered into a study database (standardised template created in Microsoft Excel). Eligibility will be confirmed by at least one member of the Guideline Committee (GC). The GC are experts in the topic and/or research methodology. Two researchers will extract data into the study database, comparing a sample of each other's work for reliability. Discrepancies or difficulties with coding will be resolved through discussion with members of the GC.</p> <p>Data to be extracted:</p> <p>Study characteristics (Study ID, Year, method or instrument, Context [Locality, Rural/Urban, Country], Recruitment [Recruitment location, Approached N, Completed screening N, Randomised N, Exclusion rate, Screening format, Screening admin, Diagnostic system, Diagnostic method/method used to define population as having a learning disability], Inclusion/exclusion criteria, Group assignment [number of groups, randomisation, N cluster], Demographics [age, sex, race, IQ, etc], Funding, Publication type, References, Risk of bias [patient selection and generalisability, Blinding, Missing outcome data, time interval between index and reference standard, any interventions in this interval])</p> <p>Comparisons (N, N post-treatment, N follow-up [if relevant], Test/Reference standard [including if self-report or informant/proxy and who it was completed by such as paid carer/professional/informal carer/family member], Target group, Group size, Admin setting of each [ie. GP, school, hospital], Admin who, Admin quality, Supervision, interval between tests)</p> <p>Outcomes (Outcome type, Outcome name, Data type, Rater, Outcome data).</p>
17.	Risk of bias (quality) assessment*	The quality of individual studies will be assessed using the appropriate NICE quality assessment checklist.
18.	Strategy for data synthesis*	<p>Where appropriate, meta-analysis will be used to combine results from similar studies (for example, in a summary receiver operating characteristic curve (SROC) and coupled forest plots). Initially, a fixed-effects model will be used but a random-effects model may be used if there is unexplained heterogeneity. If this is done, RevMan and Meta-DiSc will be used. Paired data will be used in the primary analysis.</p> <p>If a meta-analysis is not appropriate, a narrative synthesis will be used.</p>

		<p>If existing reviews are found, the review team with advice from the Guideline Committee (GC) will assess their quality, completeness, and applicability and relevance to the scope of the guideline. If the GC agree that a systematic review appropriately addresses a review question, the GC will consider searching for studies conducted or published since the review was conducted, and the GC will assess if any additional studies would likely affect the conclusions of the existing review. If new studies are likely to change the conclusions, we will update the review and conduct a new analysis. If new studies could not change the conclusions of an existing review, the GC will use the existing review to inform their recommendations.</p> <p>For areas with no evidence or limited evidence, formal consensus methods will be considered.</p>
19.	Analysis of subgroups or subsets (including sensitivity analyses)	<p>The following sensitivity analyses will be explored to test the robustness of the findings:</p> <ul style="list-style-type: none"> Exclude studies that do not contain full details confirming eligibility (for example, they do not describe the reference standard). <p>Subgroup analyses will be explored if there is heterogeneity in the results.</p>
20.	Type of review	Diagnostic accuracy
Further information		
	Existing reviews utilised in this review:	
21.	<ul style="list-style-type: none"> Updated 	None
22.	<ul style="list-style-type: none"> Not updated 	None

F.2.3 Structure for assessment (RQ1.3)

Item No.	Item	Details
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Guideline details		
1.	Guideline*	Mental health problems in people with learning disabilities guideline
2.	Guideline chapter*	Chapter 4: Identification and assessment of mental health problems
3.	Objective of review*	To determine what the key components of an assessment of mental health problems are and how should these be delivered (in what order and in what context). This may include methods and instruments used for full assessment of mental health problems used for diagnosis or assessment of the response to treatment.
Review methods		
4.	Review question(s) *	RQ1.3: In people (children, young people and adults) with learning disabilities, what are the key components of, and the most appropriate structure for, an assessment of mental health problems?
5.	Sub-question(s)	n/a

6.	Searches*	<p>Embase (inception to December 2016), Medline (inception to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (inception to December 2016)</p> <p>Other sources of evidence:</p> <ul style="list-style-type: none"> • Reference lists of included studies • Calls for evidence from registered stakeholders • PROSPERO (http://www.crd.york.ac.uk/Prospero/) • Conference abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Dissertation titles/abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Non-English language papers (with English abstracts) will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in an English language journal. <p>Note. Unpublished data will only be included where a full trial report is available with sufficient detail to properly assess the risk of bias. Authors of unpublished evidence will be asked for permission to use such data, and will be informed that summary data from the study and the study's characteristics will be published in the full guideline.</p>
7.	Condition or domain being studied*	<p>Learning disabilities and mental health problems</p> <p>Definitions:</p> <ul style="list-style-type: none"> • Learning disabilities: <ul style="list-style-type: none"> ○ Heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood. This corresponds to 'intellectual disability' as described in the major taxonomy DSM-5 (American Psychiatric Association, 2013) and 'mental retardation' in ICD-10 (WHO, 1992). • Mental health problems (as defined in the guideline).

8.	Participants/ population*	<p>Included:</p> <p>People (children, young people and adults) with learning disabilities who are suspected of having mental health problems.</p> <p>Excluded:</p> <ul style="list-style-type: none"> • studies which also include patients with borderline intelligence (IQ between 71 and 84), where results for those with and without learning disabilities have not been presented separately, and when less than 80% of the patients included have learning disabilities (or using IQ of 70 as a cut-off for learning disabilities, if the study does not describe the proportion with learning disabilities). <p>If possible, results will be stratified by the following:</p> <ul style="list-style-type: none"> • Age: Adults (18 years or older), children and young people (under 18 years), all ages combined • Underlying cause of learning disability, such as: Down’s syndrome, Fragile X syndrome, Prader-Willi syndrome, Learning disabilities (not otherwise specified) • Severity of learning disabilities: <ul style="list-style-type: none"> ○ Adults: mild = IQ 50-69, moderate = IQ 35-49, severe = IQ 20-34 or profound = IQ <20 (or as categorised by the studies) ○ Children: severity is likely to be categorised by the studies, not by IQ; use as described in studies
9.	Prior tests	Any tests used for case identification (see RQ1.2 above)
10.	Intervention(s), exposure(s), index tests	<p>Included: methods for assessment of mental health problems.</p> <p>Instruments/tools included:</p> <p>Personality disorders:</p> <p>CIRCLE (using Circumplex Model of Interpersonal Behaviour)</p> <p>Interpersonal Adjective Scale (IES) (using Circumplex Model of Interpersonal Behaviour)</p> <p>International personality disorder examination</p>

		<p>NEO Personality Inventory (using five factor model of personality)</p> <p>Personality Disorder Characteristics Checklist (PDCC)</p> <p>Psychopathy Checklist – Revised (PCL-R & PCL-SV)</p> <p>Standardised Assessment of Personality (SAP)</p> <p>Standardised Assessment of Personality – Abbreviated Scale (SAPAS) (short-form of SAP)</p> <p>Brief Non-Verbal Personality Questionnaire (FF-NPQ)</p> <p>Edward Zigler Personality Questionnaire (EZPQ)</p> <p>Anger:</p> <p>Novaco Anger Scale (NAS)</p> <p>Provocation Inventory (PDI)</p> <p>Modified Overt Aggression Scale (MOAS)</p> <p>Trauma:</p> <p>Bangor Life Events Schedule for Intellectual Disabilities (BLESID)</p> <p>The Lancaster and Northgate Trauma Scales (LANTS)</p> <p>Post-traumatic stress disorder:</p> <p>Lancaster and Northgate Trauma Scales (LANTS)</p> <p>Impact of Event Scale-Intellectual disabilities (IES-ID)</p>
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		<p>Posttraumatic Diagnostic Scale (PDS)</p> <p>Anxiety:</p> <p>Anxiety, Depression and Mood Scale (ADAMS)</p> <p>Fear Survey for Adults with Mental Retardation (FSAMR)</p> <p>Mood and anxiety semi-structured interview (MASS)</p> <p>Glasgow Anxiety Scale (GAS-ID)</p> <p>Hospital Anxiety and Depression Scale (HADS) – adapted</p> <p>Zung anxiety scale – adapted</p> <p>Depression:</p> <p>Anxiety, Depression and Mood Scale (ADAMS)</p> <p>Children’s Depression Inventory (CDI) – adapted</p> <p>Glasgow Depression Scale – carer supplement (GAS-CS)</p> <p>Mood and anxiety semi-structured interview (MASS)</p> <p>Mood, interest and pleasure questionnaire (MIPQ)</p> <p>Intellectual disability depression scale (Evans)</p> <p>Beck Depression Inventory (BDI) – adapted</p> <p>Glasgow Depression Scale for people with a learning disability (GAS-LD)</p> <p>Hospital Anxiety and Depression Scale (HADS) – adapted</p>
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		<p>Self-Report Depression Questionnaire (SRDQ)</p> <p>Zung self-rating depression scale (adapted)</p> <p>General psychopathology:</p> <p>Assessment of Dual Diagnosis (ADD)</p> <p>Child Behaviour Checklist (CBCL)</p> <p>CORE-LD</p> <p>Developmental behaviour checklist (DBC) – children</p> <p>Developmental behaviour checklist (DBC) – adults</p> <p>Diagnostic Assessment for the Severely Handicapped (DASH and DASH-II)</p> <p>Psychopathology in Autism Checklist (PAC)</p> <p>Psychopathology Checklist for Adults with Intellectual Disability (P-AID)</p> <p>Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) checklist</p> <p>Mini Psychiatric Assessment Schedule for Adults with a Developmental Disability (Mini PAS-ADD)</p> <p>Reiss Screen for Maladaptive Behaviour (RSMB)</p> <p>Reiss scales for children’s dual diagnosis</p> <p>Strength and Difficulties Questionnaire (SDQ)</p> <p>Brief symptom inventory</p> <p>Psychiatric Assessment Schedule for Adults with a Developmental Disability (PAS-ADD) – Clinical interview</p>
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		<p>Psychopathology Instrument for Mentally Retarded Adults (PIMRA)</p> <p>Health of the Nation Outcome Scales for People with Learning Disabilities (HONOS-LD)</p> <p>Instruments for assessing outcomes after treatment or risk assessment:</p> <p>Adaptive Behaviour Scale (ABS)</p> <p>Adaptive Behaviour Assessment System (ABAS)</p> <p>Clinical Global Impression/improvement scale (CGI)</p> <p>Communication Assessment Profile (CASP)</p> <p>Global assessment of function (GAF)</p> <p>Health of the Nation Outcome Scales for People with Learning Disabilities (HoNoS-LD)</p> <p>Guernsey scale</p> <p>Historical, Clinical, Risk Management-20 (HCR20)</p> <p>Structured Assessment of Protective Factors for violence risk (SAPROF)</p> <p>START Short term assessment of Risk and Treatability</p> <p>Vineland Adaptive Behaviour Scale (VABS)</p> <p>Dementia:</p> <p>The adaptive behaviour dementia questionnaire (ABDQ): screening questionnaire for dementia in Alzheimer’s disease in adults with Down syndrome</p> <p>Dementia Questionnaire for mentally retarded persons (DMR), now Dementia Questionnaire for People with Learning Disabilities (DLD)</p>
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		<p>Down Syndrome Dementia Scale (DSDS)</p> <p>Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)</p> <p>Early Signs of Dementia Checklist</p> <p>Short Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)</p> <p>Cambridge Cognitive Examination (CAMCOG) / CAMCOG-DS?</p> <p>Modified Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) / CAMDEX-DS?</p> <p>Dalton's Brief Praxis Test (BPT)</p> <p>Neuropsychological Assessment of Dementia in Adults with Intellectual Disabilities (NAID)</p> <p>Tools to assess outcomes (dementia):</p> <p>Assessment of Motor and Process Skills (AMPS)</p> <p>Cued Recall Test (CRT)</p> <p>Dementia Rating Scale (DRS)</p> <p>Down Syndrome Mental Status Examination (DSMSE)</p> <p>Evaluation of Mental Status</p> <p>Hampshire Social Services – Staff Support Levels Assessment</p> <p>Severe Impairment Battery (SIB)</p> <p>Test for severe impairment (TSI)</p>
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		<p>Tools specifically relating to communication:</p> <p>Assessment of Comprehension and Expression (ACE)</p> <p>Test for the Reception of Grammar (TROG)</p> <p>Sentence Comprehension Test</p> <p>Routes for Learning</p> <p>The Pragmatics Profile (Dewart and Summers)</p> <p>Preverbal Schedule (PVC)</p> <p>Clinical Evaluation of Language Fundamentals (CELF)</p> <p>British Picture Vocabulary Scale (BPVS 3)</p> <p>Excluded: shorter instruments that are used for case identification (see RQ1.2 above).</p>
11.	Comparator(s)/ control, reference standard	<p>Included:</p> <p>Diagnosis from full psychiatric or psychological assessment (for studies assessing risk of an event such as violence, the reference standard was the occurrence of the event)</p> <p>Excluded: None</p>
12.	Target condition	<p>Mental health problems (as defined in the guideline).</p> <p>Results will be stratified by mental health problem, if possible.</p>

13.	Types of study to be included initially*	<p>Included:</p> <p>Reviews conducted for existing guidelines and published systematic reviews</p> <p>If no existing systematic reviews address the review question, individual prospective or retrospective cohorts and cross-sectional studies may be considered. A stepped approach will be made for each area, depending on the availability of evidence.</p> <p>Excluded: Other study designs including case series or case reports</p> <p>[post-hoc note: studies including reliability data only and which did not include the appropriate reference standard were excluded]</p>
14.	Context*	<p>Included: All settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.</p> <p>Excluded: none</p>
15.	Primary/Critical outcomes*	<p>Sensitivity and specificity</p> <p>Validity and reliability (validity and reliability were felt to be particularly important in the learning disabilities population where it is difficult to administer tests and where tools used in the general population may not be appropriate)</p> <p>For consideration of the key components, and the most appropriate structure, consideration will be given to:</p> <ul style="list-style-type: none"> • the nature and content of the interview and observation • formal diagnostic methods/psychological instruments for the assessment of mental health problems • the setting(s) in which the assessment takes place • the role of the any informants

		<ul style="list-style-type: none"> • severity of learning disability • diagnostic overshadowing • genetic syndromes.
16.	Secondary/Important, but not critical outcomes*	n/a
17.	Data extraction (selection and coding)*	<p>Citations from each search will be downloaded into EndNote and duplicates removed. Records will then be screened independently by two reviewers against the eligibility criteria of the review (if there is disagreement, resolution will be by discussion or a third reviewer). However, if search results are large (that is, greater than 1000), all records will be screened by one reviewer and another reviewer will screen 10% of all references; inter-rater reliability will be assessed and reported in the guideline. The unfiltered search results will be saved and retained for future potential re-analysis. All primary-level studies included after the first scan of citations will be acquired in full and re-evaluated for eligibility at the time they are being entered into a study database (standardised template created in Microsoft Excel). Eligibility will be confirmed by at least one member of the Guideline Committee (GC). The GC are experts in the topic and/or research methodology. Two researchers will extract data into the study database, comparing a sample of each other's work for reliability. Discrepancies or difficulties with coding will be resolved through discussion with members of the GC.</p> <p>Data to be extracted:</p> <p>Study characteristics (Study ID, Year, method or instrument, Context [Locality, Rural/Urban, Country], Recruitment [Recruitment location, Approached N, Completed screening N, Randomised N, Exclusion rate, Screening format, Screening admin, Diagnostic system, Diagnostic method/method used to define population as having a learning disability], Inclusion/exclusion criteria, Group assignment [number of groups, randomisation, N cluster], Demographics [age, sex, race, IQ, etc], Funding, Publication type, References, Risk of bias [patient selection and generalisability, Blinding, Missing outcome data, time interval between index and reference standard, any interventions in this interval])</p> <p>Comparisons (N, N post-treatment, N follow-up [if relevant], Test/Reference standard [including if self-report or informant/proxy and who it was completed by such as paid carer/professional/informal carer/family member], Target</p>

		<p>group, Group size, Admin setting of each [ie. GP, school, hospital], Admin who, Admin quality, Supervision, interval between tests)</p> <p>Outcomes (Outcome type, Outcome name, Data type, Rater, Outcome data).</p>
18.	Risk of bias (quality) assessment*	The quality of individual studies will be assessed using the appropriate NICE quality assessment checklist.
19.	Strategy for data synthesis*	<p>For studies on key components of an assessment of mental health problems are and how should these be delivered: The GC will use a consensus-based approach to identify the key components of an effective assessment</p> <p>For studies on methods and instruments: Where appropriate, meta-analysis will be used to combine results from similar studies (for example, in a summary receiver operating characteristic curve (SROC) and coupled forest plots). Initially, a fixed-effects model will be used but a random-effects model may be used if there is unexplained heterogeneity. If this is done, RevMan and Meta-DiSc will be used. Paired data will be used in the primary analysis.</p> <p>If a meta-analysis is not appropriate, a narrative synthesis will be used.</p> <p>If existing reviews are found, the review team with advice from the Guideline Committee (GC) will assess their quality, completeness, and applicability and relevance to the scope of the guideline. If the GC agree that a systematic review appropriately addresses a review question, the GC will consider searching for studies conducted or published since the review was conducted, and the GC will assess if any additional studies would likely affect the conclusions of the existing review. If new studies are likely to change the conclusions, we will update the review and conduct a new analysis. If new studies could not change the conclusions of an existing review, the GC will use the existing review to inform their recommendations.</p> <p>For areas with no evidence or limited evidence, formal consensus methods will be considered.</p>

20.	Analysis of subgroups or subsets (including sensitivity analyses)	<p>The following sensitivity analyses will be explored to test the robustness of the findings:</p> <ul style="list-style-type: none"> Exclude studies that do not contain full details confirming eligibility (for example, they do not describe the reference standard). <p>Subgroup analyses will be explored if there is heterogeneity in the results.</p>
21.	Type of review	Other (elements on methods and instruments: diagnostic accuracy)
Further information		
	Existing reviews utilised in this review:	
22.	<ul style="list-style-type: none"> Updated 	None
23.	<ul style="list-style-type: none"> Not updated 	None

F.2.4 Interventions to prevent mental health problems (RQ2.1–2.13)

Item No.	Item	Details
	Guideline details	
	Guideline	Mental health problems in people with learning disabilities guideline
	Guideline chapter	Chapters 5 (Psychological interventions to prevent, treat and manage mental health problems), 6 (Pharmacological interventions to prevent, treat and manage mental health problems), and 7 (Other interventions to prevent, treat and manage mental health problems)
	Objective of review	To determine the best intervention/strategy to prevent specific mental health problems in people with learning disabilities.

Item No.	Item	Details
	Review methods	
	Review question(s)	<p>RQ2.1: In people (children, young people and adults) with learning disabilities, do psychological interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.2: In people (children, young people and adults) with learning disabilities, do social and environmental interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.3: In people (children, young people and adults) with learning disabilities, do personal and support strategies in community and residential settings which are aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.4: In people (children, young people and adults) with learning disabilities, do pharmacological interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.5: In people (children, young people and adults) with learning disabilities, do dietary interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.6: In people (children, young people and adults) with learning disabilities, do other multidisciplinary interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.7: In people (children, young people and adults) with learning disabilities, do combined interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.8: In people (children, young people and adults) with learning disabilities, do occupational interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p>

Item No.	Item	Details
		<p>RQ2.9: In people (children, young people and adults) with learning disabilities, do community interventions (for example, to reduce stigma or hate crimes) aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.10: In people (children, young people and adults) with learning disabilities, does psychoeducation aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.11: In people (children, young people and adults) with learning disabilities, do annual health checks aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.12: In people (children, young people and adults) with learning disabilities, does family carer or staff training aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ2.13: In people (children, young people and adults) with learning disabilities, do exercise interventions aimed at preventing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p>
	Sub-question(s)	As listed above.
	Searches	<p>Search 1 All review questions: Central (inception to December 2016), CDSR (inception to December 2016), CINAHL (inception to December 2016), DARE (inception to December 2016), Embase (inception to December 2016), HTA (inception to December 2016), Medline (inception to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (inception to December 2016)</p> <p>Search 2 and 3: update of Verreenooghe and Langdon (2013)</p> <p>Review questions: 2.1, 2.2, 2.3, 2.6, 2.7, 2.8, 2.9, 2.10, 2.12: Embase (2012 to December 2016), Medline (2012 to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (2012 to December 2016)</p> <p>Other sources of evidence:</p>

Item No.	Item	Details
		<p>Reference lists of included studies</p> <p>Calls for evidence from registered stakeholders</p> <p>Trial authors and drug companies</p> <p>Trial registries (http://clinicaltrials.gov and International clinical Trials Registry Platform Search Portal: http://apps.who.int/trialsearch/)</p> <p>PROSPERO (http://www.crd.york.ac.uk/Prospero/)</p> <p>Conference abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full</p> <p>Dissertation titles/abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full</p> <p>Non-English language papers (with English abstracts) will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in an English language journal.</p> <p>Note. Unpublished data will only be included where a full trial report is available with sufficient detail to properly assess the risk of bias. Authors of unpublished evidence will be asked for permission to use such data, and will be informed that summary data from the study and the study's characteristics will be published in the full guideline.</p>
	Condition or domain being studied	<p>Learning disabilities</p> <p>Definition:</p> <p>Learning disabilities:</p> <p>Heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood. This corresponds to 'intellectual disability' as described in the major taxonomy DSM-5 (American Psychiatric Association, 2013) and 'mental retardation' in ICD-10 (WHO, 1992).</p> <p>Mental health problems (as defined in the guideline).</p>
	Participants/ population	<p>Included:</p> <ul style="list-style-type: none"> • People (children, young people and adults) with learning disabilities, including people with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs

Item No.	Item	Details
		<p>may differ from those of people with other learning disabilities (for example, Down’s syndrome, Prader-Willi syndrome, Fragile X syndrome). Special consideration will be given to groups affected by equality issues, such as black, Asian and minority ethnic groups and older adults.</p> <p>Excluded:</p> <ul style="list-style-type: none"> • studies which also include patients with borderline intelligence (IQ between 71 and 84), where results for those with and without learning disabilities have not been presented separately, and when less than 80% of the patients included have learning disabilities (or using IQ of 70 as a cut-off for learning disabilities, if the study does not describe the proportion with learning disabilities) • studies to prevent challenging behaviour (or problem behaviours), including aggression and anger, as this is covered by the guideline on challenging behaviours <p>If possible, results will be stratified by the following:</p> <ul style="list-style-type: none"> • Age: Adults (18 years or older), children and young people (under 18 years), all ages combined • Underlying cause of learning disability, such as: Down’s syndrome, Fragile X syndrome, Prader-Willi syndrome, Learning disabilities (idiopathic, unspecified or mixed causes) • Severity of learning disabilities: <ul style="list-style-type: none"> • Adults: mild = IQ 50-69, moderate = IQ 35-49, severe = IQ 20-34 or profound = IQ <20 (or as categorised by the studies) • Children: categorised by IQ above or severity as categorised by the studies • (for talking therapies, by level of talking ability) • Living situation: with family, with paid carer support (including own tenancy, shared tenancies, registered group homes), alone/with partner, in congregate setting/hospital
	Intervention(s)	<p>Included:</p> <ul style="list-style-type: none"> • psychological interventions (RQ2.1) • social and physical environmental interventions (RQ2.2) • personal and support strategies in community and residential settings (RQ2.3) • pharmacological interventions (RQ2.4)

Item No.	Item	Details
		<ul style="list-style-type: none"> • dietary interventions (RQ2.5) • other multidisciplinary therapies (RQ2.6) • combined interventions (RQ2.7) • occupational interventions (RQ2.8) • community interventions (for example to reduce stigma or hate crimes) (RQ2.9) • psycho education (RQ2.10) • annual health checks (RQ2.11) • family carer or staff training (RQ2.12) • exercise interventions (RQ2.13) <p>Excluded from all:</p> <ul style="list-style-type: none"> • anger/aggression prevention (as this is covered by the challenging behaviour guideline) • papers that report of the use of any interventions in the above categories for patients with learning disabilities that do not report an explicit intent to prevent mental health problems (an exception to this will be annual health checks). <p>If possible, results will be stratified by the following:</p> <ul style="list-style-type: none"> • mental health problem which is targeted: individual disorders, all mental-ill health • for interventions involving carers: family versus paid carers • interventions aimed at a group versus those aimed at individuals.
	Comparator(s)/ control	<p>Included:</p> <ul style="list-style-type: none"> • treatment as usual • placebo / no intervention <p>Any of the other interventions (that is, head-to-head trials)</p> <p>Excluded: none</p>

Item No.	Item	Details
	Types of study to be included initially	<p>Included:</p> <ul style="list-style-type: none"> • Reviews conducted for existing guidelines and published systematic reviews • A search for RCTs (with no date restriction) will be used to supplement the existing reviews. • Crossover RCTs will only be considered if they have either performed the appropriate analyses, taking into consideration the differences in treatment within each patient, or provided the results of the interventions before crossover. <p>[post-hoc note: due to the paucity in evidence, crossover RCTs were included where there were no existing parallel studies for an intervention]</p> <ul style="list-style-type: none"> • A stepped approach will be made for each area, depending on the availability of evidence. For example, cohort or controlled before-and-after studies may be considered. • Excluded: non-randomised studies (initially), case studies, case reports.
	Context	<p>Included: All settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.</p> <p>Excluded: none</p>
	Primary/Critical outcomes	<ul style="list-style-type: none"> • Mental health • Community participation and meaningful occupation • Quality of life
	Secondary/Important, but not critical outcomes	<ul style="list-style-type: none"> • Problem behaviours • Adaptive functioning including communication skills • Service user and carer satisfaction / experience of care • Carer health and quality of life • Adverse effects of interventions • Rates of placement breakdown / out-of-area placements / rates of restrictive interventions

Item No.	Item	Details
		<ul style="list-style-type: none"> • Psychiatric admissions (including outcomes related to admission such as length of inpatient stay and least restriction of liberty) • Offending and reoffending
	Data extraction (selection and coding)	<p>Citations from each search will be downloaded into EndNote and duplicates removed. Records will then be screened independently by two reviewers against the eligibility criteria of the review (if there is disagreement, resolution will be by discussion or a third reviewer). However, if search results are large (that is, greater than 1000), all records will be screened by one reviewer and another reviewer will screen 10% of all references; inter-rater reliability will be assessed and reported in the guideline. The unfiltered search results will be saved and retained for future potential re-analysis. All primary-level studies included after the first scan of citations will be acquired in full and re-evaluated for eligibility at the time they are being entered into a study database (standardised template created in Microsoft Excel). Eligibility will be confirmed by at least one member of the Guideline Committee (GC). The GC are experts in the topic and/or research methodology. Two researchers will extract data into the study database, comparing a sample of each other's work for reliability. Discrepancies or difficulties with coding will be resolved through discussion with members of the GC.</p> <p>Data to be extracted:</p> <ul style="list-style-type: none"> • Study characteristics (study ID, year, sub-category of intervention/comparison, context [locality, rural/urban, country], recruitment [recruitment location, approached N, completed screening N, randomised N, exclusion rate, screening format, screening admin, diagnostic system, diagnostic method/method used to define population as having a learning disability], run in/washout, inclusion/exclusion criteria, group assignment [number of groups, randomisation, N cluster], participant demographics [age, sex, race, IQ, type of accommodation, other confounders, particularly if non-randomised studies considered, and so on], funding, • Publication type, References, risk of bias [sequence generation, allocation concealment, methods for identifying confounders (if non-randomised studies considered), blinding, missing outcome data, selective outcome reporting]) • Comparisons (N, N post-treatment, N follow-up, intervention, target group, dose type, dose, frequency, duration) • Outcomes (outcome type, outcome name, data type, rater, weeks post-randomisation, time point – phase, outcome data [for example, mean, SD, N, events]).

Item No.	Item	Details
	Risk of bias (quality) assessment	The quality of individual studies will be assessed using the appropriate NICE quality assessment checklist. The quality of evidence for each outcome will be assessed using the GRADE approach.
	Strategy for data synthesis	<p>Where appropriate, meta-analysis will be used to combine results from similar studies. Initially, a fixed-effects model will be used but a random-effects model may be used if there is unexplained heterogeneity. Alternatively, a narrative synthesis will be used.</p> <p>If existing reviews are found, the review team with advice from the Guideline Committee (GC) will assess their quality, completeness, and applicability and relevance to the scope of the guideline. If the GC agree that a systematic review appropriately addresses a review question, the GC will consider searching for studies conducted or published since the review was conducted, and the GC will assess if any additional studies would likely affect the conclusions of the existing review. If new studies are likely to change the conclusions, we will update the review and conduct a new analysis. If new studies could not change the conclusions of an existing review, the GC will use the existing review to inform their recommendations.</p> <p>For areas with no evidence or limited evidence, formal consensus methods will be considered.</p>
	Analysis of subgroups or subsets (including sensitivity analyses)	<p>The following sensitivity analyses will be explored to test the robustness of the findings:</p> <ul style="list-style-type: none"> • Exclude studies without blinded/masked assessment • Exclude studies that do not demonstrate the quality of the treatment (often assessed by measuring adherence to the treatment protocol) • Exclude studies that didn't use ITT • Exclude studies that used LOCF • Exclude very small studies (N <50). • Subgroups may be explored if there is heterogeneity in the results. Some potential subgroups included: <ul style="list-style-type: none"> • Individual versus group therapy • Type of treatment (ie. different types of psychological treatment) • Different indications for treatment (such as different mental health problems).
	General information	
	Type of review	Intervention (prevention)

Item No.	Item	Details
	Further information	
	Existing reviews utilised in this review:	
	Updated	<p>Included and updated: Review from the challenging behaviour guideline on annual health checks.</p> <p>Included but not updated: Livingstone N, Hanratty J, McShane R, Macdonald G. Pharmacological interventions for cognitive decline in people with Down syndrome. Cochrane Database of Systematic Reviews 2015, Issue 10. Art. No.: CD011546. DOI: 10.1002/14651858.CD011546.pub2. Review from challenging behaviour guideline on parent training</p>
	Not updated	None

F.2.5 Interventions to treat and manage mental health problems (RQ3.1–3.11)

Item No.	Item	Details
	Guideline details	
21.	Guideline	Mental health problems in people with learning disabilities guideline
22.	Guideline chapter	Chapters 5 (Psychological interventions to prevent, treat and manage mental health problems), 6 (Pharmacological interventions to prevent, treat and manage mental health problems), and 7 (Other interventions to prevent, treat and manage mental health problems)
23.	Objective of review	To determine the best intervention/strategy to reduce and manage specific mental health problems in people with learning disabilities.
	Review methods	

24.	Review question(s)	<p>RQ3.1: In people (children, young people and adults) with learning disabilities and mental health problems, do psychological interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ3.2: In people (children, young people and adults) with learning disabilities and mental health problems, do social and physical environmental interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ3.3: In people (children, young people and adults) with learning disabilities and mental health problems, do personal and support strategies in community and residential interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ3.4: In people (children, young people and adults) with learning disabilities and mental health problems, do pharmacological interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ3.5: In people (children, young people and adults) with learning disabilities and mental health problems, do dietary interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ3.6: In people (children, young people and adults) with learning disabilities and mental health problems, do other multidisciplinary therapies aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ3.7: In people (children, young people and adults) with learning disabilities and mental health problems, do combined interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ3.8: In people (children, young people and adults) with learning disabilities and mental health problems, do occupational interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p>
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		<p>RQ3.9: In people (children, young people and adults) with learning disabilities and mental health problems, do community interventions (for example, to reduce stigma or hate crimes) aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ3.10: In people (children, young people and adults) with learning disabilities and mental health problems, does psychoeducation aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ3.11: In people (children, young people and adults) with learning disabilities and mental health problems, do exercise interventions aimed at treating and managing mental health problems produce benefits that outweigh possible harms when compared to an alternative approach?</p>
25.	Sub-question(s)	As listed above.
26.	Searches	<p>Search 1 All review questions: Central (inception to December 2016), CDSR (inception to December 2016), CINAHL (inception to December 2016), DARE (inception to December 2016), Embase (inception to December 2016), HTA (inception to December 2016), Medline (inception to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (inception to December 2016)</p> <p>Search 2 and 3: Update of published reviews Verreenooghe, L. and Langdon, P.E. (2013) Review questions: 3.1,3.2,3.3,3.6,3.7,3.8,3.9,3.10: Embase (2012 to December 2016), Medline (2012 to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (2012 to December 2016)Other sources of evidence:</p> <ul style="list-style-type: none"> • Reference lists of included studies • Calls for evidence from registered stakeholders • Trial authors and drug companies • Trial registries (http://clinicaltrials.gov and International clinical Trials Registry Platform Search Portal: http://apps.who.int/trialsearch/) • PROSPERO (http://www.crd.york.ac.uk/Prospero/)

		<ul style="list-style-type: none"> • Conference abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Dissertation titles/abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Non-English language papers (with English abstracts) will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in an English language journal. <p>Note. Unpublished data will only be included where a full trial report is available with sufficient detail to properly assess the risk of bias. Authors of unpublished evidence will be asked for permission to use such data, and will be informed that summary data from the study and the study's characteristics will be published in the full guideline.</p>
27.	Condition or domain being studied	<p>Learning disabilities and mental health problems</p> <p>Definitions:</p> <ul style="list-style-type: none"> • Learning disabilities: <ul style="list-style-type: none"> ○ Heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood. This corresponds to 'intellectual disability' as described in the major taxonomy DSM-5 (American Psychiatric Association, 2013) and 'mental retardation' in ICD-10 (WHO, 1992). • Mental health problems (as defined in the guideline).
28.	Participants/ population	<p>Included: People (children, young people and adults) with learning disabilities and mental health problems</p> <p>Including people with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs may differ from those of people with other learning disabilities (for example, Down's syndrome, Prader-Willi syndrome, Fragile X syndrome). Special consideration will be given to groups affected by equality issues, such as black, Asian and minority ethnic groups and older adults.</p> <p>Excluded:</p> <ul style="list-style-type: none"> • people with behaviour that challenges (including anger/aggression and sleep disturbance) as this is covered by the preceding guideline on behaviour that challenges

		<ul style="list-style-type: none"> • studies which also include patients with borderline intelligence (IQ between 71 and 84), where results for those with and without learning disabilities have not been presented separately, and when less than 80% of the patients included have learning disabilities (or using IQ of 70 as a cut-off for learning disabilities, if the study does not describe the proportion with learning disabilities). <p>If possible, results will be stratified by the following:</p> <ul style="list-style-type: none"> • Age: adults (18 years or older), children and young people (under 18 years), all ages combined (for dementia, middle age / older adults) • Underlying cause of learning disability, such as: Down’s syndrome, Fragile X syndrome, Prader-Willi syndrome, learning disabilities (idiopathic, unspecified or mixed causes) • Severity of learning disabilities: <ul style="list-style-type: none"> • Adults: mild = IQ 50-69, moderate = IQ 35-49, severe = IQ 20-34 or profound = IQ <20 (or as categorised by the studies) • Children: categorised by IQ above or severity as categorised by the studies • (For talking therapies, by level of talking ability) • Types of mental health problems: As listed in the guideline and subject to how this is reported in the literature plus a category ‘mental health problems (general/unspecified)’ • Living situation: with family, with paid carer support (including own tenancy, shared tenancies, registered group homes), alone/with partner, in congregate setting/hospital.
29.	Intervention(s)	<p>Included:</p> <ul style="list-style-type: none"> • psychological interventions (RQ3.1) • social and physical environmental interventions (RQ3.2) • personal and support strategies in community and residential settings RQ3.3) • pharmacological interventions (RQ3.4) • dietary interventions (RQ3.5) • other multidisciplinary therapies (RQ3.6) • combined interventions (RQ3.7)

		<ul style="list-style-type: none"> • occupational interventions (RQ3.8) • community interventions (for example to reduce stigma or hate crimes) (RQ3.9) • psychoeducation (RQ3.10) • exercise interventions (RQ3.11). <p>Excluded from all:</p> <ul style="list-style-type: none"> • treatment and management of anger/aggression (as this is covered by the challenging behaviour guideline) • none. <p>If possible, results will be stratified by:</p> <ul style="list-style-type: none"> • different classes of pharmacological interventions (for RQ3.4) • interventions involving carers: family versus paid carers • interventions aimed at a group versus those aimed at individuals.
30.	Comparator(s)/ control	<p>Included:</p> <ul style="list-style-type: none"> • Treatment as usual • Placebo / no intervention • Any of the other interventions (that is, head-to-head trials) <p>Excluded: none</p>
31.	Types of study to be included initially	<p>Included:</p> <ul style="list-style-type: none"> • Reviews conducted for existing guidelines and published systematic reviews. • A search for RCTs (with no date restriction) will be used to supplement the existing reviews. • Crossover RCTs will only be considered if they have either performed the appropriate analyses, taking into consideration the differences in treatment within each patient, or provided the results of the interventions before crossover.

		<p>[post-hoc note: due to the paucity in evidence, crossover RCTs were included where there were no existing parallel studies for an intervention]</p> <ul style="list-style-type: none"> • A stepped approach will be made for each area, depending on the availability of evidence. For example, cohort or controlled before-and-after studies may be considered. <p>Excluded: non-randomised studies (initially), case studies, case reports.</p>
32.	Context	<p>Included: All settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.</p> <p>Excluded: none</p>
33.	Primary/Critical outcomes	<ul style="list-style-type: none"> • Mental health • Community participation and meaningful occupation • Psychiatric admissions (including outcomes related to admission such as length of inpatient stay and least restriction of liberty) • Quality of life
34.	Secondary/Important, but not critical outcomes	<ul style="list-style-type: none"> • Problem behaviours • Adaptive functioning including communication skills • Service user and carer satisfaction / experience of care • Carer health and quality of life • Adverse effects of interventions • Rates of placement breakdown

		<ul style="list-style-type: none"> • Out-of-area placements • Rates of restrictive interventions • Offending and reoffending
35.	Data extraction (selection and coding)	<p>Citations from each search will be downloaded into EndNote and duplicates removed. Records will then be screened independently by two reviewers against the eligibility criteria of the review (if there is disagreement, resolution will be by discussion or a third reviewer). However, if search results are large (that is, greater than 1000), all records will be screened by one reviewer and another reviewer will screen 10% of all references; inter-rater reliability will be assessed and reported in the guideline. The unfiltered search results will be saved and retained for future potential re-analysis. All primary-level studies included after the first scan of citations will be acquired in full and re-evaluated for eligibility at the time they are being entered into a study database (standardised template created in Microsoft Excel). Eligibility will be confirmed by at least one member of the Guideline Committee (GC). The GC are experts in the topic and/or research methodology. Two researchers will extract data into the study database, comparing a sample of each other's work for reliability. Discrepancies or difficulties with coding will be resolved through discussion with members of the GC.</p> <p>Data to be extracted:</p> <p>Study characteristics (study ID, year, sub-category of intervention/comparison, context [locality, rural/urban, country], recruitment [recruitment location, approached N, completed screening N, randomised N, exclusion rate, screening format, screening admin, diagnostic system, Diagnostic method/method used to define population as having a learning disability], Run In/ Washout, Inclusion/exclusion criteria, Group assignment [number of groups, randomisation, N cluster], Participant demographics [age, sex, race, IQ, type of accommodation, level of speaking ability, other confounders (particularly, if non-randomised studies considered), etc], Funding,</p> <p>Publication type, References, risk of bias [sequence generation, allocation concealment, methods for identifying confounders (if non-randomised studies considered), Blinding, Missing outcome data, Selective outcome reporting])</p> <p>Comparisons (N, N post-treatment, N follow-up, Intervention, Target group, Dose type, Dose, Frequency, Duration)</p> <p>Outcomes (Outcome type, Outcome name, Data type, Rater, Weeks post-randomisation, Time point – phase, Outcome data [e.g., mean, SD, N, events]).</p>

36.	Risk of bias (quality) assessment	The quality of individual studies will be assessed using the appropriate NICE quality assessment checklist. The quality of evidence for each outcome will be assessed using the GRADE approach.
37.	Strategy for data synthesis	<p>Where appropriate, meta-analysis will be used to combine results from similar studies. Initially, a fixed-effects model will be used but a random-effects model may be used if there is unexplained heterogeneity. Alternatively, a narrative synthesis will be used.</p> <p>If existing reviews are found, the review team with advice from the Guideline Committee (GC) will assess their quality, completeness, and applicability and relevance to the scope of the guideline. If the GC agree that a systematic review appropriately addresses a review question, the GC will consider searching for studies conducted or published since the review was conducted, and the GC will assess if any additional studies would likely affect the conclusions of the existing review. If new studies are likely to change the conclusions, we will update the review and conduct a new analysis. If new studies could not change the conclusions of an existing review, the GC will use the existing review to inform their recommendations.</p> <p>For areas with no evidence or limited evidence, formal consensus methods will be considered.</p>
38.	Analysis of subgroups or subsets (including sensitivity analyses)	<p>The following sensitivity analyses will be explored to test the robustness of the findings:</p> <ul style="list-style-type: none"> • Exclude studies without blinded/masked assessment • Exclude studies that do not demonstrate the quality of the treatment (often assessed by measuring adherence to the treatment protocol) • Exclude studies that didn't use ITT • Exclude studies that used LOCF • Exclude very small studies (N <50). <p>Subgroups may be explored if there is heterogeneity in the results. Some potential subgroups included:</p> <ul style="list-style-type: none"> • Individual versus group therapy • Type of treatment (ie. different types of psychological treatment) • Different indications for treatment (such as, different mental health problems)
General information		

39.	Type of review	Intervention
Further information		
	Existing reviews utilised in this review:	
40.	<ul style="list-style-type: none"> Updated 	None.
41.	<ul style="list-style-type: none"> Not updated 	<p>For RQ3.1, the following systematic review will be used to identify the published literature up until the search date within the review and a search for primary studies which have been published after the review's search date will be conducted. Each primary study included within the review will be obtained and examined individually against inclusion criteria and, if the study is subsequently included, data will be extracted from the primary study: Vereenooghe L, Langdon PE. Psychological therapies for people with intellectual disabilities: a systematic review and meta-analysis. <i>Research in Developmental Disabilities</i>. 2013;34:4085-102.</p> <p>Included but not updated:</p> <ul style="list-style-type: none"> Livingstone N, Hanratty J, McShane R, Macdonald G. Pharmacological interventions for cognitive decline in people with Down syndrome. <i>Cochrane Database of Systematic Reviews</i>. 2015;10:Art. No.: CD011546. DOI: 10.1002/14651858.CD011546.pub2. Review from challenging behaviour guideline (NG11) on parent training

F.2.6 Approaches for service access, coordination and communication, and engagement and empowerment (RQ4.1, 4.3, 4.4. 4.5)

Item No.	Item	Details
	Guideline details	

42.	Guideline*	Mental health problems in people with learning disabilities guideline
43.	Guideline chapter*	Chapter 8: Organisation and service delivery
44.	Objective of review*	To identify approaches which aim to improve: <ul style="list-style-type: none"> • access to services • coordination and communication with key persons and services • engagement with family and staff/advocates • service user engagement and empowerment
Review methods		
45.	Review question(s)	<p>RQ4.1: In people (children, young people and adults) with learning disabilities and mental health problems, do interventions aimed at improving accessibility of services (for example, by removing barriers) produce benefits that outweigh possible harms when compared to an alternative approach?</p> <p>RQ4.3: What is the best approach with regard to the coordination and communication with key persons and services in the life of the person with learning disabilities and mental health problems?</p> <p>RQ4.4: What are the most appropriate strategies to engaging the family and staff/advocate of people with learning disabilities in the design, implementation and monitoring of interventions for that person's mental health problems?</p> <p>RQ4.5: What are the most appropriate strategies to engage and empower service users with learning disabilities in the design, implementation and monitoring of interventions for that person's mental health problems?</p>
46.	Sub-question(s)	As listed above.
47.	Searches*	Central (inception to December 2016), CDSR (inception to December 2016), CINAHL (inception to December 2016), DARE (inception to December 2016), Embase (inception to December 2016), HTA (inception to December 2016),

		<p>Medline (inception to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (inception to December 2016). Other sources of evidence:</p> <ul style="list-style-type: none"> • Reference lists of included studies • Calls for evidence from registered stakeholders • Trial registries (http://clinicaltrials.gov and International clinical Trials Registry Platform Search Portal: http://apps.who.int/trialsearch/) • PROSPERO (http://www.crd.york.ac.uk/Prospero/) • Conference abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Dissertation titles/abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Non-English language papers (with English abstracts) will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in an English language journal. <p>Note. Unpublished data will only be included where a full trial report is available with sufficient detail to properly assess the risk of bias. Authors of unpublished evidence will be asked for permission to use such data, and will be informed that summary data from the study and the study's characteristics will be published in the full guideline.</p>
48.	Condition or domain being studied*	<p>Learning disabilities and mental health problems</p> <p>Definitions:</p> <ul style="list-style-type: none"> • Learning disabilities: <ul style="list-style-type: none"> ○ Heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood. This corresponds to 'intellectual disability' as described in the major taxonomy DSM-5 (American Psychiatric Association, 2013) and 'mental retardation' in ICD-10 (WHO, 1992). • Mental health problems (as defined in the guideline).
49.	Participants/ population*	<p>RQ4.1</p> <p>Included: People (children, young people and adults) with learning disabilities and mental health problems</p>

		<p>Including people with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs may differ from those of people with other learning disabilities (for example, Down’s syndrome, Prader-Willi syndrome, Fragile X syndrome). Special consideration will be given to groups affected by equality issues, such as black, Asian and minority ethnic groups and older adults.</p> <p>Excluded: studies which also include patients with borderline intelligence (IQ between 71 and 84), where results for those with and without learning disabilities have not been presented separately, and when less than 80% of the patients included have learning disabilities (or using IQ of 70 as a cut-off for learning disabilities, if the study does not describe the proportion with learning disabilities).</p> <p>RQ4.3</p> <p>Included: key persons and services involved in the life of the person with learning disabilities and mental health problems including family members, healthcare practitioners and other staff.</p> <p>Excluded: N/A</p> <p>RQ4.4</p> <p>Included: family and staff or advocates of people with learning disabilities and a mental health problem.</p> <p>Excluded: N/A</p> <p>RQ4.5</p> <p>Included: People (children, young people and adults) with learning disabilities and mental health problems</p> <p>Including people with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs may differ from those of people with other learning disabilities (for example, Down’s syndrome, Prader-Willi syndrome, Fragile X syndrome). Special consideration will be given to groups affected by equality issues, such as black, Asian and minority ethnic groups and older adults.</p>
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		Excluded: studies which also include patients with borderline intelligence (IQ between 71 and 84), where results for those with and without learning disabilities have not been presented separately, and when less than 80% of the patients included have learning disabilities (or using IQ of 70 as a cut-off for learning disabilities, if the study does not describe the proportion with learning disabilities)
50.	Intervention(s), exposure(s)*	<p>RQ4.1 Included: any intervention aimed at improving accessibility to services (for example, by removing barriers). Excluded: N/A</p> <p>RQ4.3 Included: any approach or supports to improve coordination and communication with key persons and services. Excluded: N/A</p> <p>RQ4.4 Included: any strategy or supports to engage family and staff/advocate in design, implementation, and monitoring of interventions administered for a person’s mental health problems. Excluded: N/A</p> <p>RQ4.5 Included: any strategy or supports to engage and empower services users in the design, implementation, and monitoring of interventions administered for a person’s mental health problems. Excluded: N/A</p>
51.	Comparator(s)/ control*	<p>RQ4.1 Included: Any alternative intervention/strategy or approach or supports</p>

		<p>Excluded: N/A</p> <p>RQ4.3, 4.4, and 4.5</p> <p>Included:</p> <ul style="list-style-type: none"> • Treatment as usual • No treatment • Waitlist control • Placebo (including attention control) • Any alternative intervention/strategy or approach or supports <p>Excluded: N/A</p>
52.	Types of study to be included initially*	<p>Included:</p> <p>Reviews conducted for existing guidelines and published systematic reviews.</p> <p>A search for RCTs (with no date restriction) will be used to supplement the existing reviews.</p> <p>Crossover RCTs will only be considered if they have either performed the appropriate analyses, taking into consideration the differences in treatment within each patient, or provided the results of the interventions before crossover.</p> <p>A stepped approach will be made for each area, depending on the availability of evidence.</p> <p>Excluded: case series or case reports</p>
53.	Context*	<p>Included: All settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.</p>

		Excluded: none
54.	Primary/Critical outcomes*	<p>RQ4.1</p> <ul style="list-style-type: none"> • Mental health • Community participation and meaningful occupation • Quality of life / service user and carer satisfaction / experience of care • Problem behaviours <p>RQ4.3</p> <ul style="list-style-type: none"> • Mental health • Community participation and meaningful occupation • Quality of life / service user and carer satisfaction / experience of care • Health and quality of life of key persons involved • Problem behaviours <p>RQ4.4</p> <ul style="list-style-type: none"> • Mental health • Community participation and meaningful occupation • Family or staff/advocate health and quality of life • Problem behaviours • Quality of life <p>RQ4.5</p>

		<ul style="list-style-type: none"> • Mental health • Community participation and meaningful occupation • Quality of life / service user and carer satisfaction / experience of care • Problem behaviours
55.	Secondary/Important, but not critical outcomes*	<p>RQ4.1</p> <ul style="list-style-type: none"> • Psychiatric admissions (including outcomes related to admission such as length of inpatient stay and least restriction of liberty) • Adaptive functioning including communication skills • Carer health and quality of life • Adverse effects of interventions • Rates of placement breakdown • Need for out-of-area specialist or secure placement • Offending and reoffending <p>RQ4.3</p> <ul style="list-style-type: none"> • Psychiatric admissions (including outcomes related to admission such as length of inpatient stay and least restriction of liberty) • Adaptive functioning including communication skills • Carer health and quality of life • Adverse effects of interventions • Rates of placement breakdown

		<ul style="list-style-type: none">• Need for out-of-area specialist or secure placement• Offending and reoffending <p>RQ4.4</p> <ul style="list-style-type: none">• Psychiatric admissions (including outcomes related to admission such as length of inpatient stay and least restriction of liberty)• Adaptive functioning including communication skills• Carer health and quality of life• Adverse effects of interventions• Rates of placement breakdown• Need for out-of-area specialist or secure placement• Offending and reoffending <p>RQ4.5</p> <ul style="list-style-type: none">• Psychiatric admissions (including outcomes related to admission such as length of inpatient stay and least restriction of liberty)• Adaptive functioning including communication skills• Carer health and quality of life• Adverse effects of interventions• Rates of placement breakdown• Need for out-of-area specialist or secure placement
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		<ul style="list-style-type: none"> • Offending and reoffending
56.	Data extraction (selection and coding)*	<p>Citations from each search will be downloaded into EndNote and duplicates removed. Records will then be screened independently by two reviewers against the eligibility criteria of the review (if there is disagreement, resolution will be by discussion or a third reviewer). However, if search results are large (that is, greater than 1000), all records will be screened by one reviewer and another reviewer will screen 10% of all references; inter-rater reliability will be assessed and reported in the guideline. The unfiltered search results will be saved and retained for future potential re-analysis. All primary-level studies included after the first scan of citations will be acquired in full and re-evaluated for eligibility at the time they are being entered into a study database (standardised template created in Microsoft Excel). Eligibility will be confirmed by at least one member of the Guideline Committee (GC). The GC are experts in the topic and/or research methodology. Two researchers will extract data into the study database, comparing a sample of each other's work for reliability. Discrepancies or difficulties with coding will be resolved through discussion with members of the GC.</p> <p>Data to be extracted:</p> <p>Study characteristics (Study ID, Year, method or instrument, Context [Locality, Rural/Urban, Country], Recruitment [Recruitment location, Approached N, Completed screening N, Randomised N, Exclusion rate, Screening format, Screening admin, Diagnostic system, Diagnostic method/method used to define population as having a learning disability], Inclusion/exclusion criteria, Group assignment [number of groups, randomisation, N cluster], Demographics [age, sex, race, IQ, etc], Funding, Publication type, References, Risk of bias [patient selection and generalisability, Blinding, Missing outcome data, time interval between index and reference standard, any interventions in this interval])</p> <p>Comparisons (N, N post-treatment, N follow-up [if relevant], Test/Reference standard [including if self-report or informant/proxy and who it was completed by such as paid carer/professional/informal carer/family member], Target group, Group size, Admin setting of each [ie. GP, school, hospital], Admin who, Admin quality, Supervision, interval between tests)</p> <p>Outcomes (Outcome type, Outcome name, Data type, Rater, Outcome data).</p>
57.	Risk of bias (quality) assessment*	The quality of individual studies will be assessed using the appropriate NICE quality assessment checklist. The quality of evidence for each outcome will be assessed using the GRADE approach.

58.	Strategy for data synthesis*	<p>Where appropriate, meta-analysis using a random-effects model will be used to combine results from similar studies. Alternatively, a narrative synthesis will be used.</p> <p>If existing reviews are found, the review team with advice from the Guideline Committee (GC) will assess their quality, completeness, and applicability and relevance to the scope of the guideline. If the GC agree that a systematic review appropriately addresses a review question, the GC will consider searching for studies conducted or published since the review was conducted, and the GC will assess if any additional studies would likely affect the conclusions of the existing review. If new studies are likely to change the conclusions, we will update the review and conduct a new analysis. If new studies could not change the conclusions of an existing review, the GC will use the existing review to inform their recommendations.</p> <p>For areas with no evidence or limited evidence, formal consensus methods will be considered.</p>
59.	Analysis of subgroups or subsets (including sensitivity analyses)	<p>The following sensitivity analyses will be explored to test the robustness of the findings:</p> <ul style="list-style-type: none"> • Exclude studies without blinded/masked assessment • Exclude studies that do not demonstrate the quality of the treatment (often assessed by measuring adherence to the treatment protocol) • Exclude studies that didn't use ITT • Exclude studies that used LOCF • Exclude very small studies (N <50). <p>Subgroup analyses will be explored if there is heterogeneity in the results.</p>
60.	Type of review	Service delivery
Further information		
	Existing reviews utilised in this review:	
61.	<ul style="list-style-type: none"> • Updated 	The following review was partially included and updated:

		<p>Balogh R, Ouellette-Kuntz H, Bourne L, Lunsy Y, Colantonio A. Organising health care services for persons with an intellectual disability. Cochrane Database of Systematic Reviews 2008, Issue 4. Art. No.: CD007492. DOI: 10.1002/14651858.CD007492.</p> <p>Note that this was partially included due to slightly different purpose (also included physical health) and also different inclusion/exclusion criteria used. Also note that the Cochrane review was in the process of being updated but had not been completed in time to be included in the guideline.</p>
62.	<ul style="list-style-type: none"> • Not updated 	None.

F.2.7 Models for transition between services (RQ4.2)

Item No.	Item	Details
Guideline details		
1.	Guideline*	Mental health problems in people with learning disabilities guideline
2.	Guideline chapter*	Chapter 8: Organisation and service delivery
3.	Objective of review*	To determine effective models or supports for transition between services for people with learning disabilities and mental health problems.
Review methods		

4.	Review question(s) *	RQ4.2: In people (children, young people and adults) with learning disabilities and mental health problems, what are the effective models or supports for transition between services (for example, young person to adult, adult to older adult, NHS to social care/residential)?
5.	Sub-question(s)	<ul style="list-style-type: none"> • Young person to adult transition • adult to older adult transition • NHS to social care/residential transition
6.	Searches*	<p>Central (inception to December 2016), CDSR (inception to December 2016), CINAHL (inception to December 2016), DARE (inception to December 2016), Embase (inception to December 2016), HTA (inception to December 2016), Medline (inception to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (inception to December 2016)Other sources of evidence:</p> <ul style="list-style-type: none"> • Reference lists of included studies • Calls for evidence from registered stakeholders • Trial registries (http://clinicaltrials.gov and International clinical Trials Registry Platform Search Portal: http://apps.who.int/trialsearch/) • PROSPERO (http://www.crd.york.ac.uk/Prospero/) • Conference abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Dissertation titles/abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Non-English language papers (with English abstracts) will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in an English language journal. <p>Note. Unpublished data will only be included where a full trial report is available with sufficient detail to properly assess the risk of bias. Authors of unpublished evidence will be asked for permission to use such data, and will be informed that summary data from the study and the study's characteristics will be published in the full guideline.</p>

7.	Condition or domain being studied*	<p>Learning disabilities and mental health problems</p> <p>Definitions:</p> <ul style="list-style-type: none"> • Learning disabilities: <ul style="list-style-type: none"> ○ Heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood. This corresponds to 'intellectual disability' as described in the major taxonomy DSN-5 (APA, 2013) and 'mental retardation' in ICD-10 (WHO, 1992). • Mental health problems (as defined in the guideline).
8.	Participants/ population*	<p>Included: People (children, young people and adults) with learning disabilities and mental health problems</p> <p>Including people with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs may differ from those of people with other learning disabilities (for example, Down's syndrome, Prader-Willi syndrome, Fragile X syndrome). Special consideration will be given to groups affected by equality issues, such as black, Asian and minority ethnic groups and older adults.</p> <p>Excluded:</p> <ul style="list-style-type: none"> • studies which also include patients with borderline intelligence (IQ between 71 and 84), where results for those with and without learning disabilities have not been presented separately, and when less than 80% of the patients included have learning disabilities (or using IQ of 70 as a cut-off for learning disabilities, if the study does not describe the proportion with learning disabilities)
9.	Intervention(s), exposure(s)*	<p>Included:</p> <p>Any model or supports for transitioning between services</p> <p>Excluded: N/A</p>
10.	Comparator(s)/ control*	<p>Included:</p> <ul style="list-style-type: none"> • Treatment as usual

		<ul style="list-style-type: none"> • No treatment • Waitlist control • Placebo (including attention control) • Any alternative model for transition <p>Excluded: N/A</p>
11.	Types of study to be included initially*	<p>Included:</p> <p>Reviews conducted for existing guidelines and published systematic reviews.</p> <p>A search for RCTs (with no date restriction) will be used to supplement the existing reviews.</p> <p>Crossover RCTs will only be considered if they have either performed the appropriate analyses, taking into consideration the differences in treatment within each patient, or provided the results of the interventions before crossover.</p> <p>A stepped approach will be made, depending on the availability of evidence.</p> <p>Excluded: case series or case reports</p>
12.	Context*	<p>Included: All settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.</p> <p>Excluded: none</p>
13.	Primary/Critical outcomes*	<ul style="list-style-type: none"> • Mental health • Community participation and meaningful occupation • Quality of life / service user and carer satisfaction / experience of care

		<ul style="list-style-type: none"> • Problem behaviours <p>To answer this question, consideration should be given to:</p> <ul style="list-style-type: none"> • the design, structure and delivery of care pathways • the nature and duration of support provided during transition.
14.	Secondary/Important, but not critical outcomes*	<ul style="list-style-type: none"> • Psychiatric admissions (including outcomes related to admission such as length of inpatient stay and least restriction of liberty) • Adaptive functioning including communication skills • Carer health and quality of life • Adverse effects of interventions • Rates of placement breakdown • Out-of-area placements • Rates of restrictive interventions • Offending and reoffending
15.	Data extraction (selection and coding)*	<p>Citations from each search will be downloaded into EndNote and duplicates removed. Records will then be screened independently by two reviewers against the eligibility criteria of the review (if there is disagreement, resolution will be by discussion or a third reviewer). However, if search results are large (that is, greater than 1000), all records will be screened by one reviewer and another reviewer will screen 10% of all references; inter-rater reliability will be assessed and reported in the guideline. The unfiltered search results will be saved and retained for future potential re-analysis. All primary-level studies included after the first scan of citations will be acquired in full and re-evaluated for eligibility at the time they are being entered into a study database (standardised template created in Microsoft Excel). Eligibility will be confirmed by at least one member of the Guideline Committee (GC). The GC are experts in the topic and/or research methodology. Two researchers</p>

		<p>will extract data into the study database, comparing a sample of each other's work for reliability. Discrepancies or difficulties with coding will be resolved through discussion with members of the GC.</p> <p>Data to be extracted:</p> <p>Study characteristics (Study ID, Year, method or instrument, Context [Locality, Rural/Urban, Country], Recruitment [Recruitment location, Approached N, Completed screening N, Randomised N, Exclusion rate, Screening format, Screening admin, Diagnostic system, Diagnostic method/method used to define population as having a learning disability], Inclusion/exclusion criteria, Group assignment [number of groups, randomisation, N cluster], Demographics [age, sex, race, IQ, etc], Funding, Publication type, References, Risk of bias [patient selection and generalisability, Blinding, Missing outcome data, time interval between index and reference standard, any interventions in this interval])</p> <p>Comparisons (N, N post-treatment, N follow-up [if relevant], Test/Reference standard [including if self-report or informant/proxy and who it was completed by such as paid carer/professional/informal carer/family member], Target group, Group size, Admin setting of each [ie. GP, school, hospital], Admin who, Admin quality, Supervision, interval between tests)</p> <p>Outcomes (Outcome type, Outcome name, Data type, Rater, Outcome data).</p>
16.	Risk of bias (quality) assessment*	<p>The quality of individual studies will be assessed using the appropriate NICE quality assessment checklist. The quality of evidence for each outcome will be assessed using the GRADE approach.</p>
17.	Strategy for data synthesis*	<p>Where appropriate, meta-analysis using a random-effects model will be used to combine results from similar studies. Alternatively, a narrative synthesis will be used.</p> <p>If existing reviews are found, the review team with advice from the Guideline Committee (GC) will assess their quality, completeness, and applicability and relevance to the scope of the guideline. If the GC agree that a systematic review appropriately addresses a review question, the GC will consider searching for studies conducted or published since the review was conducted, and the GC will assess if any additional studies would likely affect the conclusions of the existing review. If new studies are likely to change the conclusions, we will update the review and conduct a new analysis. If new studies could not change the conclusions of an existing review, the GC will use the existing review to inform their recommendations.</p>

		For areas with no evidence or limited evidence, formal consensus methods will be considered.
18.	Analysis of subgroups or subsets (including sensitivity analyses)	<p>The following sensitivity analyses will be explored to test the robustness of the findings:</p> <ul style="list-style-type: none"> • Exclude studies without blinded/masked assessment • Exclude studies that do not demonstrate the quality of the treatment (often assessed by measuring adherence to the treatment protocol) • Exclude studies that didn't use ITT • Exclude studies that used LOCF • Exclude very small studies (N <50). <p>Subgroup analyses will be explored if there is heterogeneity in the results.</p>
19.	Type of review	Service delivery
Further information		
	Existing reviews utilised in this review:	
20.	<ul style="list-style-type: none"> • Updated 	<p>The following review was partially included and updated:</p> <p>Balogh R, Ouellette-Kuntz H, Bourne L, Lunskey Y, Colantonio A. Organising health care services for persons with an intellectual disability. Cochrane Database of Systematic Reviews 2008, Issue 4. Art. No.: CD007492. DOI: 10.1002/14651858.CD007492.</p> <p>Note that this was partially included due to slightly different purpose (also included physical health) and also different inclusion/exclusion criteria used. Also note that the Cochrane review was in the process of being updated but had not been completed in time to be included in the guideline.</p>
21.	<ul style="list-style-type: none"> • Not updated 	None.

F.2.8 Service structures, training and supervision to support practitioners in delivery effective interventions (RQ4.6)

Item No.	Item	Details
Guideline details		
22.	Guideline*	Mental health problems in people with learning disabilities guideline
23.	Guideline chapter*	Chapter 8: Organisation and service delivery
24.	Objective of review*	To determine the best way to support practitioners in delivering effective interventions for people with learning disabilities and mental health problems.
Review methods		
25.	Review question(s) *	RQ4.6: What are the most appropriate service structures, training and supervision to support practitioners in the effective delivery of interventions for people (children, young people and adults) with learning disabilities and mental health problems?
26.	Sub-question(s)	n/a
27.	Searches*	<p>Central (inception to December 2016), CDSR (inception to December 2016), CINAHL (inception to December 2016), DARE (inception to December 2016), Embase (inception to December 2016), HTA (inception to December 2016), Medline (inception to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (inception to December 2016)Other sources of evidence:</p> <ul style="list-style-type: none"> • Reference lists of included studies • Calls for evidence from registered stakeholders

		<ul style="list-style-type: none"> • Trial registries (http://clinicaltrials.gov and International clinical Trials Registry Platform Search Portal: http://apps.who.int/trialsearch/) • PROSPERO (http://www.crd.york.ac.uk/Prospero/) • Conference abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Dissertation titles/abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Non-English language papers (with English abstracts) will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in an English language journal. <p>Note. Unpublished data will only be included where a full trial report is available with sufficient detail to properly assess the risk of bias. Authors of unpublished evidence will be asked for permission to use such data, and will be informed that summary data from the study and the study’s characteristics will be published in the full guideline.</p>
28.	Condition or domain being studied*	<p>Learning disabilities and mental health problems</p> <p>Definitions:</p> <ul style="list-style-type: none"> • Learning disabilities: <ul style="list-style-type: none"> ○ Heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood. This corresponds to ‘intellectual disability’ as described in the major taxonomy DSM-5 (APA, 2013) and ‘mental retardation’ in ICD-10 (WHO, 1992). • Mental health problems (as defined in the guideline).
29.	Participants/ population*	<p>Included: Health care practitioners involved in delivering interventions to people (children, young people and adults) with learning disabilities and mental health problems</p> <p>Including treating people with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs may differ from those of people with other learning disabilities (for example, Down’s syndrome, Prader-Willi syndrome, Fragile X syndrome). Special</p>

		<p>consideration will be given to groups affected by equality issues, such as black, Asian and minority ethnic groups and older adults.</p>
30.	<p>Intervention(s), exposure(s)*</p>	<p>Included: Any service structure, training or supervision programme, including:</p> <ul style="list-style-type: none"> • Assertive Community Treatment (ACT) • Care management training • Care pathway and outcome-based service models • Case management (including intensive case management) • Clinical networks providing specialist input • Community learning disabilities teams • Coordination approaches (that is, Care Programme approach) • Crisis resolution teams • Early Intervention Teams (for psychosis) • Green light toolkit • Improving Access to Psychological Therapies (IAPT) • Learning Disabilities Child and Adolescent Mental Health Service (CAMHS) • Outreach/ Inreach services (including assertive outreach teams and prison inreach services) • Sure start • Staff skills development and training routed in a care pathway-based service delivery and competencies framework <p>Excluded: N/A</p>

31.	Comparator(s)/ control*	<p>Included:</p> <ul style="list-style-type: none"> • Treatment as usual • No treatment • Waitlist control • Placebo (including attention control) • Any alternative staff training or education programme <p>Excluded: N/A</p>
32.	Types of study to be included initially*	<p>Included:</p> <p>Reviews conducted for existing guidelines and published systematic reviews.</p> <p>A search for RCTs (with no date restriction) will be used to supplement the existing reviews.</p> <p>Crossover RCTs will only be considered if they have either performed the appropriate analyses, taking into consideration the differences in treatment within each patient, or provided the results of the interventions before crossover.</p> <p>A stepped approach will be made, depending on the availability of evidence.</p> <p>Excluded: case series or case reports</p>
33.	Context*	<p>Included: All settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.</p> <p>Excluded: none</p>
34.	Primary/Critical outcomes*	<ul style="list-style-type: none"> • Healthcare practitioner health and well-being • Mental health (of people with learning disabilities) • Community participation and meaningful occupation • Quality of life / service user and carer satisfaction / experience of care

		<ul style="list-style-type: none"> • Problem behaviours
35.	Secondary/Important, but not critical outcomes*	<ul style="list-style-type: none"> • Psychiatric admissions including outcomes related to admission such as length of inpatient stay and least restriction of liberty • Adaptive functioning including communication skills • Carer health and quality of life • Adverse effects of interventions • Rates of placement breakdown • Need for out-of-area specialist or secure placement • Rates of restrictive interventions • Offending and reoffending
36.	Data extraction (selection and coding)*	<p>Citations from each search will be downloaded into EndNote and duplicates removed. Records will then be screened independently by two reviewers against the eligibility criteria of the review (if there is disagreement, resolution will be by discussion or a third reviewer). However, if search results are large (that is, greater than 1000), all records will be screened by one reviewer and another reviewer will screen 10% of all references; inter-rater reliability will be assessed and reported in the guideline. The unfiltered search results will be saved and retained for future potential re-analysis. All primary-level studies included after the first scan of citations will be acquired in full and re-evaluated for eligibility at the time they are being entered into a study database (standardised template created in Microsoft Excel). Eligibility will be confirmed by at least one member of the Guideline Committee (GC). The GC are experts in the topic and/or research methodology. Two researchers will extract data into the study database, comparing a sample of each other's work for reliability. Discrepancies or difficulties with coding will be resolved through discussion with members of the GC.</p> <p>Data to be extracted:</p> <p>Study characteristics (study ID, year, sub-category of intervention/comparison, context [locality, rural/urban, country], recruitment [recruitment location, approached N, completed screening N, randomised N, exclusion rate, screening format, screening admin, diagnostic system, Diagnostic method/method used to define</p>

		<p>population as having a learning disability], Run In/ Washout, Inclusion/exclusion criteria, Group assignment [number of groups, randomisation, N cluster], Participant demographics [age, sex, race, IQ, type of accommodation, level of speaking ability, other confounders (particularly, if non-randomised studies considered), etc], Funding,</p> <p>Publication type, References, risk of bias [sequence generation, allocation concealment, methods for identifying confounders (if non-randomised studies considered), Blinding, Missing outcome data, Selective outcome reporting])</p> <p>Comparisons (N, N post-treatment, N follow-up, Intervention, Target group, Dose type, Dose, Frequency, Duration)</p> <p>Outcomes (Outcome type, Outcome name, Data type, Rater, Weeks post-randomisation, Time point – phase, Outcome data [e.g., mean, SD, N, events]).</p>
37.	Risk of bias (quality) assessment*	<p>The quality of individual studies will be assessed using the appropriate NICE quality assessment checklist. The quality of evidence for each outcome will be assessed using the GRADE approach.</p>
38.	Strategy for data synthesis*	<p>Where appropriate, meta-analysis using a random-effects model will be used to combine results from similar studies. Alternatively, a narrative synthesis will be used.</p> <p>If existing reviews are found, the review team with advice from the Guideline Committee (GC) will assess their quality, completeness, and applicability and relevance to the scope of the guideline. If the GC agree that a systematic review appropriately addresses a review question, the GC will consider searching for studies conducted or published since the review was conducted, and the GC will assess if any additional studies would likely affect the conclusions of the existing review. If new studies are likely to change the conclusions, we will update the review and conduct a new analysis. If new studies could not change the conclusions of an existing review, the GC will use the existing review to inform their recommendations.</p> <p>For areas with no evidence or limited evidence, formal consensus methods will be considered.</p>

39.	Analysis of subgroups or subsets (including sensitivity analyses)	<p>The following sensitivity analyses will be explored to test the robustness of the findings:</p> <ul style="list-style-type: none"> • Exclude studies without blinded/masked assessment • Exclude studies that do not demonstrate the quality of the treatment (often assessed by measuring adherence to the treatment protocol) • Exclude studies that didn't use ITT • Exclude studies that used LOCF • Exclude very small studies (N <50). <p>Subgroups may be explored if there is heterogeneity in the results.</p>
40.	Type of review	Service delivery
Further information		
	Existing reviews utilised in this review:	
41.	<ul style="list-style-type: none"> • Updated 	<p>The following review was partially included and updated:</p> <p>Balogh R, Ouellette-Kuntz H, Bourne L, Lunsky Y, Colantonio A. Organising health care services for persons with an intellectual disability. Cochrane Database of Systematic Reviews 2008, Issue 4. Art. No.: CD007492. DOI: 10.1002/14651858.CD007492.</p> <p>Note that this was partially included due to slightly different purpose (also included physical health) and also different inclusion/exclusion criteria used. Also note that the Cochrane review was in the process of being updated but had not been completed in time to be included in the guideline.</p>
42.	<ul style="list-style-type: none"> • Not updated 	<p>Chaplin R. (2004) General psychiatric services for adults with intellectual disability and mental illness. Journal of Intellectual Disability Research (48) 1: 1-10. – review aimed to identify if studies in specialist or general psychiatric services have better outcomes – included here as ‘not updated’ as only addressed a small part of the review question; also identified one RCT but the rest were non-randomised</p>

F.2.9 Interventions, training, support to improve health and wellbeing of family carers and staff (RQ5.1)

Item No.	Item	Details
Guideline details		
43.	Guideline	Mental health problems in people with learning disabilities guideline
44.	Guideline chapter	Chapter 9: Interventions for family carer and staff health and wellbeing
45.	Objective of review	To determine which is the best way to engage family carers and staff of people with learning disabilities and mental health problems to improve their own health and well-being.
Review methods		
46.	Review question(s) *	RQ5.1: In family carers and staff caring for people (children, young people and adults) with learning disabilities and mental health problems, which interventions, training and support improve the health and well-being of the family and staff as well as that of the person with learning disabilities when compared to an alternative approach?
47.	Sub-question(s)	n/a

48.	Searches*	<p>Central (inception to December 2016), CDSR (inception to December 2016), CINAHL (inception to December 2016), DARE (inception to December 2016), Embase (inception to December 2016), HTA (inception to December 2016), Medline (inception to December 2016), PreMedline (inception to December week 2 2016), PsycINFO (inception to December 2016)Other sources of evidence:</p> <ul style="list-style-type: none"> • Reference lists of included studies • Calls for evidence from registered stakeholders • Trial registries (http://clinicaltrials.gov and International clinical Trials Registry Platform Search Portal: http://apps.who.int/trialsearch/) • PROSPERO (http://www.crd.york.ac.uk/Prospero/) • Conference abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Dissertation titles/abstracts will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in full • Non-English language papers (with English abstracts) will be assessed for eligibility and potentially eligible studies will be checked to determine if they have been published in an English language journal. <p>Note. Unpublished data will only be included where a full trial report is available with sufficient detail to properly assess the risk of bias. Authors of unpublished evidence will be asked for permission to use such data, and will be informed that summary data from the study and the study’s characteristics will be published in the full guideline.</p>
49.	Condition or domain being studied*	<p>Learning disabilities and mental health problems</p> <p>Definitions:</p> <ul style="list-style-type: none"> • Learning disabilities: <ul style="list-style-type: none"> ○ Heterogeneous conditions, but are defined by 3 core criteria: lower intellectual ability (usually defined as an IQ of less than 70), significant impairment of social or adaptive functioning and onset in childhood. This corresponds to 'intellectual disability' as described in the major taxonomy DSM-5 (American Psychiatric Association, 2013) and 'mental retardation' in ICD-10 (WHO, 1992). • Mental health problems (as defined in the guideline).

50.	Participants/ population*	<p>Included: Family carers and staff caring for people (children, young people and adults) with learning disabilities and mental health problems.</p> <p>This includes family carers and staff caring for people with genetic conditions associated with learning disabilities and mental health problems, if some of their mental health problems and needs may differ from those of people with other learning disabilities (for example, Down’s syndrome, Prader-Willi syndrome, Fragile X syndrome). Special consideration will be given to groups affected by equality issues, such as black, Asian and minority ethnic groups and older adults.</p> <p>Definitions:</p> <ul style="list-style-type: none"> • Family carer: <ul style="list-style-type: none"> ○ Has personal experience of caring for 1 or more persons with LD and mental health problems who is a family member; see comment below ○ Has personal contact with a family member who has LD and mental health problems, even though that individual may not reside in the family home; ○ Is not paid to have a personal, continuous relationship with a person with LD and mental health problems. ○ Not all family carers may be related by blood, but choose to support a person with a learning disability in the way described above • Staff: <ul style="list-style-type: none"> ○ Is paid to care for 1 or more persons with LD and mental health problems. <p>Excluded:</p> <ul style="list-style-type: none"> • Family carers and staff caring for people with learning disabilities who do not have mental health problems <p>If possible, results will be stratified by the following:</p> <ul style="list-style-type: none"> • Age of person being cared for: Adults (18 years or older), children and young people (under 18 years), all ages combined (for dementia, middle age / older adults) • Underlying cause of learning disability, such as: Down’s syndrome, Fragile X syndrome, Prader-Willi syndrome, Learning disabilities (idiopathic, unspecified or mixed causes)
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		<ul style="list-style-type: none"> • Severity of learning disabilities: • Adults: mild = IQ 50-69, moderate = IQ 35-49, severe = IQ 20-34 or profound = IQ <20 (or as categorised by the studies) • Children: categorised by IQ above or severity as categorised by the studies • (for talking therapies, by level of talking ability) • Types of mental health problems: As listed in the guideline and subject to how this is reported in the literature plus a category 'mental health problems (general/unspecified)' • Living situation: with family, with paid carer support (including own tenancy, shared tenancies, registered group homes), alone/with partner, in congregate setting/hospital
51.	Intervention(s), exposure(s)*	<p>Included: Any intervention, training or support with the aim of improving health and wellbeing of family carers and staff caring for people with learning disabilities and mental health problems including:</p> <ul style="list-style-type: none"> • Acceptance and Commitment Therapy • Cognitive behaviour therapy (CBT) • Mindfulness • Stress inoculation training • Supported communication including Intensive Interaction, Augmented and Alternative Communication (AAC), Picture Exchange, Communication System (PECS), Individualised Sensory Environment (ISE) <p>Excluded: N/A</p>
52.	Comparator(s)/ control*	<p>Included:</p> <p>Placebo / no intervention</p> <p>Any of the other interventions (that is, head-to-head trials)</p> <p>Excluded: N/A</p>
53.	Types of study to be included initially*	<p>Reviews conducted for existing guidelines and published systematic reviews.</p> <p>A search for RCTs (with no date restriction) will be used to supplement the existing reviews.</p>

		<p>A stepped approach will be made for each area, depending on the availability of evidence. For example, if no RCTs are found considering intervention, training or support for family carers and staff caring for people with learning disabilities who have mental health problems, RCTs aimed at family carers and staff caring for people with learning disabilities who do not have mental health problems may be considered as indirect evidence.</p> <p>Crossover RCTs will only be considered if they have either performed the appropriate analyses, taking into consideration the differences in treatment within each patient, or provided the results of the interventions before crossover.</p> <p>Excluded: non-randomised studies (initially), case studies, case reports.</p>
54.	Context*	<p>Included: All settings in which care commissioned by health and social care is provided, including health, social care and educational settings. Forensic and criminal justice services where people with learning disabilities and mental health problems are assessed and cared for are also included.</p> <p>Excluded: none</p>
55.	Primary/Critical outcomes*	<ul style="list-style-type: none"> • Carer health and quality of life / carer satisfaction • Relationship between carer and person being cared for (measured by observational measures of staff support of expressed emotion on the relationship)
56.	Secondary/Important, but not critical outcomes*	<ul style="list-style-type: none"> • Carer burn out/stress • Carer resilience

57.	Data extraction (selection and coding)*	<p>Citations from each search will be downloaded into EndNote and duplicates removed. Records will then be screened independently by two reviewers against the eligibility criteria of the review (if there is disagreement, resolution will be by discussion or a third reviewer). However, if search results are large (that is, greater than 1000), all records will be screened by one reviewer and another reviewer will screen 10% of all references; inter-rater reliability will be assessed and reported in the guideline. The unfiltered search results will be saved and retained for future potential re-analysis. All primary-level studies included after the first scan of citations will be acquired in full and re-evaluated for eligibility at the time they are being entered into a study database (standardised template created in Microsoft Excel). Eligibility will be confirmed by at least one member of the Guideline Committee (GC). The GC are experts in the topic and/or research methodology. Two researchers will extract data into the study database, comparing a sample of each other's work for reliability. Discrepancies or difficulties with coding will be resolved through discussion with members of the GC.</p> <p>Data to be extracted:</p> <p>Study characteristics (study ID, year, sub-category of intervention/comparison, context [locality, rural/urban, country], recruitment [recruitment location, approached N, completed screening N, randomised N, exclusion rate, screening format, screening admin, diagnostic system, Diagnostic method/method used to define population as having a learning disability], Run In/ Washout, Inclusion/exclusion criteria, Group assignment [number of groups, randomisation, N cluster], Participant demographics [age, sex, race, and other confounders (particularly, if non-randomised studies considered), and those of the person with learning disabilities that they are caring for (as above and including IQ, type of accommodation, level of speaking ability), etc], Funding,</p> <p>Publication type, References, risk of bias [sequence generation, allocation concealment, methods for identifying confounders (if non-randomised studies considered), Blinding, Missing outcome data, Selective outcome reporting])</p> <p>Comparisons (N, N post-treatment, N follow-up, Intervention, Target group, Dose type, Dose, Frequency, Duration)</p> <p>Outcomes (Outcome type, Outcome name, Data type, Rater, Weeks post-randomisation, Time point – phase, Outcome data [e.g., mean, SD, N, events]).</p>
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58.	Risk of bias (quality) assessment*	The quality of individual studies will be assessed using the appropriate NICE quality assessment checklist. The quality of evidence for each outcome will be assessed using the GRADE approach.
59.	Strategy for data synthesis*	<p>Where appropriate, meta-analysis will be used to combine results from similar studies. Initially, a fixed-effects model will be used but a random-effects model may be used if there is unexplained heterogeneity. Alternatively, a narrative synthesis will be used.</p> <p>If existing reviews are found, the review team with advice from the Guideline Committee (GC) will assess their quality, completeness, and applicability and relevance to the scope of the guideline. If the GC agree that a systematic review appropriately addresses a review question, the GC will consider searching for studies conducted or published since the review was conducted, and the GC will assess if any additional studies would likely affect the conclusions of the existing review. If new studies are likely to change the conclusions, we will update the review and conduct a new analysis. If new studies could not change the conclusions of an existing review, the GC will use the existing review to inform their recommendations.</p> <p>For areas with no evidence or limited evidence, formal consensus methods will be considered.</p>
60.	Analysis of subgroups or subsets (including sensitivity analyses)	<p>Sensitivity analyses will be explored if there is heterogeneity in the results:</p> <ul style="list-style-type: none"> • Exclude studies without blinded/masked assessment • Exclude studies that do not demonstrate the quality of the treatment (often assessed by measuring adherence to the treatment protocol) • Exclude studies that didn't use ITT • Exclude studies that used LOCF • Exclude very small studies (N <50). <p>Subgroups may be explored if there is heterogeneity in the results.</p>
61.	Type of review	Intervention
Further information		

Mental health problems in people with learning disabilities
Appendix F: Review questions and final review protocols

	Existing reviews utilised in this review:	
62.	<ul style="list-style-type: none">• Updated	Included but not updated: the review completed for the challenging behaviour guideline was included as indirect evidence.
63.	<ul style="list-style-type: none">• Not updated	None

Appendix G: High-priority research recommendations

The Guideline Committee has made the following recommendations for research. The Committee's full set of research recommendations is detailed in the full guideline.

G.1 Develop case identification tools for common mental health problems

Develop or adapt reliable and valid tools for the case identification of common mental health problems in people with learning disabilities, for routine use in primary care, social care and education settings.

G.1.1 Why this is important

Mental health problems are often overlooked and therefore untreated in people with learning disabilities. This includes common mental health problems such as depression and anxiety disorders, or dementia in Down's syndrome. As a result, the identification of mental health problems in people with learning disabilities was a priority for this guideline.

While case identification tools exist and are recommended for use in the general population, no suitable tools were found that help with initial identification for people with learning disabilities. Research to develop and validate such tools would be valuable when this guideline is updated. More reliable identification should help with early intervention and provide better outcomes, and earlier identification could also reduce costs for the NHS and social care. No relevant ongoing trials were identified.

Existing tools with the best psychometric properties could be adapted and validated for use with people with learning disabilities, or new tools could be developed that are appropriate for use. The tools should be readily available and useable in routine health, social care and education settings (such as by GPs or caregiving staff).

Tools should first be adapted or developed for the most common mental health problems within this population:

- dementia, depression and anxiety in adults
- depression and anxiety in children and young people.

A series of cohort studies are needed to validate the tools (new or existing). The studies could include the following outcomes:

- sensitivity and specificity
- predictive validity.

G.2 Psychological interventions for children and young people with internalising disorders

For children and young people with learning disabilities, what psychological interventions (such as cognitive behavioural therapy and interpersonal therapy) are clinically and cost effective for treating internalising disorders?

G.2.1 Why this is important

There is some evidence for the use of psychological interventions for internalising disorders in children and young people within the general population, and in adults with learning disabilities. However no evidence was found to indicate which interventions for internalising disorders are effective in children and young people with learning disabilities, or what adaptations are most helpful.

Psychological interventions commonly used within the general population (such as cognitive behavioural therapy and interpersonal therapy) should be adapted and tested in large randomised controlled trials. This research is crucial to improving the mental health outcomes in this population, and would have a significant impact upon updates of this guideline.

Important outcomes could include:

- effect on the mental health problem
- cost effectiveness
- health-related quality of life.

G.3 Psychological interventions for depression and anxiety disorders in adults with mild to moderate learning disabilities

For adults with milder learning disabilities, what is the clinical and cost effectiveness of psychological interventions such as cognitive behavioural therapy (modified for people with learning disabilities) for treating depression and anxiety disorders?

G.3.1 Why this is important

Psychological interventions such as cognitive behavioural therapy (CBT) are clinically and cost-effective treatments for anxiety and depression within the general population. While there is some evidence to suggest that these interventions may be useful in treating depression in people with learning disabilities, this is limited. Further research is also needed for CBT for anxiety disorders such as generalised anxiety disorder, obsessive compulsive disorder and post-traumatic stress disorder. The existing evidence on CBT for learning disabilities is based on small feasibility trials, with various and inconsistent adaptations across the studies. Many therapists are also reluctant to use CBT in this population. As a result, people with learning disabilities may be missing out on effective treatments. Effective treatments would reduce unnecessary suffering and impairment, improve quality of life and ultimately should reduce the demand for mental health and social care services.

Modifications of CBT need to be tested in large randomised controlled trials, and any modifications should be clearly explained and documented. In order to achieve an appropriate sample size, several different services may need to cooperate. Important outcomes could include:

- effect on the mental health problem
- cost effectiveness
- health-related quality of life.

G.4 Pharmacological interventions for anxiety disorders in people with autism and learning disabilities

What is the clinical and cost effectiveness and safety of pharmacological interventions for anxiety disorders in people with autism and learning disabilities?

G.4.1 Why this is important

Anxiety disorders are common in people with learning disabilities, and in particular in people with autism and learning disabilities. However, there is no high-quality evidence on pharmacological interventions for anxiety disorders in people with learning disabilities. People with learning disabilities may be more susceptible to adverse events, and have particular difficulty communicating side effects. There may also be differences in effectiveness compared with the general population. These uncertainties about side effects and effectiveness may contribute to the under-treatment of mental health problems in people with learning disabilities. Research is therefore needed to determine the safety and effectiveness of pharmacological interventions and make it clear what treatments are effective for anxiety in people with autism and learning disabilities. Clarity over this issue could have a substantial impact upon quality of life for people with learning disabilities and their carers as well as reducing costs to the NHS.

Randomised controlled trials should be carried out to compare the clinical and cost effectiveness of pharmacological interventions for anxiety disorders in this population. Several services may need to collaborate in order to ensure sufficient sample size. Researchers would need to take into account factors such as genotype and pharmacological treatment for other conditions when designing these trials. Important outcomes could include:

- effect on the mental health problem
- side effects
- cost effectiveness
- health-related quality of life.

G.5 Psychosocial interventions for people with more severe learning disabilities

For people with more severe learning disabilities, what is the clinical and cost effectiveness of psychosocial interventions to treat mental health problems?

G.5.1 Why this is important

People with more severe learning disabilities whose communication is non-verbal are likely to need tailored interventions to address mental health problems. Research is

particularly limited on mental health problems in people with more severe learning disabilities. Further research is needed into different types of interventions, such as social interactions and building resilience. This research would fill a need within mental health services, which are currently limited in their ability to provide effective interventions to this group.

Randomised controlled trials should be carried out to compare the clinical and cost effectiveness of psychosocial interventions, which may include multiple components, to prevent and treat mental health problems in people with more severe learning disabilities. Several services may need to collaborate in order to ensure sufficient sample size. Important outcomes could include:

- effect on the mental health problem
- cost effectiveness
- health-related quality of life.

When designing these trials, appropriate measures will need to be developed for mental health problems in people with more severe learning disabilities.

G.6 The experiences of people with learning disabilities and mental health problems in services

What experience do people with learning disabilities have of services designed to prevent and treat mental health problems and how does this relate to clinical outcomes?

G.6.1 Why this is important

Mental health service provision for people with learning disabilities is complex and varies across the UK. There appears to be no high-quality evidence or ongoing research for any particular approach. Evidence on the experiences, aspirations and mental health of young people as they prepare for adulthood would help in the development of preventative strategies. Evidence on what service models are most effective and acceptable to people with learning disabilities would help to improve service design, staffing decisions and patient outcomes. This is also an area of national priority, as explained in the NHS Five Year Forward View.

To understand what experience people with learning disabilities have of services, a series of studies covering the following should be conducted:

- The experiences and life course trajectories of young people (aged 13-17 years) in terms of their aspirations and goals, including whether the support they and their families get affects their mental health and their expected outcomes as they prepare for adulthood.
- The experience people have of mental health inpatient services (specialist learning disability services or non-specialist services), including factors that may have prevented the need for admission and how inpatient admission affects them. Studies should include economic modelling.
- The experience people have of being discharged from mental health inpatient services (specialist learning disability services or non-specialist services), after a stay of one year or more. In particular: the factors that may have helped them to be discharged earlier, what support is effective after discharge, and how to lower the risk of readmission.
- The experiences people have during a crisis, including how effective crisis support is in meeting their needs, minimising risk and helping them recover.
- The experiences of people with milder learning disabilities (including people on the autistic spectrum) and common mental health problems (such as anxiety or depression) in accessing community-based interventions.