NICE National Institute for Health and Care Excellence

Appendix A: Summary of evidence from surveillance

2020 surveillance of mental health problems in people with learning disabilities: prevention, assessment and management (2016) NICE guideline NG54

Summary of evidence from surveillance

Studies identified in searches are summarised from the information presented in their abstracts.

Feedback from topic experts was considered alongside the evidence to reach a view on the need to update each section of the guideline.

1.1 Using this guideline with other NICE guidelines

Surveillance proposal

This section of the guideline should not be updated. An editorial amendment will be made to recommendation 1.1.2 in order to cross refer to other relevant NICE guidelines that sit in the mental health services guideline group. This will ensure that some of the current gaps around independent advocacy, criminal justice settings and interventions for common mental health problems that would be relevant for this population are fully covered.

Intelligence gathering

This section of the guideline discusses improving the experience of care by referring to NICE Guidelines on service user experience in adult mental health, patient experience in adult NHS services, mental health and challenging behaviour and learning disabilities. It also recommends areas to consider which are specific to people with learning disabilities (LD) when using current NICE guidelines on mental health problems.

One topic expert suggested that the term learning disabilities should be amended to intellectual disabilities (ID). There is a paragraph in section 2.1.1 of the full guideline which states that 'the term learning disabilities is synonymous with the term 'intellectual disabilities', used commonly within the academic literature' and therefore it is felt that the commonalities between the two terms have been covered and the use of learning disabilities is suitable.

Intelligence was found which suggests that relevant information found in other NICE guidelines is missing from NG54, which would support this population further.

In particular, a topic expert noted the guideline does not discuss independent advocacy and that having appropriate access to advocacy services is essential for people with mental health conditions who communicate with health and care professionals. This population group may experience difficulty in expressing their views, having their feelings taken seriously, or being involved in decisions about their own care. Independent advocates can offer support where people with LD and mental health conditions may not have the confidence or knowledge needed. Recommendation 1.1.2 in NG54 suggests taking decision making capacity into account during care, however there is no mention of independent advocacy within the guideline.

NG108 Decision making and mental capacity was published after NG54 and was written for a population group with mental health problems and LD. This guideline discusses using advocacy to support decision-making and assessment under the Mental Capacity Act.

During the surveillance process it was noted that according to the scope, NG54 is also for the criminal justice setting, however there are very few recommendations that are specifically relevant to this setting. NICE have a guideline NG66 Mental health of adults in contact with the criminal justice system which published after NG54. This guideline includes adults with LD and gives relevant recommendations around assessment, management, risk assessment, risk management and care planning for this population group in this setting.

Another setting that was noted by one of our topic experts as needing further consideration was residential care settings. NG54 includes recommendations for care workers however, who may work in a variety of settings, including residential homes so it is not believed this is a gap in the guideline.

NG54 recommendation 1.1.2 suggests using this guideline alongside other NICE guidelines on specific mental health problems but it does not specifically cross refer to other Mental Health Services guidelines. Current NICE guidelines on mental health services such as CG123 Common mental health problems: identification and pathways to care recommend that when a person presents with a common mental health disorder and a mild LD or mild cognitive impairment, where possible healthcare professionals should provide or refer the same interventions as for other people with the same common mental health disorder. Therefore it is agreed that other NICE guidelines on mental health are relevant to this population group. However, NICE have grouped together some products on Mental Health Services which contain 9 published guidelines which are not specifically mentioned in NG54. Within these 9 guidelines are: NG108 Decision making and mental capacity; NG66 Mental health of adults in contact with the criminal justice system and CG123 Common mental health problems: identification and pathways to care. It is therefore suggested that this mental health services group should be cross referred to in recommendation 1.1.2 in order to ensure these are considered during the care of people with LD and metal health conditions.

Impact statement

No evidence was found during this surveillance review, but intelligence was considered which highlighted gaps in this guideline. These gaps were regarding independent advocacy; a

lack of recommendations relevant to criminal justice settings and a lack of recommendations relevant to residential settings. Residential settings are already covered by NG54 as all recommendations are written for carers, who may work in residential settings.

It is suggested that this section is amended to include a cross referral to NICE Mental Health Services guidelines group in order to address these gaps. This grouping includes relevant guidelines such as: NG108 Decision making and mental capacity guideline to empower people to make their own decisions about their care if possible and considered independent advocacy; NG66 Mental Health of adults in contact with the criminal justice system to assess and manage adults who may have LD and mental health problems in this setting; and the guideline CG123 Common mental health problems: identification and pathways to care which is relevant as it aims to improve access to services for adults and how mental health problems are identified and assessed, and makes recommendations on local care pathways. It is believed that using NG54 alongside these guidelines will strengthen the current recommendations and improve the care for this population group.

1.2 Organisation and delivery of care and support

Surveillance proposal

This section of the guideline should not be updated. An editorial amendment will be made to recommendation 1.1.2 of the guideline in order to cross refer to other NICE guidelines. This will ensure that some of the current gaps around discharge planning and follow up for outpatients that would be relevant for this population are fully covered.

2020 surveillance summary

A survey of children (1) (n=7,977) was conducted in the UK. It included those with ID and mental health problems; those with ID but without mental health problems; those with mental health problems but without ID and those children with no ID and no mental health problems. Its aim was to consider levels of access to specialist mental health services. The results showed that children with ID and mental health problems and children with only mental health problems access services at low rates, although no statistical data was provided in the abstract. The rates for these groups were higher however than the children who only had ID. The study concluded that low levels of service access suggest that there is unmet need among children with ID, mental health problems and those with both conditions.

A sequential mixed methods study (2) used 21 interviews with patients and carers in the UK to formulate a questionnaire that was completed by staff from The Improving Access to Psychological Therapies (IAPT) service and specialist ID services (n=452). The aim was to understand how people with ID were assessed by these services. The results suggested that being eligible to access these services was achieved dynamically and iteratively, by patients and their families and carers negotiating with staff and service structures. The barriers and facilitators to eligibility and access were noted as: identification; navigation; permeability of

services; appearances; adjudications; offers and resistance; and operating conditions. These were only presented as a list in the abstract and were not separated out into barriers or facilitators. No statistical data was provided within the abstract. It was concluded that the principles of inclusiveness within The Improving Access to Psychological Therapies (IAPT) service needed improvement.

A national register study (3) of two separate cohorts aged over 55 years, one with ID (n = 7936) and one without, considered data with the aim of showing the utilisation of inpatient and outpatient specialist psychiatric health care over a 10-year period. The results showed that patients with ID had an increased risk of visits to: unplanned inpatient (RR 1.95); unplanned outpatient (RR 1.59); planned inpatient (RR 2.02); and planned outpatient (RR 1.93) specialist psychiatric health care services compared with the general population. Those who were older in the cohort tended to utilise less health care services. Those who received psychiatric health care the previous year tended to have a higher risk of health care utilisation in the following year. Mental disorders in people with ID predicted increased risk of health care utilisation.

An observational study (4) considered two cohorts of adults in Canada (n=66484), one of individuals with intellectual and developmental disabilities (IDD) and one with IDD and mental illness. These groups were compared to those who had no IDD but did have mental illness. The aim was to assess the rate of hospital readmissions. The results showed that adults with IDD and mental illness were 1.7 times more likely to be readmitted to hospital within 30 days after discharge. No statistical data was reported in the abstract. The study concluded that discharge planning and outpatient follow-up is important in this population group.

An updated Cochrane review (5) (n=7 RCTs), the original of which was used in the development of NG54, considered interventions for delivering healthcare for adults with learning disabilities and mental health needs. In this update 1 extra RCT was included however the results of the Cochrane review remained the same. The review concludes that there is no high-quality evidence focusing on the organisation of health services for people with an ID and physical problems. There are also very few high-quality studies of organisational interventions targeting mental health needs.

A mixed method needs assessment (6) using focus group interviews was conducted with the aim of identifying gaps and challenges in delivering care for young people (n=126) with ID and mental health disorders in Australia. Six themes were identified. These were: access to services and information about services; communication between service providers and with clients and carers; the divide between mental health and ID; early intervention and health promotion; capacity building of service providers; and capacity building of clients and carers. No statistical data was provided within the abstract. It was noted that transition from child to adult services is a particularly challenging time for patients, families, and carers.

Transition

An observational study (7) was conducted with young people with ID (n=55) and a sample of age-matched controls. The aim of the study was to understand why the transition to

adulthood increases incidence of mental health disorders in young people with ID and methods of predicting mental health symptoms. The study considered potential risk and protective factors for anxiety and depression such as: demographic variables; coping styles; sense of hopelessness; unmet achievement of adulthood milestones; self-reflection; and insight. The results found that higher maladaptive coping styles increased depressive symptoms in both population groups. Young people with ID were less likely to have achieved adulthood milestones compared to those with no ID. Increased insight was associated with fewer anxiety issues, however young people with ID had lower levels of insight compared with young people with no ID. No statistical data was reported in the abstract. The study concluded that targeting insight and maladaptive coping could help predict anxiety and depression in young people with ID.

A cross sectional analysis (8) was completed of young people with (n=5556) and without (n=810,333) ID in Scotland using data from Scotland's Census 2011. The aim of the study was to compare the health of these population groups during their transition to adulthood and to understand whether transition to adulthood is associated with their health. Seven health outcomes were considered: general health; mental health; physical disabilities; hearing impairment; visual impairment; long-term illness; and day-to-day activity limitations. The results were adjusted according to age and gender and showed that young people with ID were more likely to have poorer health outcomes compared to those without ID. Young people with ID aged 19-24 were more likely to have poorer mental health than young people with ID aged 13-18. No statistical data was reported in this abstract. The study concluded that transition between child and adult services must be planned carefully to ensure that the increased development of mental health conditions are properly managed.

Intelligence gathering

This section covers: the organisation of effective care; staff coordination and communication; and staff training and supervision.

When considering the organisation of effective care, one topic expert asked the surveillance review to focus on implementation of services, the nature of services and access to services. Recommendations 1.2.1 and 1.2.2 already note that service delivery systems should be developed and implemented in partnership with patients and carers, and that care should be regularly audited to assess effectiveness, accessibility and acceptability. One patient group asked if there was any evidence around the effectiveness of specialist tertiary centres. Another topic expert suggested that patients need access to multi-disciplinary teams to ensure a holistic approach to meeting their needs. The recommendations in this section refer to designated leadership teams which consist of healthcare professionals, educational staff, social care practitioners and health and local authority commissioners and therefore it is believed that these recommendations do consider holistic approaches when considering need for this population group. No further intelligence on service delivery was found.

Another topic expert noted that there are few recommendations regarding delivery of care for children and young people in this guideline. The NHS Long Term Plan specifically focuses on the health of children with LD as a commitment within the service going forward. NG43

Transition from children's to adults' services for young people using health or social care services is cross referenced in NG54 and this guideline specifically references The Children and Families act. NG54 Recommendation 1.2.4 states that health and care professionals should ensure that young people with LD and mental health problems have in place plans that address their health, social, educational and recreational needs (including Education, Health and Care Plans), as part of their transition to adult services and adulthood.

A topic expert suggested that this guideline should recommend that out of area hospital admissions should be avoided. Recommendation 1.2.6 already notes that patients who need inpatient treatment should be treated within a locally available service where possible, so it is not felt this is an area that needs amending at this time. In regard to recommendations for outpatient treatment, NG53 Transition between inpatient mental health settings and community or care home settings has sections on hospital discharge and follow up support that would be useful for this population group. This guideline can be found under the mental health services link which NG54 will be cross referring to.

No intelligence was found in regard to staff communication or coordination.

In regard to the recommendations around staff training and supervision, the NHS Long Term plan states NHS staff will receive information and training on supporting people with a learning disability and/ or autism. Sustainability and Transformation Partnerships (STPs) and integrated care systems (ICSs) will be expected to make sure all local healthcare providers are making reasonable adjustments to support people with a learning disability or autism. One topic expert suggested that this guideline should link to the new mandatory training on learning disability and autism for all NHS staff. However, it is outside of NICE's remit to cover specific training. Recommendation 1.2.9 suggests areas that health and care professionals could be trained in if they are likely to come into contact with people with LD. The recommendations in NG54 are also for professionals who are not employed by the NHS and therefore they cannot be limited to assuming that all who are using the guidance have received appropriate training or link to training specifically for NHS staff. Therefore this section will not be updated.

Impact statement

Evidence was found from three studies to suggest that young people with LD and mental health problems have low rates of accessing specialist services and that access to services is a challenge for young people with ID and mental health disorders. Intelligence also suggested that NICE should consider the accessibility of services. There are no recommendations within NG54 about how to improve accessibility to services, or encourage patients to use services, however no further evidence was found to suggest solutions in this area. Therefore there will be no amendment to the guideline at this time. Intelligence requested that NICE consider the effectiveness of specialist tertiary services, the implementation of services and the nature of services, however no evidence was found for these areas either.

Three studies considered the transition of young people with LD into adulthood and concluded that this was a period of time when mental health problems are more prevalent in this population group. Two of the studies concluded that the transition between child and

adult services needed to be well planned and fully considered. Children's mental health is at the forefront of the NHS Long Term Plan. NG54 currently recommends putting plans in place for transition to adult services and adulthood and cross references to the NICE guideline on transition from children's to adults' services. This important area is therefore adequately covered and there will be no amendments to this section of the guideline.

Children's health is considered throughout this guideline, looked after children are specifically mentioned in a later section of the guideline, and no further evidence regarding children was found, therefore it is believed that children are adequately represented within the guideline and no amendment is needed.

Evidence was found to suggest that adults with intellectual and development disabilities and mental health problems had a higher rate of readmission to hospital. It was suggested that discharge planning and outpatient follow up were important areas of service. NG53 Transition between inpatient mental health settings and community or care home settings already covers these areas in this population group and is another guideline that is found under the mental health services section of NICE guideline. It is therefore reaffirmed that NG54 should ensure these guidelines are accessible and referred to.

Intelligence was considered around the need for staff training and avoiding out of area hospital emissions, both of which are either covered by recommendations within the guideline or are not usually specified within NICE guidelines, therefore no impact on this section of the guideline will be needed at this time.

1.3 Involving people with learning disabilities, and their family members, carers or care workers, in mental health assessment and treatment

Surveillance proposal

No new information was identified at the surveillance review.

This section of the guideline should not be updated.

1.4 Support and interventions for family members and carers

Surveillance proposal

This section of the guideline should not be updated. An editorial amendment will be made to cross refer to the NICE guideline on NG150 Supporting Adult Carers which will ensure that families and carers of people with ID and mental health problems are fully supported in order for them to provide the best possible care to those who rely on them.

2020 surveillance summary

Parents (n=100) of children with an ID were interviewed (9) from a child psychiatry outpatient department with the aim of understanding more about their mental health and challenges. Out of the sample 85% considered their child's ID to be a major concern to them. The severity of the ID did not affect the parental psychopathology. It was concluded that depression is the most common psychopathology within parents and that children with ID should be seen and treated as a family unit to ensure that parents' psychological needs are also considered.

An observational study (10) considered the observed and self-reported behaviour of parents (n=156) who had children aged 4 or 5 years, with ID. The aim of the study was to understand if parenting behaviour can cause the anxiety and depression that children with ID are at increased risk of developing. The study concluded that children with ID are at higher risk of receiving unsupportive, negative parenting compared to children of typical development. No statistical data was reported in this abstract. Children of fathers who were depressed were more likely to receive unsupportive parenting and in turn develop internalising behaviours such as anxiety and depression.

Intelligence gathering

This section covers support for people who care for those who have LD and mental health problems. It considers formally assessing families and carers regarding their own physical and mental health and recommends using specific NICE guidelines if mental health problems are found.

Two topic experts asked us to consider evidence regarding the effectiveness of social care personal budgets. No evidence or further intelligence was found regarding these.

One topic expert considered that there were gaps in NG54 regarding future care planning, advance care planning and replacement care. The expert suggested that these areas could be adequately covered by cross referencing to NG150 Supporting adult carers. This guideline recently published and contains recommendations regarding: assessing carer's needs and putting carer support plans in place; social and community support; training; psychological and emotional support for carers; and end of life care.

Impact statement

Evidence was found from 2 studies that suggests parental mental health is very important for the health and wellbeing of children with ID. The studies highlighted depression as being more prevalent in families of these population groups. NG54 gives advice on how to support family members and carers but it does not give recommendations around carer support plans, advance care planning or replacement care, which intelligence suggested was a gap that needed addressing. Therefore it is suggested that recommendation 1.4.1 cross refers to the NICE guideline NG150 Supporting adult carers which covers these areas to ensure that families and carers are fully supported.

Intelligence was found regarding social care personal budgets, however no further evidence or information was discovered to suggest a need to update the guideline at this time.

1.5 Social and physical environment interventions

Surveillance proposal

This section of the guideline should not be updated.

2020 surveillance summary

An observational study (11) considered the efficacy of a person-centred planning intervention in people with LD and challenging behaviour/or mental health problems (n=102). The aim of this intervention which coordinates a person's support, identifies outstanding needs and increases communication was to treat this population within the community and avoiding inpatient admissions. The study assessed the number of people admitted to the inpatient services before and after the intervention, the length of inpatient admissions and analysed qualitative feedback from participants. The results showed that following the intervention the number of inpatient admissions increased. There was a significant fall in the time individuals stayed in hospital however, and qualitative feedback showed that professionals, carers and patients saw this intervention as helpful. No statistical data was provided in this abstract.

Impact statement

No intelligence was found on this section. One study highlighted an intervention that was aimed at keeping patients out of hospital and treating them within the community, however the results did not show a positive impact on decreasing inpatient admissions. Therefore there will be no change to this section of the guideline at this time.

1.6 Annual health check

Surveillance proposal

This section of the guideline should not be updated.

An editorial amendment will be made to cross refer to the Learning Disability Annual Health Check electronic clinical template (2017) to ensure that NG54s recommendations have more information and more clarity in the way that annual health checks should be delivered.

2020 surveillance summary

A retrospective chart review (12) was conducted using physical health information from a standard head-to-toe assessment of adult outpatients with ID (n=78) in a specialist psychiatric service. These were compared to health information collated at intake and patient/carer perspectives. The aim of the study was to report rates of physical health issues and completion of recommended health screenings in adults with ID and mental health conditions. The results showed that patients with ID had at least one physical health issue

the majority of which had been missed during the intake examination. No statistical data was provided in this abstract.

Health assessments of adults (13) with ID (n=1023) and binary logistic regressions, adjusted for specific confounders, were used to establish association between independent and dependent variables. The aim of the study was to understand the association between physical ill health and mental ill health in people with ID and whether physical multi-morbidity can predict mental ill health. The results showed that physical multi-morbidity was not associated with mental ill health in this cohort, however that rates of physical multi-morbidity in this population were overwhelming.

An observational study (14) considered adults with ID (n=21,859) and adults without ID (n=152,846). The aim of the study was to evaluate whether annual health checks reduce emergency hospitalisation for adults with ID. The results showed that adults with ID were significantly more likely to have emergency hospital admissions than those without ID. The results also showed that annual health checks had no effect on overall emergency admissions compared with controls, however this result was not statistically significant. GP practices where annual health check participation was high showed a significant reduction in preventable emergency admissions for patients with ID, compared to those patients who had minimal participation.

Intelligence gathering

This section of the guideline covers recommendations regarding annual health checks for people with LD. One topic expert noted that recommendations around the care of physical health is limited in this guideline and there are gaps in regard to recommendations around health screening. During the development of NG54 the full guideline noted that "despite extensive review, no evidence was found that allowed the guideline committee (GC) to make recommendations about dietary and physical exercise interventions to prevent mental health problems. However, encouraging people to have a healthy lifestyle, and the provision of advice about diet and exercise, is one of the functions of the annual health check". During the surveillance review no further evidence was found regarding dietary and physical exercise interventions. The topic expert also asked for more clarity around who should deliver the annual health check, however recommendation 1.6.1 specifies that GPs should offer an annual health check.

During the surveillance review it was noted that NG96 Care and support of people growing older with LD provides more detailed recommendations around health checks and screening for older adults with LD. This includes information regarding health action plans, common age related concerns, dentistry and it also references the Care Act 2014. NG96 also covers "annual health checks" as a term within the guideline and clearly specifies this as "an NHS initiative for adults and young people aged 14 and over with learning disabilities to provide additional health support and help to identify health conditions that could otherwise go undetected" which is how these are described within the NHS Long Term Plan. However, NG96 is only for the adult population and does not includes children and young people. The NHS Long Term Plan notes that services should "ensure that children with learning

disabilities have their needs met by eyesight, hearing and dental services, (and) are included in reviews as part of general screening services". A cross referral to this NG96 therefore wouldn't be enough to cover these missing areas.

NHS England has a summary and overview of the Learning Disability Annual Health Check electronic clinical template (2017) which was published after NG54 and includes information around visual, hearing and dental and covers adults and young people aged 14 and over. It is suggested that NG54 cross references to this template to alleviate any concerns with clarification and absent information regarding annual health checks in people with LD.

Impact statement

Two studies suggested that physical health is a concern in people with LD. One study suggested that annual health checks were ineffective at reducing hospital admissions, however the results were not statistically significant. One topic expert suggested that the recommendations in this section were too limited and needed further clarification and information, especially around screening for physical health problems. No evidence was found that considered interventions to improve diet and physical exercise for this population group therefore there can be no amendment to the guideline in this area. However an NHS Learning Disability Annual Health template was found which contains more information and clarification around what an annual health check is and what it would consist of which includes information on health screening and diet. It is therefore suggested that NG54 cross references to this template in the preamble before the first recommendation in this section to ensure that during annual health checks all important information is fully covered and that people with LD and mental health conditions receive the best possible health care physically as well as mentally.

1.7 Identification and referral

Surveillance proposal

This section of the guideline should not be updated.

2020 surveillance summary

An observational study (15) analysed symptoms of dementia from a cohort of people with Down Syndrome (DS) (n=162) who were either stable, prodromal or who had Alzheimer's disease. The aim of the study was to understand the initial informant reported symptoms of dementia and its association with Alzheimer's disease in people with DS. The results showed that non-amnestic symptoms (such as disinhibition, apathy, and executive dysfunction) and amnestic symptoms were present before evidence of informant-reported cognitive decline. Reported symptoms increased as people progressed to Alzheimer's disease.

Intelligence gathering

One topic expert asked if NICE had found any evidence on other measures to define children's ID, rather than the use of the adult measures.

Impact statement

One study looked at symptoms that are usually early indicators, present prior to formal assessment, in people with DS who have dementia. Examples of non-amnestic symptoms were reported in the abstract to be disinhibition, apathy and executive dysfunction. Recommendation 1.7.1 covers these symptoms in their list which contains: loss of skills or needing more prompting to use skills; social withdrawal; irritability; avoidance; agitation; loss of interest in activities they usually enjoy. Therefore no amendment to the guideline is needed at this time.

No evidence was found regarding the best way to measure children's intellectual disabilities and therefore there will be no amendment to the guideline at this time.

1.8 Assessment

Surveillance proposal

This section of the guideline should not be updated.

2020 surveillance summary

A hierarchical cluster analysis (16) and a secondary data collection exercise was performed in 18 NHS provider organisations with the aim of extending the needs-based mental health classification system to accommodate those with ID. No statistical data was provided within the abstract. The study concluded that extending the needs-based mental health classification system can incorporate those with ID.

An observational study (17) created a new scale entitled Psychological Therapies Outcome Scale-Intellectual Disabilities with the aim of understanding psychological therapy outcome measures and tested it with people who had ID (n=175). There were three outcome measures: anger and mood; positive wellbeing; and anxiety. Psychological distress was measured by combining anger and mood and positive wellbeing. The results correlated with the Global Severity Index of the Brief Symptom Inventory. The study concluded that this scale was psychometrically robust and could be used with people with ID to measure their psychological distress and wellbeing.

A cross sectional study (18) considered children with ID (n=423) of which 35.4% had depression and/or anxiety. The aim of the study was to understand what factors are associated with depression and anxiety among this population group. Predictor variables included sociodemographics, ID severity, co-morbid conditions (ASD, epilepsy, cerebral palsy, DS and ADHD), physical factors (i.e. physical activity, sleep duration and pain) and social factors (e.g. participation in activities and bully victimisation). After adjustments were made for factors such as race and physical and social factors the following were seen to be

significantly associated with depression and anxiety in children with ID: ASD; DS; ADHD; pain; and bully victimisation.

A cross sectional study (19) of people with ID in England (n=229) who did not have specific mental health problems were examined to understand the association between self-reported stigma and symptoms of anxiety and depression (psychological distress). The results of the study showed that self-reported stigma was positively associated with psychological distress; higher use of health services; contact with the police; and service refusal. It was negatively associated with quality of life. No statistical data was provided in the abstract.

A narrative review (20) (n=17 studies) considered the role of shame associated with psychological distress in adults with mild-to-moderate ID. The results showed that adults with ID can experience difficulties with external and internal shame which can increase psychological distress.

Dementia assessments

A quasi-experimental study (21) performed Dementia Care Mapping on older people in the Netherlands who had ID (n=113) and compared the results with older people who had ID but received care as usual (n=111). The aim was to understand if Dementia Care Mapping influenced this population's quality of life. The results showed that Dementia Care Mapping had no significant effect on the quality of life of the intervention group. No statistical data was provided within the abstract.

A qualitative analysis (22) considered data from care staff; managers; behavioural specialists; Dementia Care Mappers and Dementia Care Mapper trainers (n=53). The aim of the study was to evaluate the use of Dementia Care Mapping in older adults with ID. The results showed that staff considered Dementia Care Mapping to be valuable because it provided new knowledge and skills. No statistical data was provided within the abstract. It was concluded that the tool supported staff in their work with older people with ID.

A multicentre validation study (23) in Italy evaluated the use of the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) in adults with ID (n=200). The study concluded that DSQUID is psychometrically valid and user-friendly and was therefore approved for use for dementia screening in adults with ID. No statistical data was provided within the abstract.

Intelligence gathering

This section covers recommendations around: conducting a mental health assessment; further assessment; assessment tools; risk assessment; mental health assessment during a crisis; and the mental health care plan.

During the surveillance process a number of NICE mental health guidelines were assessed for impact. These included: CG123 Common mental health problems: identification and pathways to care; CG91 Depression in adults with a chronic physical health problem: recognition and management and CG90 Depression in adults: recognition and management. These three guidelines have this same recommendation: "for people with significant language

or communication difficulties, for example people with sensory impairments or a learning disability, consider using the Distress Thermometer and/or asking a family member or carer about the person's symptoms to identify possible depression. If a significant level of distress is identified, investigate further". The Distress Thermometer is not mentioned in NG54, however many recommendations suggest using NICE guidelines on specific mental health problems which would cover these three guidelines and we have already suggested an editorial amendment above to cross reference to CG123.

One topic expert suggested that the section on mental health assessment during a crisis needed expanding to include preventing a crisis and community support. The Five Year Forward View suggests that there should be investment in crisis resolution and home treatment teams which will reduce the need to inappropriately send people out of area for non-specialist inpatient care. The NHS Long-Term Plan also states that "the NHS will ensure that a 24/7 community-based mental health crisis response for adults and older adults is available across England by 2020/21". NICE Guideline CG136 Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services is cross referenced in recommendation 1.1.1 in NG54 and contains a section on Assessment and Referral in a Crisis. No further intelligence was found regarding crisis management.

Public Health England have published a guidance on Dementia and people with learning disabilities: making reasonable adjustments - guidance which references NG54 and its recommendations around assessment for people with Dementia.

NHS England and Pathway Associates has published the *Beyond the high fence From the unheard voices of people with a learning disability, autism* or *both* document which states that according to NHS England policy everyone with a LD in a mental health hospital should have a care and treatment review every six months. There are no other recommendations in NG54 around when mental health reviews should take place, however during the development of NG54 it was noted that NICE guidelines do not usually make reference to policy documents, such as the NHS England documents, as they are guidelines based on the clinical evidence reviewed.

Impact statement

Evidence was found to show that a needs-based mental health classification system can incorporate those with ID, however the study does not specify which system in the abstract. NG54 recommendation 1.8.6 already states that during mental health assessments clinicians should establish or review a diagnosis using a classification system so no impact on the guideline is necessary at this time.

One study noted that the Psychological Therapies Outcome Scale was safe and effective to use with people with ID to measure their psychological distress and wellbeing. Intelligence found that other NICE guidelines recommend the Distress Thermometer to measure psychological distress. There is not enough evidence to recommend the Psychological Therapies Outcome Scale in this guideline and no further evidence or intelligence was found on this tool. NG54 already recommends using the guideline in line with other mental health

guidelines that recommend the Distress Thermometer. Therefore there will be no amendments to the guideline at this time.

Two studies highlighted risk factors for psychological distress in this population. These were ASD; DS; ADHD; pain; bullying and victimisation and self-reported stigma. One study highlighted shame as a risk factor. NG54 recommendation 1.8.4 suggests professionals should be aware of underlying physical health conditions or sensory or cognitive impairments and to also assess for problems that may be associated with particular behavioural phenotypes. Section 2.5 of the full guideline also lists associated characteristics and causes of distress and states that "People with learning disabilities can be the victim of bullying, harassment, hate crimes, and sadly stigma is not uncommon, and is associated with mental health problems in people with learning disabilities". Therefore this information is acknowledged within the guideline and no amendment of the guideline is needed at this time.

Three studies considered dementia care in this population group. Dementia Care Mapping was not seen as significantly effective in one quantitative study but was deemed to be useful by care workers in a qualitative study. No further evidence or intelligence was found on the effectiveness of this tool and therefore due to inconclusive evidence there will be no amendment to the guideline at this time. One study was found which advocated the use of the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID). This tool is already recommended in NG54 recommendation 1.8.16 and therefore there will be no amendment to the guideline at this time.

One topic expert asked NICE to expand the crisis management section of the guideline. NG54 cross refers to NICE Guideline CG136 Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services which contains a section on Assessment and Referral in a Crisis therefore there will be no amendment to the guideline at this time.

Current NHS Policy states that patients with a LD in a mental health hospital should have a care and treatment review every six months. This guideline recommends how to conduct an assessment and it is presumed that each setting will follow policy in regard to when this review should take place. Therefore there will be no amendment to the guideline at this time.

1.9 Psychological interventions

Surveillance proposal

This section of the guideline should not be updated.

2020 surveillance summary

A randomised controlled trial (RCT) (24) assigned adults with mild to moderate LD and depression in the UK to either the behavioural activation intervention (BeatIt) (n=84) or to a guided self-help intervention (StepUp) (n=77) for 12 months. The outcome was effect on the Glasgow Depression Scale for people with a Learning Disability (GDS-LD) score. People in

both groups showed significant improvement in outcomes, however the difference in outcomes between the two groups was not significant. Cost effectiveness was also evaluated with StepUp being considered the most cost effective, however no data was given for this in the abstract.

An observational study (25) compared three groups of children: those with LD and attention-deficit hyperactivity disorder (ADHD) who participated in the near-peer mentoring programme (n=99); those with LD and ADHD who did not participate in the near-peer mentoring programme (n=51); and those who had no LD or ADHD who did not need to attend a mentoring programme (n=81). Participants self-assessed regarding their own anxiety, depression, interpersonal relations, and self-esteem. The aim of the study was to assess whether mentoring interventions can help to alleviate socio-emotional impairments and mental health challenges that are associated with LD and ADHD. The results showed that children with LD and ADHD had higher levels of depression and lower levels of interpersonal relations than those children who did not have LD or ADHD. These scores were significantly and positively adjusted after mentoring, however no statistical data was provided in the abstract of this study. Those children who received mentoring were reported to have significantly stable scores, however the children who had LD and ADHD who were not mentored showed significant decreases in both self-esteem and interpersonal relations, and increases in depression.

An observational study (26) considered adults with mild LD (n=57) who received 2 30-minute therapeutic sessions, one with a dog and a therapist and the other with only a therapist. The participants completed The State-Trait Anxiety Inventory (STAI) before and after their therapeutic sessions. The aim of the study was to assess whether levels of anxiety decreased when a dog was present during therapy. The results showed a statistically significant decrease in levels of anxiety when a dog was present during therapy.

A literature review of qualitative and quantitative studies (n=11) (27) considered the use of cognitive behaviour therapy (CBT) in people with ID and: anxiety; depression; or a mixed clinical presentation. The results showed that CBT was feasible and well-tolerated and may be effective in reducing symptoms of depression in adults with mild ID.

A systematic review (n=12) and meta-analysis (28) considered the effectiveness of interventions for adults with mild to moderate ID and mental health problems. No significant effect was found with any type of intervention (psychotherapy, biological or system level) on any outcome (behavioural problems, depression, anxiety, quality of life and functioning).

An ongoing study was found which is looking at promoting positive behaviour and emotional readiness in special education children in a school setting.

Another ongoing study is considering a tablet app to support and empower people with learning disabilities to play an active role in their healthcare.

An ongoing study was found which is considering cognitive behaviour therapy for children with ASD to help them cope with their emotions and better handle day to day stress. This study is due to publish in 2022.

These studies will be monitored and results assessed for impact on publication.

Intelligence gathering

One topic expert suggested that exercise, pets and social interaction were useful interventions to consider for people with LD and mental health disorders. It is suggested that exercise and general nutrition would be covered and encouraged during the annual health check. There were also two references to positive attitudes and positive behaviour support. During the development of NG54 it was stated that no high-quality evidence was found for the use of Positive Behavioural support that would have allowed the committee to recommend its use. It was also noted that Positive Behaviour Support is not an intervention in itself but more of an overarching approach. Positive Behaviour Support is advocated in the STAMP programme which is discussed in the next section.

One topic expert enquired if there was any evidence regarding the efficacy of cognitive behavioural therapy for ASD. NICE's guideline CG142 Autism spectrum disorder in adults: diagnosis and management recommendation 1.6 covers interventions for coexisting mental disorders which recommends adaptations to the method of delivery of cognitive and behavioural interventions for adults with autism and coexisting common mental disorders.

Another topic expert enquired if there was any evidence regarding parent training and whether these should be held in groups of 10-15 people. They also asked why NICE recommend holding 8-12 sessions. No evidence was found during surveillance regarding parent training or the specific number that could be in a group however during the development of NG54 available evidence suggested that there was no difference in the clinical effectiveness between individual and group parent training; therefore group parent training was selected as it would be more cost-effective than parent training delivered individually. The committee also considered other benefits resulting from group psychological interventions, such as meeting with other parents and carers experiencing similar situations and exchanging such experiences, sharing ideas and receiving peer support, which was not captured within the existing evidence. During the development of NG54 the committee noted that the NICE guideline NG11 on people with learning disabilities and behaviour that challenges recommended group parent training typically consisting of 8 to 12 sessions lasting 90 minutes each and this was considered reasonable from a clinical and cost-effectiveness perspective. Moreover, the committee considered that a percentage of children with LD have both behaviour that challenges and mental health problems and parent training might be used to address both. Therefore, the committee decided to recommend the same number and duration of group parent training sessions for children with LD and mental health problems, given also that the same economic evidence base was used in both areas (i.e. children with LD and behaviour that challenges and children with LD and mental health problems).

Impact statement

Evidence was found regarding interventions which were successful at reducing psychiatric distress including: behavioural activation intervention; self-help intervention; CBT; mentoring

and the use of animals. Topic experts asked for evidence regarding the use of pets; positive behavioural support; exercise and social interaction.

Recommendation 1.9.1 states that health and care professionals should refer to NICE guidelines on specific mental health problems. CG90 Depression in adults: recognition and management gives recommendations around behaviour activation interventions and self-help interventions. CBT is already considered within Section 1.9 of NG54. There are no recommendations regarding mentoring for mental health problems or using animals to alleviate anxiety in this population. These interventions were not considered during the development of NG54 and only one study was found for each intervention through the surveillance review. Therefore there is not enough evidence on these interventions to amend the guideline at this time. Positive behaviour support has been noted to be an approach and not an intervention, exercise will be covered during the annual health checks and social interaction is noted as important in NG54 section 1.5 social and physical environment interventions. One systematic review and meta analysis stated that there are no effective psychological interventions for this population group. Therefore there will be no amendment to the guideline at this time.

One topic expert also asked for further information around parent training. No evidence was found regarding this intervention to amend current recommendations and therefore there will be no update to the guideline at this time.

1.10 Pharmacological interventions

Surveillance proposal

This section of the guideline should not be updated.

2020 surveillance summary

A population-based study (29) considered adults in Canada with intellectual and developmental disablities (n=51,881) with and without a psychiatric diagnosis who were receiving pharmacological interventions. The aim of the study was to see the prevalence of those who received more than one medication. The results showed that 39% of the cohort received pharmacological interventions and this rose to 56% when only those in care homes were considered. No statistical data was provided in the abstract however. It was noted that 28% of people prescribed antipsychotic medication did not have a documented psychiatric diagnosis. It was concluded that more attention should be given towards how antipsychotics are prescribed and monitored.

An observational study (30) identified data from a national register on prescription of antipsychotics in older adults with ID (n=7936). Those adults with severe/profound ID, behaviour impairment and those living in special housing were highly associated with prescriptions for sedating antipsychotics. The study concluded that antipsychotic medication

is prescribed for older people with ID who have not been diagnosed with psychiatric disorders.

A retrospective chart audit (31) considered patients with ID who had been referred to a specialised psychiatric outpatient clinic (n=517). The aim of the study was to identify predictors of psychotropic polypharmacy. The results showed that 70% of patients received at least one psychotropic medication, and 22% received psychotropic polypharmacy. No statistical data was provided within the abstract however. Being a woman; living in supervised residential settings; and receiving a psychiatric diagnosis in two or more diagnostic categories were positively associated with receiving psychotropic polypharmacy.

A population-based cohort study (32) considered patient characteristics including sociodemographic characteristics, measures of clinical comorbidity and health service use associated with antipsychotic initiation in adults with intellectual and developmental disabilities in Ontario (n=39244). Out of this cohort, 18% initiated a psychiatric drug, of which 27% had no psychiatric diagnosis. No statistical data was provided within this abstract. The results showed that being male, residing in a group home, prior use of antipsychotics, a recent visit to hospital or a visit to a psychiatrist were positively associated with antipsychotic initiation.

A cohort study using UK data from The Health Improvement Network (33) compared adults with ID who had been prescribed antipsychotic drugs (n=9013) to a control group of adults without ID who were prescribed antipsychotic drugs (n=34 242). The aim of the study was to note the prevalence of movement side effects. After adjusting for confounders, the results showed that the overall incidence of recorded movement side effects was significantly higher in those adults with ID than those without. The study concluded that professionals should assess for these side effects in people who have been prescribed antipsychotic drugs.

A mirror image and reverse mirror image study (34) considered data from national health registers in Denmark regarding people with ID who had been prescribed clozapine (n=405). This study aimed to investigate the effectiveness of clozapine initiation and termination on psychiatric admissions; inpatient days; self-harm; overdose and psychopharmacological treatment in patients with ID. The results showed that clozapine reduced hospital admissions, but this was non-significant. The results showed a significant decrease in inpatient days. There were no changes to incidents of self-harm; overdose; or psychopharmacological treatment. Terminated hospital admissions rose significantly in adults who had clozapine terminated.

A cohort study (35) considered people (n=7936) with and without ID, autism spectrum disorder (ASD) and dementia. The aim was to investigate the use of antipsychotics, benzodiazepine derivatives, and drugs in this population group. The results showed that people with ID, ASD and dementia were significantly more likely to receive antipsychotics than those with ID, ASD but without dementia, or those with just dementia and no ID or ASD.

Intelligence gathering

Intelligence was found regarding the NHS England programmes on Stopping The Over-Medication of children and young People with a learning disability, autism or both (STOMP) and Supporting Treatment and Appropriate Medication in Paediatrics (STAMP). These are focusing on reducing pharmacological interventions and increasing the use of psychological interventions in children and young people with LD.

Impact statement

One study considered the use of clozapine in people with ID and mental health disorder. This drug had some effect on time in hospital, however a non-significant effect on admission to hospital. Section 1.10 refers to the NICE guidelines on specific mental health problems and one of these is CG178 Psychosis and schizophrenia in adults: prevention and management which recommends the use of clozapine in certain circumstances.

Evidence was found to suggest that there is a high prevalence of pharmacological intervention use in people with ID and intelligence supported this fact. Four studies were found to suggest that people with ID are more likely to be prescribed antipsychotic medication, even if they have not been diagnosed with a psychiatric condition. Four studies were found to suggest that living in a residential setting was associated with a higher prescription rate of antipsychotics. Another study highlighted that movement side effects should be considered when prescribing pharmacological interventions for this population group.

Section 1.10 sets out specific principles for delivering pharmacological interventions to this population group. NG54 recommends considering all health conditions; establishing a review schedule to reduce polypharmacy; monitoring and reviewing the benefits and possible harms or side effects; and for those who have no psychotic symptoms annually documenting the reasons for continuing the prescription if it is not reduced or discontinued. These recommendations are for all health and care professionals, including those working in care homes. It is therefore believed that NG54 Section 1.10 makes adequate recommendations for the safety of this population group when prescribing pharmacological interventions and there is no need to amend this section of the guideline at this time.

1.11 Occupational interventions

Surveillance proposal

No new information was identified at this surveillance review.

This section of the guideline should not be updated.

Areas not currently covered in the guideline

In surveillance, evidence was identified for areas not covered by the guideline. This new evidence has been considered for possible addition as a new section of the guideline.

Grief and bereavement in people with learning disabilities

Surveillance proposal

This section should not be added.

2020 surveillance summary

An observational study (36) considered questionnaires completed by professionals (n=149) evaluating the grieving process of adults with ID (n=380). The aim of the study was to examine the characteristics associated with the grieving process among this population group. The results showed three dimensions: understanding of the concept of death, coping with the loss and post-bereavement reactions. There were significant differences associated with level of ID, time since loss and residential setting, however data was not given to confirm these results.

An observational study (37) from the US with a thematic analysis approach considered the perceptions of the grief process of people with intellectual and developmental disabilities according to their care workers (n=60). The results showed three themes: reactions to loss; processing the loss and incorporating the loss. There were no statistical data in the abstract however. The study concluded that more tailored support systems could be put into place.

Intelligence gathering

One topic expert noted that many people with LD are being cared for by elderly parents and they asked NICE to consider if there is any evidence about grief, bereavement and the mental health impact on people with LD. NG54 does not currently have any recommendations on how to care for people with LD who are suffering from bereavement.

Impact statement

Intelligence asked for the surveillance review to consider the effects of grief and bereavement in this population group. Two studies were found which noted the characteristics of dealing with grief which were similar to the way people who do not have ID cope with grief, however this was not confirmed within the studies. No studies were found which compared people with and without ID regarding the assessment or management of grief. NICE does not have any guidelines which currently give specific advice around grief in any population group. As there is limited evidence around this area, no amendments to the guideline will be made at this time.

Trauma informed care in people with learning disabilities

Surveillance proposal

This new section should not be added.

2020 surveillance summary

A cross sectional study (38) from 2 mental health trusts in the Netherlands aimed to understand the association between trauma and ID in severely mentally ill patients (n=570), 40% of which had borderline intellectual functioning. Trauma was assessed using the Trauma Screening Questionnaire. The results showed that trauma was found in 86% of patients with 42% having suspected post traumatic stress disorder (PTSD). Out of those patients with borderline intellectual functioning, a higher percentage were associated with traumatic experiences compared to those who did not have borderline intellectual functioning, although statistical data regarding the significance of this was not given.

Clinical interviews (39) were conducted with people who had ID (n=56). The aim of the study was to understand the association between child maltreatment and mental health problems. Participants were asked to self-report on childhood abuse, PTSD, and depression. Of those interviewed 87% reported at least one aversive experience on the family violence spectrum, and 50% reported a violent physical attack later in adulthood. 25% were diagnosed with PTSD and almost 27% had a critical score on the depression scale. No statistical data was provided within the abstract. Child abuse in the family was the only independent predictor of PTSD symptom severity. The study concluded that child maltreatment can increase risk of mental health problems in adulthood in people with ID.

This observational study (40) aimed to validate the adapted PTSD section of the Anxiety Disorders Interview Schedule for Children (ADIS-C) for the assessment of PTSD in children (n=80) with mild to borderline ID. Children were interviewed using this adapted interview schedule and were assessed using the DSM-IV-TR and DSM-5 criteria. The results from both tests closely matched which supported the reliability and validity of their adapted interview schedule in children with mild to borderline ID. No statistical data was provided within the abstract. The study concluded that this clinical interview could help improve detection of PTSD and the need for trauma focused intervention for this population group.

A cross-sectional study (41) involved outpatient and inpatient children with intellectual and developmental disabilities and mental health problems (n=330) who were assessed by clinicians. The aim of the study was to see if patient type, safety risk, exposure to trauma and family dysfunction were related to service complexity. The results showed that older age, higher family dysfunction, higher safety risk and high cumulative trauma were associated with higher service complexity in outpatients. There was no data within the abstract to confirm this however.

A systematic review (42) of group studies (n=8) and case studies (n=10) considered trauma reactions in individuals with ASD and ID. The aim of the study was to see if ASD or ID influenced the risk of and vulnerability to exposure to trauma and adverse events. The

results showed that symptoms involving alterations in thought and behaviour were more easily identified than symptoms of reexperiencing and avoidance. Warning signs of trauma and abuse are therefore difficult to identify in this population group.

An ongoing study is considering whether eye movement desensitisation and reprogramming (EMDR) is an effective treatment for people with ID who have been exposed to traumatic events. This study is due to publish in 2024 and the results will be assessed for impact on publication, however this study will be more relevant to the NICE guideline NG116 Post-traumatic stress disorder.

Intelligence gathering

Intelligence was found from 3 topic experts which highlighted the importance of assessing and managing trauma in this population group as they are at high risk of experiencing trauma due to the lack of timely and appropriate care and support. Two topic experts asked if there was any evidence whether early intervention on the effects of childhood trauma could prevent mental health disorder and challenging behaviours.

One topic expert asked NICE to consider trauma and attachment-based models of diagnosis and interventions and another noted that children, young people and adults with severe LD who also have challenging behaviour, are at increased risk of experiencing trauma and other mental health problems, and therefore should also be highlighted as a group for whom special considerations should be made in regard to their social and physical environment. The topic expert went on to say that this is especially important as there is currently a significant move in social care to trauma-informed approaches, including peer support workers and the development of resilient communities.

The Department of Health recommend in their Core Capabilities Framework for Supporting Autistic People that care workers should understand the potential role of traumatic events in the lives of autistic people, including by families and peers such as childhood neglect and bullying and be able to provide trauma informed care so that autistic people are not traumatised by services.

NG11 notes that as part of the initial assessment of behaviour that challenges, care workers should take into account life history, including any history of trauma or abuse. NG54 does not make any recommendations around trauma or trauma informed care currently.

During the development of NG54 the committee noted that no studies were identified which met the inclusion criteria for areas such as anger, personality disorders, PTSD, trauma, and the assessment of communication. The committee decided not to make any recommendations other than referring to relevant NICE guidelines for those disorders where effective implementation of the assessment and intervention recommendations requires that practitioners follow advice on assessment and outcome measures provided in the guideline. During the development of NG54, a controlled before-and-after trial was found which compared CBT versus Applied Behaviour Analysis (ABA) for children with trauma which appeared to show that ABA is favourable over CBT on most subscales on the Achenbach assessment tool. However, this study was considered to be low quality. As such, the

committee did not consider that they could draw any conclusions from this evidence on the treatment of PTSD. They were particularly concerned about the lack of evidence on PTSD in people with LD as they are a vulnerable group who are at risk of trauma, abuse and neglect. No further evidence was found regarding ABA during the surveillance review.

NICE currently have guidelines NG116 on Post Traumatic Stress Disorder which would be valid for this population group and NG10 Violence and aggression: short-term management in mental health, health and community settings which is due to be updated to incorporate recommendations around trauma informed care and support. NG10 can be found in the list of guidelines under mental health services. For the care of children, NG45 already refers to PH28 Looked after children and young people, which refers to trauma and post traumatic stress.

Impact statement

Evidence and intelligence was identified that stated that effects of trauma were found in the majority of people who had ID. It was also noted that PTSD was high in this population group. One study showed that high levels of trauma were associated with service complexity and that children who suffer from maltreatment tend to have a higher prevalence of mental health disorders. A topic expert asked if early intervention could help this population group, however another study noted that it is very difficult to notice warning signs for trauma or PTSD. One study used the Anxiety Disorders Interview Schedule for Children (ADIS-C) for the assessment of PTSD and the results were favourable, however this was not compared to any other assessment tools.

NG54 does not currently contain any recommendations regarding trauma informed care or PTSD assessment. However very little evidence was found regarding the early identification, assessment or management of trauma within this population therefore there is not a strong case for adding this as a new area of the guideline at this time. The guideline does refer to NG11 which suggests history of trauma and abuse should be considered in this population group. The guideline will also cross refer to mental health services guidelines which will include NG10 Violence and aggression which will soon contain further information regarding trauma informed care. It is suggested that this area is highlighted as one to consider at the next surveillance review and that the research recommendation requesting further research for CBT for anxiety disorders such as generalised anxiety disorder, obsessive compulsive disorder and post-traumatic stress disorder remains within the guideline.

Research recommendations

1) 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.

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

2) Development of and validation (including diagnosis) of assessment tools for mental health problems in people with learning disabilities.

Summary of findings

A new scale entitled Psychological Therapies Outcome Scale-Intellectual Disabilities with the aim of understanding psychological therapy outcome measures was shown to be robust when used with people with LD. However there was not enough evidence regarding the efficacy of this tool in terms of patient-reported outcomes for it to be included in the guideline.

Two studies considered Dementia Care Mapping. One study found its use offered no significant improvement in people's quality of life, however one study found that Dementia Care Mapping was valuable for health and care professionals. There was not enough evidence regarding the efficacy of this tool in terms of patient-reported outcomes for it to be included in the guideline.

3) 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?

Summary of findings

No new evidence relevant to the research recommendation was found. An ongoing study was found which is considering cognitive behaviour therapy for children with ASD to help them cope with their emotions and better handle day to day stress.

4. 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?

Summary of findings

A literature review of qualitative and quantitative studies (n=11) considered the use of cognitive behaviour therapy (CBT) in people with ID and: anxiety; depression; or a mixed clinical presentation. The results showed that CBT was feasible and well-tolerated and may be effective in reducing symptoms of depression in adults with mild ID. The cost-effectiveness was not considered. This evidence does not affect the current recommendations which state "Consider cognitive behavioural therapy, adapted for people with learning disabilities (see recommendation 1.9.2 on intervention adaptation methods), to treat depression or subthreshold depressive symptoms in people with milder learning disabilities".

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

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified. Topic experts asked NICE to specifically consider this population during the surveillance review.

6. 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?

Summary of findings

Evidence was found from three studies to suggest that young people with LD and mental health problems have low rates of accessing specialist services; that the access of services relies on iterative negotiation between carers and services and that access to services is a challenge for young people with ID and mental health disorders. There was no evidence to state how this relates to clinical outcomes however, and therefore no further recommendations around accessibility are suggested for this guideline.

7. Develop patient-reported outcome and experience measures for use with people with learning disabilities and mental health problems.

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

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

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

9. What is the clinical and cost effectiveness and safety of pharmacological interventions such as antipsychotics for ADHD or conduct disorder in children with learning disabilities?

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

10. In people with learning disabilities, what is the clinical and cost effectiveness of physical exercise for reducing anxiety or depressive symptoms?

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

11. For people with learning disabilities, what is the clinical and cost effectiveness of social networks, or other social interventions, for improving the symptoms of severe mental health problems?

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

12. For people with milder learning disabilities, what psychosocial interventions (either adapted from those used in the non-learning disabled population or developed specifically for those with learning disabilities), are effective for the treatment of mental health problems?

Summary of findings

Evidence was found regarding interventions which were successful at reducing psychiatric distress including: behavioural activation intervention; self-help intervention; mentoring and the use of animals. Behavioural activation interventions and self-help interventions were included in other NICE guidelines developed for specific mental health problems. Not enough evidence was provided regarding the use of distress thermometers or dementia care mapping tools for them to be included in the guideline.

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

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

14. For people with milder learning disabilities, what is the clinical and cost effectiveness of delivering treatment for psychosis within a learning disabilities service, compared with a generic mental health service (including with support from learning disabilities specialists)?

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

15. For people with milder learning disabilities, what is the clinical and cost effectiveness of delivering treatment for mental health conditions other than psychosis within a learning disabilities service, compared with a generic mental health service including with support from learning disabilities specialists?

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

16. What is the clinical and cost effectiveness of interventions for the health and well-being of family carers and staff caring for people with learning disabilities and mental health problems?

Summary of findings

No new evidence relevant to the research recommendation was found and no ongoing studies were identified.

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