



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

Surveillance report

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## Surveillance decision

We will not update the guideline on mental health problems in people with learning disabilities (NICE guideline NG54).

## Reasons for the decision

New evidence and information identified during surveillance was considered not to have an impact on current guideline recommendations. Overall, new evidence found was considered to support the current recommendations or, for areas where only 1 study was found, it was felt that additional evidence was needed to confirm results, therefore no impact on the recommendations is anticipated. It was noted during surveillance that some of the gaps within the recommendations can be rectified by cross referencing to other NICE guidelines or Department of Health and Social Care documents that have published since the guideline was developed and therefore, there will be some editorial amendments made to the guideline.

Evidence or intelligence was identified during surveillance in the following areas of the guideline:

## Independent advocacy

Topic expert feedback 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. It is noted that [NICE's guideline on decision making and mental capacity](#) was published after NICE guideline NG54 and was written for a population group with mental health problems and learning disabilities. This guideline discusses using advocacy to support decision making and assessment under the Mental Capacity Act. It is therefore suggested that NICE guideline NG54 should be used alongside this guideline as well as other [mental health services guidelines](#) and these will be cross referred to from NICE guideline NG54 recommendation 1.1.2. NICE is also developing a guideline on [advocacy services for adults with health and social care needs](#) and this will be assessed for impact on publication.

## Criminal justice settings

NICE guideline NG54 is applicable to the criminal justice setting, however there are very few recommendations that are specifically relevant to this setting. [NICE's guideline on mental health of adults in contact with the criminal justice system](#) published after NICE guideline NG54. This guideline includes adults with learning disabilities and gives relevant recommendations around assessment, management and care planning for this population group in this setting. It is therefore suggested that NICE guideline NG54 should be used alongside this guideline as well as other [mental health services guidelines](#) and these will be cross referred to from NICE guideline NG54 recommendation 1.1.2.

## Discharge planning and outpatient follow up

Evidence was found to suggest that adults with intellectual and developmental disabilities and mental health problems had a higher rate of readmission to hospital for any reason. It was suggested by topic experts that discharge planning and outpatient follow up were important areas of service. [NICE's guideline on transition between inpatient mental health settings and community or care home settings](#) already covers these areas in this population group. It is therefore suggested that NICE guideline NG54 should be used alongside this guideline as well as other [mental health services guidelines](#) and these will be cross referred to from NICE guideline NG54 recommendation 1.1.2.

## Supporting adult carers

Topic expert feedback highlighted gaps in NICE guideline NG54 regarding future care planning, advance care planning and replacement care. Feedback suggested that these areas could be adequately covered by cross referencing to [NICE's guideline on supporting adult carers](#). The NICE guideline on supporting adult carers 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. It is therefore suggested that recommendation 1.4.1 in NICE guideline NG54 cross references to this guideline in order to support carers further.

## The content of the annual health check

Topic expert feedback suggested that the recommendations around the annual health check were too limited and needed further clarification and information, especially around screening for physical health problems. The NHS Long Term Plan also states that the NHS

will bring hearing, sight and dental checks to children and young people with a learning disability. 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 [the NHS Learning Disability Annual Health Check electronic clinical template](#) (2017) contains more information and clarification around what an annual health check is and what it would consist of, which includes information on health screening, diet, hearing, sight and dental checks. It is therefore suggested that the preamble text before recommendation 1.6.1 in NICE guideline NG54 cross references to this template in order to improve the clarity and implementation of these recommendations.

Some topic experts and stakeholders requested NICE focus on other gaps in the guideline, however limited evidence and intelligence was found in these areas therefore no amendments to the guideline will take place. These areas included: service accessibility and attendance; social care personal budgets; psychological interventions; grief and bereavement and trauma informed care.

For further details and a summary of all evidence identified in surveillance, see [appendix A](#).

# Overview of 2020 surveillance methods

NICE's surveillance team checked whether recommendations in [NICE's guideline on mental health problems in people with learning disabilities](#) remain up to date.

The surveillance process consisted of:

- Feedback from topic experts and patient groups via a questionnaire.
- A search for new or updated Cochrane reviews and national policy.
- Examining related NICE guidance and quality standards and NIHR signals.
- A search for ongoing research.
- Examining the NICE event tracker for relevant ongoing and published events.
- Literature searches to identify relevant evidence.
- Assessing the new evidence against current recommendations to determine whether or not to update sections of the guideline, or the whole guideline.
- Consulting on the proposal with stakeholders.
- Considering comments received during consultation and making any necessary changes to the proposal.

For further details about the process and the possible update decisions that are available, see [ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual](#).

## Evidence considered in surveillance

### Search and selection strategy

We searched for new evidence related to the whole guideline and, after liaising with topic experts, also added the search terms: bereavement; grief; and trauma.

We found 36 studies in a search for observational studies and randomised controlled trials

published between 1 December 2015 and 6 May 2020.

We also included:

- 4 relevant studies from a total of 29 identified by topic experts
- 1 study identified through comments received after publication of the guideline.

From all sources, we considered 41 studies to be relevant to the guideline.

See [appendix A](#) for details of all evidence considered, and references.

## Selecting relevant studies

Studies were excluded if they were conducted in countries outside of the Organisation for Economic Co-operation and Development (OECD) or the population sample was below 50 as per the full guideline inclusion criteria.

All studies suggested by topic experts were included if they were within the included study design from the original guideline development.

## Ongoing research

We checked for relevant ongoing research; of the ongoing studies identified, 4 studies were assessed as having the potential to change recommendations. Therefore, we plan to check the publication status regularly and evaluate the impact of the results on current recommendations as quickly as possible. These studies are:

- [Promoting positive behaviour and emotional readiness in special education children: Effectiveness of a school-wide health care policy TIME-IN.](#)
- [My Health Guide: A trial of a tablet app to support people with learning disabilities.](#)
- [The Secret Agent Society: Operation Regulation intervention - transdiagnostic trial.](#)
- [A therapist-led treatment for symptoms of post-traumatic stress disorder \(PTSD\) in adults with intellectual disabilities \(ID\) using eye movement desensitisation and reprocessing \(EMDR\).](#)

## Intelligence gathered during surveillance

### Views of topic experts

We considered the views of topic experts who were recruited to the NICE Centre for Guidelines Expert Advisers Panel to represent their specialty. For this surveillance review, topic experts completed a questionnaire about developments in evidence, policy and services related to the guideline.

We received 9 questionnaire responses from: an academic professor; a pharmacist; a paediatrician; a physiotherapist; a commissioning manager; a speech and language therapist; a voluntary worker; a nurse and NHS England. We also received a questionnaire response from a charity.

The main areas of topic expert interest were:

- Independent advocacy (see [reasons for the proposal](#)).
- Implementation of services. NICE guideline NG54 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. No further evidence or intelligence was found in this area therefore there will be no impact to the guideline.
- Care of children and young people. [NICE's guideline on transition from children's to adults' services for young people using health or social care services](#) is cross referenced in NICE guideline NG54 and this guideline specifically references The Children and Families act. NICE guideline NG54 recommendation 1.2.4 states that health and care professionals should ensure that young people with learning disabilities 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. Therefore it is believed that this area is adequately represented within the guideline across the NICE portfolio of guidance and no amendment is needed.
- Social care personal budgets. No evidence was identified to suggest a need to update the guideline at this time.
- Support for carers (see [reasons for the proposal](#)).

- The lack of clarification and content of annual health checks (see [reasons for the proposal](#)).
- Psychological interventions such as pets and parent training. Only 1 study was found regarding the efficacy of interventions involving pets and no evidence was found to contradict the current recommendation around parent training, therefore there will be no amendment to the guideline at this time.
- Grief and bereavement in people with learning disabilities. Two studies were found that noted the characteristics of dealing with grief in this population group were similar to the way people who do not have intellectual disabilities cope with grief. No studies were found that compared people with and without intellectual disabilities regarding the assessment or management of grief. As there is limited evidence around this area, no amendments to the guideline will be made at this time.
- Trauma informed care. NICE guideline NG54 does not currently contain any recommendations regarding trauma informed care or post-traumatic stress disorder assessment. 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 NICE's guideline on challenging behaviour and learning disabilities, however, which suggests history of trauma and abuse should be considered in this population group.

## Implementation of the guideline

Topic experts and stakeholders suggested that the guideline is not being implemented in practice because the recommendations were not specific with clear details of responsibility and accountability. The use of guidelines in practice was also reported as being unpredictable, slow and complex. This information was forwarded to our implementation team for them to consider whether action is needed.

## Views of stakeholders

Stakeholders are consulted on all surveillance reviews except if the whole guideline will be updated and replaced. Because this surveillance proposal is to not update the guideline, we consulted with stakeholders.

Overall, 7 stakeholders commented. Comments were received from 3 Royal Colleges, NHS

England, 2 charities, and the Care Quality Commission. Five agreed with the decision not to update and 2 (1 Royal College and 1 charity) did not agree. Of those that did not agree with the surveillance proposal, 1 organisation believed that the guideline should include more guidance around grief and bereavement and trauma informed care. They also requested that the guideline be firmer in its recommendations that annual health checks should be completed each year. The other organisation requested that the guideline be updated to include recommendations regarding dysphagia.

After considering the stakeholders comments, the surveillance decision remains the same. Limited evidence was found regarding grief, bereavement and trauma informed care and the guideline already recommends that health checks should be provided annually by GPs. The guideline also only considers the prevention, assessment and management of mental health in people with learning difficulties and any neurological conditions related to this are out of scope.

Stakeholders were also asked about their views on the impact of COVID-19 on services. Concerns were raised around the fact that many people with learning disabilities and/or autism were not having their health and support needs appropriately met, especially with the move to online care. Comments were also made regarding mental illness being the next wave of the pandemic. It was noted that the impact is clearly higher in children who are differently abled. This equality issue has been flagged for consideration across the COVID-19 rapid guidance suite. The issue around face-to-face appointments being replaced by virtual appointments is currently being investigated across the NICE guideline portfolio. NHS England have also voiced their concerns over the impact of COVID-19 on this population group in their document [Implementing phase 3 of the NHS response to the COVID-19 pandemic](#) where the importance of the annual health checks are reaffirmed.

See [appendix B](#) for full details of stakeholders' comments and our responses.

See [ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual](#) for more details on our consultation processes.

## Equalities

The following equalities issues were identified during the surveillance process:

## **Access to mental health services among people with autism**

It was noted that autism is commonly a barrier to accessing mental health services for children with mild or moderate learning disabilities. No evidence was found regarding service delivery for this population and therefore no amendments to the guideline were considered necessary at this time. Recommendations on organisation and delivery of care can be found in [NICE's guideline on autism spectrum disorder in adults: diagnosis and management](#).

### **Age**

No specific evidence regarding the elderly and the very young was identified during guideline development or this surveillance. However, the guideline committee did attempt to address these issues with recommendations around transition (recommendation 1.2.4) and with specific recommendations relating to the identification (recommendation 1.5.5) and assessment (recommendation 1.6.16) of possible dementia. No amendments to these recommendations were considered necessary at this time.

## **Health inequalities and premature mortality and morbidity**

[NICE's guideline on community engagement: improving health and wellbeing and reducing health inequalities](#) covers community engagement approaches to reduce health inequalities, ensure health and wellbeing initiatives are effective and help local authorities and health bodies meet their statutory obligation. No evidence was found regarding this equality issue during the surveillance process therefore no amendments were considered necessary to the guideline at this time.

## **Cultural difference in understanding of mental health and approaches to treatment**

During development of the guideline, a potential equality issue regarding ethnicity was identified and the following recommendations were included: recommendation 1.2.2 '...provide a person-centred integrated programme of care' and recommendation 1.2.8 'all people...should have a key worker who...helps services communicate with the person and their family...in a format and language suited to the person's needs and preferences'. No further evidence was found during surveillance regarding the understanding of mental health and approaches to treatment in different cultures and therefore no amendments to the guideline were considered necessary at this time.

## **Gender and transgender**

One stakeholder noted that there were no recommendations within the guideline that were specific to gender or for transgender people with learning disabilities. No evidence was found to suggest that these population groups required different interventions and therefore no amendment to the guideline is needed at this time.

## **Overall decision**

After considering all evidence and other intelligence and the impact on current recommendations, we propose that no update is necessary.

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