

**Research Briefing**

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# Learning disabilities: health policies



## Summary

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## Summary

Around 1.5 million people in England have a learning disability. The Government and NHS England are working to reduce health inequalities for people with a learning disability and have established national programmes to improve care and outcomes.

Tackling learning disabilities is one of the clinical priority areas in the [NHS Long Term Plan](#) (January 2019). The Plan committed the NHS to tackling the causes of morbidity and premature death for people with these conditions and set several targets, such as increasing annual health checks for people with a learning disability, introducing designated keyworkers for children and young people, and halving inpatient care for this group by 50% by 2023/24 (compared to 2015 levels).

[In February 2023, there were 2,045 people with a learning disability and autistic people receiving inpatient care](#), of which over half (56%) had a total stay of two years or longer.

The [Health and Care Act 2022](#) introduced a new legal requirement for all health and social care service providers registered with the Care Quality Commission (CQC) to provide employees with training on autism and learning disabilities (called [Oliver McGowan Training](#)).

In July 2022, the Department for Health and Social Care (DHSC) published an updated [Building the right support for people with a learning disability and autistic people: action plan](#) focusing on six areas to develop community services and reduce reliance on inpatient mental health beds.

The Government also proposed in the [Draft Mental Health Bill 2022](#) to amend the criteria for detention under the Mental Health Act 1983, so a person could not be subject to long-term detention for treatment for autism or a learning disability.

NHS England's [learning from lives and deaths reviews programme \(LeDeR\)](#) (formerly known as the learning disability mortality review) started in April 2017.

LeDeR is a programme which aims to improve care, reduce health inequalities, and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people received.

Integrated Care Systems (ICSs) are now responsible for ensuring that LeDeR reviews are completed on the health and social care received by people with a learning disability and autistic people (aged four years and over) who have died. ICSs are also responsible for ensuring the implementation of actions to

improve the quality of services for people with a learning disability and autistic people to reduce health inequalities and premature mortality.

# 1

## Health policies

There are approximately 1.5 million people with a learning disability in England. There have been successive Government and NHS policies to improve outcomes for this group. On average, the life expectancy of women with a learning disability is 18 years shorter and for men is 14 years shorter than in the general population.<sup>1</sup>

The [Government's 2022-23 mandate to NHS England](#) focused on improving services for people with learning disabilities and on supporting them in the community to reduce reliance on mental health inpatient care. This was felt to be particularly important given the impact of COVID-19 on access to NHS services.

Information on Government and NHS programmes of work to improve care and outcomes is provided in the following sections.

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<sup>1</sup> NHS Digital, [Health and Care of People with Learning Disabilities: Experimental Statistics: 2016 to 2017](#)

## 2

## The NHS Long Term Plan

Tackling learning disabilities is one of the clinical priority areas in the [NHS Long Term Plan](#) (January 2019). The Plan committed the NHS to tackling the causes of morbidity and premature death for people with these conditions, and set several targets:

- The plan included a target to increase the uptake of **annual health checks** for people with a learning disability to at least 75% of those eligible. This was achieved in June 2021 (see Box 1).

### 1 Learning disability health check scheme

The [health check scheme](#) is an enhanced service for General Practitioners (GPs) who receive an additional payment from NHS England for each qualifying check.

The checks are available to patients aged 14 and over and should be offered to everyone on a GP learning disability register. To support practices and to ensure they have an accurate and complete register of these patients, NHS England has published guidance on [Improving identification of people with learning disability](#).

In June 2021, three quarters of people with a learning disability aged 14 and over had received an annual health check two years ahead of the NHS Long Term Plan target.<sup>2</sup>

- The NHS and partners will introduce **hearing, sight and dental checks for children and young people** with a learning disability, autism or both in special residential schools
- The NHS will expand the **Stopping over medication** of people with a learning disability, autism or both and Supporting Treatment and Appropriate Medication in Paediatrics (STOMP-STAMP) programmes to end the overmedication of people with a learning disability or autism. This is considering evidence that psychotropic medicine is more likely to be inappropriately prescribed to people with a learning disability or autism.<sup>3</sup>

<sup>2</sup> NHS England, [Three in four people with a learning disability receive NHS annual health check](#), June 2021

<sup>3</sup> Public Health England, [Prescribing of psychotropic drugs to people with learning disabilities and/or autism by general practitioners in England](#), (PDF) 2015

- The NHS will continue to fund the **Learning Disabilities Mortality Review Programme** (now called the learning from lives and deaths programme). This supports local areas to review the deaths of people with learning disabilities, to understand factors leading to premature mortality and what actions are needed to address health inequalities (see section 1.5)
- By 2023/24, a **‘digital flag’ in the patient record** would ensure staff know a patient has a learning disability or autism.
- By 2023/24 children and young people with a learning disability, autism or both, with the most complex needs, will have a **designated keyworker**. This would be initially rolled out to children and young people who are inpatients or at risk of being admitted to hospital. It will be extended to vulnerable children with a learning disability or autism, such as looked after and adopted children and those in transition between services.
- **NHS staff will receive training** on learning disabilities and autism. Further information on recently introduced mandatory training is provided below (see section 1.2).

The Long Term Plan also committed to halving **inpatient provision** for people with a learning disability and/or autism by 2023/24, compared to 2015 levels (on a like for like basis and taking into account population growth).

There are concurrent targets for the maximum numbers of adult and children in inpatient units - for every one million adults, there will be no more than 30 people with a learning disability and/or autism in inpatient care. For children and young people, the maximum is 12 to 15 children per one million. Further information on reducing inpatient care is provided in section 1.3.



## 3

## Mandatory staff training

The [Health and Care Act 2022](#) introduced a new legal requirement for all health and social care service providers registered with the Care Quality Commission (CQC) to provide employees with training on autism and learning disabilities (called [Oliver McGowan Training](#)). Further detail is provided below.

Mandatory staff training on learning disabilities was recommended by the [Learning Disability Mortality Review Programme \(PDF\)](#) in 2017.<sup>4</sup>

The Government response accepted this recommendation and noted that despite the introduction of the Learning Disability Core Skills Education and Training Framework in 2016, some staff did not possess the required knowledge and skills. The Government committed to introduce mandatory training:

We will take immediate steps (detailed below) to remind employers of their responsibilities to raise the profile of the Framework<sup>5</sup>, stimulate provision of training generally and to measure uptake. But persistent inequalities have endured for some of our most vulnerable citizens for too long. For this reason, we will consult on options for delivering mandatory learning disability training for all relevant staff. Consultation will take place with people with lived experience, the wider learning disability sector, NHS and social care providers and the general public to ensure that proposals are practicable and effective and to avoid any training becoming a ‘box-ticking exercise’.<sup>6</sup>

Consultation took place in February 2019. The [Government’s response](#) was published in November 2019.<sup>7</sup> Over 5,000 responses were received, the vast majority of which were supportive of the principle of mandatory training.

In 2019, the Government invested £1.4 million to develop the Oliver McGowan Mandatory Learning Disability and Autism Training for health and care staff.<sup>8</sup> The training is named after Oliver McGowan, whose death highlighted the need for improved training and led his parents to campaign for legislative change.<sup>9</sup>

<sup>4</sup> The Learning Disabilities Mortality Review (LeDeR) Programme, [Annual Report](#), (PDF) December 2017, Summary of recommendations, page 31.

<sup>5</sup> The [Learning Disability Core Skills Education and Training Framework](#) (PDF), July 2016

<sup>6</sup> Department of Health & Social Care, NHS England, [The Government response to the Learning Disabilities Mortality Review \(LeDeR\) Programme Second Annual Report](#), (PDF), September 2018, paras 35-38

<sup>7</sup> DHSC, [Learning disability and autism training for health and care staff - GOV.UK](#), November 2019

<sup>8</sup> DHSC, [All inpatients with learning disability or autism to be given case reviews](#), 5 November 2019

<sup>9</sup> See the campaign website Oliver McGowan – Oliver’s campaign for more information

The training has been trialled and evaluated and an e-learning package has been produced. Interactive and face-to-face training is being made available in 2023.<sup>10</sup> The content is informed by the Core capabilities framework for supporting people with a learning disability and autistic people.<sup>11</sup>

The [Health and Care Act 2022](#) introduced a new legal requirement for all health and social care service providers registered with the CQC to ensure their employees receive training on autism and learning disability at a level appropriate to their role. It also placed a duty on the Secretary of State to issue a Code of Practice setting out requirements for the content, delivery and accreditation of training.<sup>12</sup>

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<sup>10</sup> Health Education England, [The Oliver McGowan Mandatory Training on Learning Disability and Autism](#), 22 December 2022

<sup>11</sup> [Supporting autistic people and/or people with a learning disability - Skills for Health](#)

<sup>12</sup> [Health and Care Act 2022 \(legislation.gov.uk\)](#) section 181

## 4

## Reducing inpatient care

The NHS Long Term Plan set a target to reduce inpatient provision for autistic people and people with a learning disability by 50% (compared to 2015 levels) and support more people in the community by 2023/24.

In February 2023, there were 2,045 people with a learning disability and autistic people receiving inpatient care, of which over half (56%) had a total stay of two years or longer.<sup>13</sup>

In July 2022, the DHSC published an updated [Building the right support for people with a learning disability and autistic people: action plan](#) focusing on six areas to develop community services and reduce reliance on inpatient mental health beds.

The Government's [Draft Mental Health Bill 2022](#) proposes to amend the criteria for detention under the Mental Health Act 1983 so a person could not be subject to long-term detention for treatment for autism or learning disability.

### 4.1

### Winterbourne View and Transforming Care

In 2011, the BBC's Panorama programme exposed the abuse of patients at Winterbourne View, an independent hospital for people with learning disabilities and/or autism. Further inspections by the CQC of 150 hospitals and care homes for people with a learning disability found inadequate practice in inpatient services, including poor person-centred care, limited appropriate activities and a lack of monitoring and learning from incidents of restraint.<sup>14</sup>

In response, in 2012 the DHSC published the [Transforming Care programme \(PDF\)](#), which pledged to move people inappropriately placed in hospital to community-based care no later than 1 June 2014. This target was missed; a report by the Transforming Care Steering Group found there were more people being admitted to long-term institutions than those discharged.<sup>15</sup>

<sup>13</sup> [Learning Disability Services Monthly Statistics, AT: February 2023, MHSDS: December 2022 Final - NDRS \(digital.nhs.uk\)](#)

<sup>14</sup> Care Quality Commission, [Learning Disability reports](#) [last accessed 6 April 2023]

<sup>15</sup> Transforming Care and Commissioning Steering Group, [Winterbourne View - Time for change](#), November 2014

A [subsequent report by the Steering Group](#) in 2015 found progress was being made, but the programme had not delivered tangible benefits in terms of new community facilities or closures.

In 2016, the group recommended a commissioner for learning disabilities be appointed to promote and protect the rights of all people with learning disabilities and autistic people in England.<sup>16</sup> The Government said the recommendation would be considered but “new statutory roles and legislation are not necessarily the answer to promoting and protecting the rights of people with learning disabilities and their families.”<sup>17</sup>

In February 2015, the National Audit Office (NAO) published [Care Services for People with Learning Disabilities and Challenging Behaviour](#). The NAO said the Government had not met its central goal of moving people out of hospital by June 2014 because it “underestimated the complexity and level of challenge in meeting the commitments in its action plan.”<sup>18</sup>

During a Public Accounts Committee evidence session on the NAO report in February 2015, the Chief Executive of NHS England announced a planned closure programme for NHS mental health hospitals and changes in commissioning practices for NHS inpatients within the independent sector.<sup>19</sup> This would be accompanied by a transition plan for people with learning disabilities within these hospitals from 2016–17.<sup>20</sup>

## 4.2 Building the Right Support

In October 2015, NHS England, in partnership with the Local Government Association (LGA) and the Directors of Adult Social Services (ADASS), published a national action plan to close inpatient facilities for people with a learning disability and autistic people. The [Building the Right Support](#) plan aimed to shift money from inpatient services to the community and reduce the use of inpatient beds by 35% - 50% over three years (between 2015-2018).<sup>21</sup>

In 2019, the NHS Long Term Plan included the new deadline of 2023/24 to achieve the 50% reduction in inpatient care. This deadline was criticised by charities such as Mencap, who described the situation as a “domestic human rights scandal”.<sup>22</sup>

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<sup>16</sup> ACEVO, [Time-for-change](#) (PDF), 2016

<sup>17</sup> [PQ 28525 \[on Learning Disability\] 1 March 2016](#)

<sup>18</sup> NAO, [Care Services for People with Learning Disabilities and Challenging Behaviour](#), 2015

<sup>19</sup> Public Accounts Committee, [Care services for people with learning disabilities and challenging behaviour](#), (PDF) 27 March 2015, HC 973 2014-15, para 15

<sup>20</sup> As above, p5

<sup>21</sup> NHS England, [Building the right support](#), (PDF) October 2015

<sup>22</sup> Mencap Press Release, [Government due to miss deadline for releasing people with a learning disability locked away in inpatient units, warns Mencap](#), 21 March 2019

In February 2020, the Equalities and Human Rights Commission launched a legal challenge against the Secretary of State for Health and Social Care over the failure to move people with learning disabilities and autism into appropriate accommodation. The Commission said:

We have sent a pre-action letter to the Secretary of State for Health and Social Care, arguing that the Department of Health and Social Care (DHSC) has breached the European Convention of Human Rights (ECHR) for failing to meet the targets set in the Transforming Care program and Building the Right Support program.

These targets included moving patients from inappropriate inpatient care to community-based settings, and reducing the reliance on inpatient care for people with learning disabilities and autism.

Following discussions with the DHSC and NHS England, we are also not satisfied that new deadlines set in the NHS Long Term Plan and Planning Guidance will be met.

This suggests a systemic failure to protect the right to a private and family life, and right to live free from inhuman or degrading treatment or punishment.

[...]

The DHSC has 14 days to respond to our pre-action letter. Alternatively, we have offered to suspend the legal process for three months if DHSC agrees to produce a timetabled action plan detailing how it will address issues such as housing and workforce shortages at both national and regional levels.<sup>23</sup>

## 4.3 Building the right support action plan (2022)

In July 2022, the DHSC published an updated [Building the right support for people with a learning disability and autistic people: action plan](#). Progress against commitments in the plan is monitored by the Building the Right Support Delivery Board, chaired by the Minister of State for Care and Mental Health.<sup>24</sup>

The action plan focuses on six areas to develop community services and reduce reliance on inpatient mental health beds:

- Ensuring people are safe and that they receive quality health and social care through improving the experience of mental health settings, supporting people to move out of long-term segregation, improving advocacy and training the workforce.
- Making it easier to leave hospital by refreshing the policy for Care (Education) and Treatment Reviews, using the Community Discharge

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<sup>23</sup> Equality and Human Rights Commission, [Health Secretary faces legal challenge for failing patients with learning disabilities and autism](#), 12 February 2020

<sup>24</sup> Department of Health & Social Care, [Building the right support for people with a learning disability and autistic people](#), July 2022

Grant and improving outcomes for neurodivergent people in the criminal justice system.

- Ensuring people receive the right housing, care and support in the community by reviewing best practice, investing in supported housing and ensuring the right services are commissioned.
- Supporting children and young people by ensuring quicker diagnosis, improving Special Educational Needs and Disabilities (SEND) provision and training educational staff in autism awareness.
- Making cross-government changes to improve system collaboration, including by reforming the Mental Health Act and integrating health and care.
- Ensuring local and national accountability by the Board holding commitment owners accountable for delivery.<sup>25</sup>

Providers of specialist services for autistic people and people with a learning disability are assessed against [guidance by the CQC](#). From September 2022, providers registering with the CQC who do not plan to provide these services must agree to a condition that they “must not” provide these services. Should the provider decide to provide the services, they must apply to have the condition removed.<sup>26</sup>

## 4.4 Inpatient case reviews

In October 2020, the CQC published a [report into restraint, segregation and seclusion](#) in care services for people with a mental health condition, learning disability or autistic people.<sup>27</sup> The CQC found the majority of mental health hospitals did not provide a therapeutic environment, many people did not have a clear care and treatment plan or a treatment plan to support them to leave hospital.<sup>28</sup>

In response, the Government committed to providing a case review for every inpatient with a learning disability or autism in a mental health hospital. The Government also committed to providing every patient with a date for discharge, or where this is not appropriate, a clear explanation of why and a plan to move them closer towards being ready for discharge into the community.<sup>29</sup>

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<sup>25</sup> As above.

<sup>26</sup> CQC, [‘We are strengthening regulation of services for people with a learning disability and autistic people to improve people’s experiences and outcomes’](#), 31 August 2022

<sup>27</sup> CQC, [Out of sight – who cares?: Restraint, segregation and seclusion review](#), October 2020

<sup>28</sup> As above.

<sup>29</sup> Department of Health & Social Care, [All inpatients with learning disability or autism to be given case reviews](#), November 2019

## 4.5

## Safe and Wellbeing reviews

Following the deaths of three adults with learning disabilities at Cawston Park hospital between 2018 and 2020, the Norfolk Safeguarding Adults Board carried out a [safeguarding adults review](#) (September 2021).<sup>30</sup> Following publication of the review, NHS England undertook a national review to check the safety and wellbeing of all people with a learning disability and people with autism cared for in a mental health inpatient setting.

[NHS England's thematic report on Safe and Wellbeing reviews](#) (February 2023) was based on individual reviews of 1,770 children, young people and adults carried out between October 2021 and May 2022. The reviews found that many people had received poor care and high levels of restrictive practice. Additionally, nearly half of the people reviewed had needs that could be met outside of hospital. Some did not have clear plans in place for their care or treatment, or for discharge out of their current hospital setting.<sup>31</sup>

In response, NHS England said many of the findings were already being addressed by measures in the NHS Long Term Plan but noted “there are areas where there needs to be a stronger focus or a different approach.”<sup>32</sup> There’s a commitment to work with partners and those with lived experience over the next 12 months (from February 2023) to “look at specific actions that will address the challenges and themes highlighted through this thematic review”.<sup>33</sup>

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<sup>30</sup> Correction made on 11 April 2023.

<sup>31</sup> NHS England, [Safe and wellbeing reviews: thematic review and lessons learned](#), February 2023

<sup>32</sup> As above, conclusions.

<sup>33</sup> As above.

## 5

## Mental Health Act reform

In 2018, an Independent Review of the Mental Health Act 1983 (applicable in England and Wales) was conducted to understand rising rates of detention under the Act; the disproportionate numbers of people from black, Asian and minority ethnic groups in the detained population; and investigate concerns about some processes in the Act being out of step with a modern mental health system. The resulting report, [Modernising the Mental Health Act](#), found:

[...] the Mental Health Act isn't providing the right type of support and care for people with learning disabilities, autism or both. The Mental Health Act is being used in a way that is not in line with its intended purpose, and is too often being used compensate for the lack of adequate and meaningful support within the community.<sup>34</sup>

In January 2021, the Government published a series of proposals for legislative change, including on how the Act would apply to autistic people and people with a learning disability, in a [white paper on Reforming the Mental Health Act](#).<sup>35</sup> The Government held a [consultation on the proposed changes](#) between January and April 2021, before publishing its response in August 2021.<sup>36</sup>

### 5.1

### Proposed reforms

In June 2022, the Government published the [Draft Mental Health Bill 2022](#). The draft Bill would amend the criteria for detention under the Act so autism and learning disability would not be conditions for which a person could be subject to longer term detention for treatment (section 3). This would mean people with a learning disability or autistic people could only be detained for treatment if they are suffering from a co-occurring mental disorder. The changes would not apply to patients in the criminal justice system.<sup>37</sup>

Measures in the draft Bill would place Care (Education) and Treatment Reviews (C(E)TRs) for persons with learning disability and autistic people on a statutory footing. C(E)TRs are part of current NHS policy and aim to reduce unnecessarily long hospital stays. They focus on whether the patient is safe and receiving the right care and treatment. By placing the reviews on a

<sup>34</sup> DHSC, [Modernising the Mental Health Act – final report from the independent review](#), December 2018, p31

<sup>35</sup> DHSC, [Reforming the Mental Health Act](#), January 2021

<sup>36</sup> DHSC, [Reforming the Mental Health Act: government response](#), 24 August 2021

<sup>37</sup> DHSC and MoJ, [Draft Mental Health Bill 2022](#), 27 June 2022, clause 1



statutory footing, the draft Bill seeks to ensure outcomes from reviews are followed up and barriers to progress are overcome.<sup>38</sup>

The draft Bill would also require Integrated Care Boards (ICBs) to create and maintain a “risk register” for their area of autistic people and people with a learning disability at risk of hospital admission. The register would be used to put in place preventative measures to avoid admission and inform local commissioning. ICBs and local authorities would have a duty to seek to ensure they meet the needs of people with a learning disability and autistic people without detaining them.<sup>39</sup>

## 5.2 Pre-legislative scrutiny

In July 2022 a [Joint Select Committee was established](#) to consider the draft Bill. Following a call for evidence and a series of evidence sessions, [the Committee published its report](#) on 19 January 2023.<sup>40</sup>

The Committee took evidence from witnesses saying hospitals are not the correct environment in which to provide support for people with learning disabilities and autistic people. Most witnesses supported changing the definition of “mental disorder” to exclude learning disability and autism in principle.<sup>41</sup>

The Committee also received evidence about a lack of community alternatives for those diverted away from hospital, with provision described as “worryingly low”.<sup>42</sup> The Committee said it is clear there will need to be a “sustained programme of investment” to expand community services, but it was “still not clear to [the Committee] whether the Government is able to deliver on these commitments in the long term.”<sup>43</sup>

There were concerns that limiting how the Act would apply to autistic people and people with a learning disability could lead to unintended consequences, such as detention under the Mental Capacity Act or diagnosing alternative mental health conditions to justify using the Mental Health Act.<sup>44</sup>

Another concern was that individuals from this group could be diverted into the criminal justice system.<sup>45</sup> The Government told the Committee they had

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<sup>38</sup> As above, clause 2

<sup>39</sup> As above, clause 2

<sup>40</sup> Joint Committee on the Draft Mental Health Bill, [Report - Draft Mental Health Bill 2022](#), 19 January 2023, HC 696 2022-23

<sup>41</sup> As above, para 150

<sup>42</sup> As above, paras 108-110

<sup>43</sup> As above, para 145

<sup>44</sup> As above, para 159

<sup>45</sup> As above, paras 164-175

introduced neurodiversity support managers in prisons and were improving staff training.<sup>46</sup>

The Committee made the following recommendations to Government:

- Changes to the criteria should be the same for both civil patients and those in the criminal justice system.
- Review the Building the right support action plan (see section 2.4) to reflect how the needs of those no longer eligible for long-term detention under the Act will be met in the community.
- Review the Mental Capacity Act to ensure it cannot be used as an alternative detention route.
- Monitor the outcomes for those no longer eligible for long-term detention for a rise in use of the Mental Capacity Act or detention in the criminal justice system.
- Introduce a provision in the Bill to extend the detention of people with learning disabilities and autistic people under section 2 of the Act in “exceptional circumstances”.
- Reduce the maximum interval between C(E)TRs from twelve to six months and strengthen the wording of the legislation to emphasise the duty on ICBs and Local Authorities to action the outcomes.
- Rename the “risk register” as the “Dynamic Support Register” and impose a “firm duty” on ICBs and Local Authorities to ensure an adequate supply of community provision.
- Review eligibility for section 117 aftercare,<sup>47</sup> to consider its extension to those detained under other sections of the Act.<sup>48</sup>

More information can be found in the Library briefing on [Reforming the Mental Health Act](#).

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<sup>46</sup> As above, para 173

<sup>47</sup> Section 117 of the Mental Health Act 1983 entitles people who have been detained in hospital under Section 3 of the Mental Health Act to receive free aftercare services to reduce the risk of future admission.

<sup>48</sup> Joint Committee on the Draft Mental Health Bill, [Report - Draft Mental Health Bill 2022](#), 19 January 2023, HC 696 2022-23, paras 178-182, 191-192, 208-213

## 6

## Learning from lives and deaths review programme

NHS England's [learning from lives and deaths reviews programme \(LeDeR\)](#) (formerly known as the learning disability mortality review programme) started in April 2017.

LeDeR aims to improve care, reduce health inequalities, and prevent premature mortality of people with a learning disability and autistic people by reviewing information about the health and social care support people receive.

Integrated Care Systems (ICSs) are now responsible for ensuring LeDeR reviews are completed on the health and social care received by people with a learning disability and autistic people (aged four years and over) who have died. ICSs are also responsible for ensuring actions are implemented to improve the quality of services for people with a learning disability and autistic people to reduce health inequalities and premature mortality.

In March 2021, NHS England published [Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\) policy 2021](#) (PDF) which set out the core aims and values of the LeDeR programme and the expectations of different parts of the health and social care system in delivering the programme from June 2021.<sup>49</sup> Reviews of the health and social care received by autistic people who have died were also included within LeDeR's remit for the first time.

The LeDeR programme grew out of the Department of Health's [Confidential Inquiry into the Premature Deaths of People with Learning Disabilities \(CIPOLD, PDF\)](#).<sup>50</sup> The Inquiry investigated the avoidable or premature deaths of people with learning disabilities through reviews of individual deaths. It found the most common reasons for premature deaths in this group were delays or problems with diagnosis or treatment, and problems with identifying needs and providing appropriate care in response to changing needs.<sup>51</sup>

The inquiry made recommendations, such as introducing named professionals to coordinate patient care across different services, and

<sup>49</sup> NHS England, [Learning from lives and deaths – People with a learning disability and autistic people \(LeDeR\) policy 2021](#), (PDF) March 2021

<sup>50</sup> DoH, [Confidential Inquiry into the Premature Deaths of People with Learning Disabilities](#) (PDF), March 2013

<sup>51</sup> As above, p4

proactively using annual health checks and health action plans to identify and plan for health and care needs.

In June 2015, NHS England announced a three-year national review of premature deaths of people with learning disabilities. The first report of the [Learning Disability Mortality Review Programme](#) (2018) found that in 13% of its reviews into the deaths of people with learning disabilities, the person's health had been adversely affected by factors such as delays in treatment, organisational dysfunction and gaps in service provision. It set out nine national recommendations, including:

- Strengthening collaboration and information between care providers, including integration of health and care records;
- All people with learning disabilities with two or more long-term conditions should have a local, named care coordinator;
- Mandatory learning disabilities awareness training provided to all staff, delivered in conjunction with people learning disabilities and their families.<sup>52</sup>

The Government accepted the recommendations and committed to several actions, including a public consultation on mandatory learning disability training.

[The third annual report was published in May 2019](#). The review found many cases where a patient's received care fell so far short of expected good practice that it significantly impacted on their well-being or directly contributed to their cause of death. The report made twelve recommendations for education and health and care systems, including:

- Support to recognise deteriorating health in people with learning disabilities
- Care co-ordination and better communication between agencies
- Transition planning for young people
- Training for staff.<sup>53</sup>

In May 2019, the NHS announced £5 million in funding to accelerate the pace at which reviews are completed.<sup>54</sup>

NHS England and NHS Improvement also published a report outlining activity taking place locally and nationally in response to the reviews.<sup>55</sup> This described

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<sup>52</sup> The Learning Disability Mortality Review (LeDeR) Programme, [Annual Report 2017](#), May 2018, page 8

<sup>53</sup> The Learning Disability Mortality Review (LeDeR) Programme, [Annual Report 2018](#), May 2019

<sup>54</sup> NHS England, [NHS invests £5 million to improve care for people with a learning disability](#), 21 May 2019

<sup>55</sup> NHS England and NHS Improvement, [Learning Disability Mortality Review \(LeDeR\) Programme: Action from Learning](#), May 2019

national action in clinical areas such as cancer and sepsis, as well as initiatives in individual hospitals, such as targeted schemes to improve reasonable adjustments and increase uptake of medical tests for this group.

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