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Women and Equalities Committee

Inequalities in healthcare and employment for people with a learning disability and autistic people

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Women and Equalities Committee

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Summary

Approximately 1.3 million people in England have a learning disability, 29% of whom are diagnosed as autistic. People with a learning disability and autistic people face significant health inequalities, including an unacceptable level of premature and avoidable deaths compared to the general population. While there have been some improvements in recent years, including the introduction of mandatory learning disability and autism training for all healthcare staff, overall care and outcomes too often still fall below acceptable standards.

People with lived experience of a learning disability told us of the challenges they faced in getting the healthcare support they needed. People with a learning disability can ask to go on the learning disability register, which entitles them to receive reasonable adjustments, such as support with making decisions and, vitally, access to an annual health check. Yet around

75% of people with a learning disability are not registered, and many struggle to convince their GP and practice staff to add them to the register. The Government needs to work with stakeholders to investigate why eligible people are not on the learning disability register and take appropriate action to increase registration, including an awareness raising campaign.

Learning disability nurses can help people with a learning disability to access good healthcare but there is a shortage of these nurses in both primary and secondary care. The Government has committed to train and recruit more disability nurses. Alongside that commitment the Government should support them to go into senior leadership roles within hospital and community health services to help drive the necessary improvements to health outcomes for people with a learning disability. The Government should also reestablish a national board with a focus on improving health

inequalities for people with a learning disability and autistic people across all health and social care services.

Reducing the current waiting time for an autism diagnosis is crucial to tackling health inequalities for autistic people, however the backlog is getting worse. The funding committed to date to support these assessments has been inadequate and needs to be radically increased. Understanding of how autism presents in women and girls needs to be improved so that they can receive the support they need before they reach crisis and to prevent misdiagnosis and inappropriate care. The Government acknowledged this need in the National Disability Strategy but has made no progress in delivering the promised autism public understanding initiative. The Department for Health and Social Care should develop

and trial an initiative aimed at improving public understanding of autism in women and girls by the end of 2024.

The Government has fallen short on its commitment to halve the number of people with a learning disability and autistic people inappropriately detained in mental health hospitals. Promises to bring forward a new Mental Health Bill to help address this concern have gone unmet. Meanwhile, the number of autistic people in mental health settings and exposed to the harm that those settings can present is increasing.

The Government must make more progress in reducing the number of people with learning disabilities and/or autism detained in mental health settings. It needs to learn from previous lessons and increase support for community-based alternatives to detention and do more to stop people reaching crisis in the first instance.

People with a learning disability and autistic people can and want to work and thrive when they get the opportunities to do so. However, they face the widest employment gap of all people with disabilities and find it difficult to get their foot in the door.

Several Government measures are in place to help reduce the disability employment gap, but some schemes are difficult to access and require improvement. The Government should ensure that work to improve Disability Confident and Access to Work includes reviewing the extent to which those policies are helping employers to recruit and support people with a learning disability and autistic people. The Access to Work scheme should be made easier to access for people with learning disabilities and delays in processing applications need to be tackled.

People with a learning disability and autistic people who do not have an Education, Health

and Care Plan should be exempted from the Maths and English skills requirement for apprenticeships. The Work and Health programme, due to end later this year, should be extended for a further 12 months and the recommendations of the Government's Review of Autism Employment must be implemented, including, as a priority, the appointment of a task group to be chaired by someone independent of government who represents autistic people and their needs. To underpin this work the Government should publish a new disability employment goal based on relative measures and set out how it plans to achieve it; that goal should include a specific target for people with a learning disability and autistic people.

Introduction

1. This is the final report based on findings from our inquiry into the National Disability Strategy. It considers the inequalities facing people with a learning disability and autistic people, specifically in access to healthcare and employment opportunities.
2. Approximately 1.3 million people in England have a learning disability. A learning disability is a reduced intellectual ability. It is lifelong and will affect many areas of someone's life, for example completing household tasks, managing money, or travelling independently. There are some health conditions where someone is more likely to have a learning disability. For example, everyone with Down's syndrome has some level of learning disability, as do many people with cerebral palsy or autism. Some people with epilepsy may also have a learning disability. The term 'learning disability' is often confused with 'learning difficulty'—such as dyslexia, attention

deficit-hyperactivity disorder (ADHD), dyspraxia and dyscalculia. It is possible for someone to have a learning disability and a learning difficulty, both of which exist on a scale and can be mild to severe.

3. There are approximately 700,000 autistic people in the UK—around 1% of the population. Autism is a spectrum condition which can affect how people communicate and interact with the world. Autistic people may experience anxiety, especially in social situations or when encountering change, they may have over- or under-sensitivity to touch, noise, smell or taste and highly focused interests. Autism can affect someone psychologically and physically, and impact their quality of life and that of their family. While autism is not a learning disability, around 29% of people with a learning disability are diagnosed as autistic.

Health inequalities

4. People with a learning disability and autistic people face significant health inequalities, leading to lower life expectancy and more avoidable deaths than the general population. The latest Learning Disability Mortality Review (LeDeR), published in November 2023, found the median age of death was 62.9 years for people with a learning disability and 55 years for autistic people with a learning disability. In the general population, the median age at death was 86.1 years for females and 82.6 years for males. The review noted that ethnicity was strongly associated with age at death and that people from an ethnic minority background with a learning disability (black, black British, Caribbean or African and Asian British) were more likely to die younger than those who were white.

5. The LeDeR review also revealed that 42% of deaths of people with a learning disability

(including autistic people with a learning disability) were avoidable, compared to 22% of the general population. Avoidable deaths are defined as “deaths where, if certain possible and reasonable steps were taken, then the death may not have happened in the way that it did, and it therefore can be classed as having been avoidable”. The common causes of avoidable deaths were linked to cardiovascular conditions, respiratory infections and cancers.

6. 2022 was the first year in which the LeDeR reviewed the deaths of autistic adults without a learning disability. Of the 36 reviews included, it found the most common causes of death were suicide, drug and alcohol related deaths and accidental deaths, such as falls. The authors noted, however, that because the number of reviews was small, the report could only draw limited conclusions at present about the quality of care for autistic people without a learning disability.

7. The LeDeR review acknowledged that there had been some improvements in recent years such as more person centred care, better management and prevention of covid-19 and improved uptake of annual health checks for people with a learning disability. However it said, “things may not be improving fast enough, and overall care and outcomes all too often still fall below acceptable standards compared to the general population”. It remarked on the disproportionate gap in avoidable deaths between people with a learning disability and the general population, stating that “further efforts are required to reduce this”.

8. Previous research has found that avoidable deaths for people with a learning disability were often the result of poor healthcare rather than due to a lack of preventative measures. Factors included difficulties and delays in diagnosis, a lack of reasonable adjustments, patients not identified (‘flagged’) as having a learning disability and the misapplication of

Do not attempt cardiopulmonary resuscitation (DNACPR) orders. The latter are notices on a patient's file to instruct a doctor not to attempt resuscitation if their heart or breathing stops. A March 2024 Parliamentary and Health Service Ombudsman report found that conversations with patients and their families around DNACPRs were happening too late or in some cases not at all, and found a lack of information and awareness around the decision-making process.

9. A major factor contributing to the early and avoidable deaths of people with a learning disability, including those with autism, is 'diagnostic overshadowing'. This can occur when a healthcare professional attributes someone's symptoms or behaviours to their learning disability or autism without exploring other physical or mental health determinants. It means co-existing health conditions remain undiagnosed, some of which can be life threatening such as cancer. Jim Blair, Consultant

Learning Disabilities Nurse and Associate Professor Intellectual (Learning) Disabilities, told us that diagnostic overshadowing “is a hidden killer for people with a learning disability”.

10. Parents we spoke to as part of an engagement event at the Hamelin Trust, an Essex-based charity for people with learning disabilities, told us of the anxiety they felt when their child transitioned from paediatric to adult health services. A community paediatrician will see a child with a learning disability for all their health needs and then hand that patient over to a General Practitioner (GP) when they become an adult. Parents were worried that without the paediatrician’s expertise and knowledge of the patient, their young person would not get the same level of care as an adult that they received as a child. Jim Blair noted parents’ concerns in his evidence, one of whom remarked “the loss of the central paediatric consultant at transition is huge. The GP becomes the specialist and with the best will in the world [they] don’t have

the right knowledge”. Learning disability nurses can help adults with a learning disability and their families to access good healthcare but, as we discuss later (see paragraph 15), there is a shortage of those nurses in both primary (GPs, eye care, dentists and pharmacies) and acute (hospital) care.

Learning disability and autism training

11. In response to the 2017 LeDeR review, the Government consulted on mandatory learning disability and autism training for all healthcare staff. Five years later, Parliament passed the Health and Care Act 2022 which places a legal duty on all registered health and social care providers to ensure their employees, from administrative staff to clinical practitioners, receive such training. The Oliver McGowan Mandatory Learning Disability and Autism Training programme—named after an 18 year old whose death and parents’ subsequent

campaign highlighted the need for improved training—is the Government’s preferred and recommended training programme.

12. The training is in two tiers: tier 1 for staff who require a general awareness; and tier 2 for those who provide care and make more complex care decisions. The Government has made a preliminary estimate that over the first three years of training roll-out, 1,036,000 healthcare staff would be trained at Tier 1 level, and 1,186,000 staff would be trained at Tier 2 level. For adult social care, over the same period, it estimates that 840,000 staff would be trained at Tier 1 level, and 492,000 staff would be trained at Tier 2 level. The Government has said that it will publish a final assessment on the number of staff expected to undertake the training in due course.

13. For both tiers, the training is in two parts. The first part of both tiers is an e-learning package, which over 1.7 million people have

completed. The second part of the Tier 1 training is an hour long online interactive session co-delivered by a person with a learning disability or an autistic person which, as of December 2023, 12,741 people had completed. The second part of tier 2 training is a full day, in-person training session co-delivered by a person with a learning disability or an autistic person. The latest NHS England figures from December 2023 show that 9,012 people have completed the second part of the Tier 2 training. The majority of those who have taken the training are NHS staff. The Government has also consulted on a draft Code of Practice on the content, delivery and accreditation of that training.

14. Stakeholders have welcomed the introduction of mandatory training for staff in health and social care. Ciara Lawrence, Engagement Lead at Mencap, the learning disability charity, told us it is important “because it will not only change attitudes of staff but

make them think about how they talk to and treat people”. Care England, an organisation which represents the adult social care sector, said the training “if done properly, will help raise awareness for those with learning disabilities and autism and ensure those with ‘hidden’ disabilities are given high-quality care”. Jim Blair agreed the training was essential but cautioned that it would “not be a panacea because training necessarily needs to be tailored to specific settings e.g., primary care, mental health inpatient, community, and forensic services”.

Learning disability nurses

15. Learning disability nurses are fully qualified nurses who provide specialist healthcare and support to people with a learning disability, their families and carers. They work in the community as well as in liaison roles both in hospitals and primary care settings. Learning disability nurses, Jim Blair observed, “are the only health professionals specifically qualified to work with

people who have a learning disability and are extremely well placed to address diagnostic overshadowing”. He noted the importance of having those nurses in all healthcare settings, including on hospital wards such as respiratory care and cardiac care units. He added:

You really have to have significant leadership. You need to have learning disability nurses in significant positions of power to change things, and to lead, shape and direct the services. They should not just be in junior posts.

16. The number of learning disability nurses in England has decreased in recent years leading to a national shortage. In September 2023, there were 13,011 learning disability nurses in England registered with the Nursing & Midwifery Council (NMC), compared to 13,528 in September 2018. We note that NMC data do not show the roles in which those nurses are currently employed, nurses can hold more

than one qualification and do not always work in fields in which they are registered. We do know, however, that as of January 2024, there were 3,095 learning disability nurses working in NHS England hospital and community health services, compared to 5,498 in January 2010.

Over the same period, the number of people with a learning disability has increased from an estimated 1,191,000 to approximately 1.3 million people. A 2020 review by Health Education England found that in some areas there were no learning disability liaison nurses working in primary or acute care settings. In others, there was one nurse working across several sites.

The Royal College of Nursing has also observed inconsistencies across primary and acute healthcare settings in the level of seniority that learning disability nurses held.

17. Several reports have noted the challenges with the recruitment and retention of learning disability nurses. The removal of bursaries for nurse education in 2016 (reinstated in 2020),

for example, has been described by the Royal College of Nursing as having hit learning disability nursing hardest as the profession attracts mostly mature students who may have greater financial commitments. A lack of knowledge around the role of learning disability nurses and clear routes into leadership roles and career pathways may also contribute to low numbers entering and staying in the profession.

18. The NHS and the Government have recognised the need to train more learning disability nurses as part of the NHS Long Term Workforce Plan, published in June 2023. That plan identified a potential disability nursing shortfall of 1,200 by 2036–37 and committed to increasing the number of learning disability nursing training places by 100% (over 1,000 places) by 2031–32. Interventions notwithstanding, the NHS expects potential medium-term shortfalls in the learning disability

nursing profession (among others) as it will take time to put the additional education and training capacity in place.

19. Health inequalities continue to be significant among people with learning disabilities and autism, including an unacceptable level of premature and avoidable deaths compared to the general population. Although some measures are now in place to monitor mortality, such as the annual Learning Disability and Mortality Review (LeDeR), and mandatory training on learning disability and autism, it is clear that more effort is required to improve health outcomes. Significant progress has been made in rolling out part one of the Oliver McGowan Mandatory Training on Learning Disability and Autism but the number of staff who have completed part two is low and availability is constrained while training capacity increases.

20. *The Government should set out clear targets for the rollout of part two of the Oliver McGowan Mandatory Training on Learning Disability and Autism to help increase take up. The training should include elements tailored to specific health settings.*

21. *We welcome the commitment to train and recruit more learning disability nurses to help address some of the shortfall within the profession. Alongside that commitment the Government should support more learning disability nurses to go into senior leadership roles within hospital and community health services to help drive the necessary improvements to health outcomes for people with a learning disability.*

Learning disability register

22. People with a learning disability of any age can ask to go on their GP's learning disability register. The GP will assign a diagnostic

code to the patient's record which indicates a learning disability. GPs use NHS England guidance and their clinical judgement to make a diagnosis, seeking further support if necessary—for example from specialist learning disability services. The NHS guidance sets out that people with certain diagnoses should be automatically added to the register.

23. Once they are on the learning disability register, patients can receive reasonable adjustments, such as easy read information, longer appointments and support with making decisions. The register also prioritises people for covid-19 boosters and entitles them to a free flu jab. Registered patients also have access to an annual health check. Ciara Lawrence, Engagement Lead at Mencap, told us of her positive experience when she required a blood test:

They put really small things into place that made such a huge difference to me.

And instead of walking out crying and having a tantrum, I walked out smiling, because I felt empowered, I felt they had listened to me and they had put in place all the reasonable adjustments that I needed, and it was great.

24. Annual health checks can help to identify previously unrecognised health problems, including serious and life-threatening conditions such as cancer. The 2020 LeDeR annual report found that the likelihood of dying between the ages of 18 and 49 was 1.5 times greater for those who did not receive an annual health check in the previous year. To help tackle the causes of morbidity among people with learning disabilities and autistic people, the NHS Long Term Plan, published in 2019, set a target to ensure at least 75% of people on the learning disability register had received an annual health check by 2023–24. The NHS achieved this target by the end of 2022–23. However, although there were approximately 1.3 million

people with a learning disability in England, as of March 2024 only 347,840 (approximately 25%) were recorded on the learning disability register, meaning many people with a learning disability are missing out on healthcare to which they are entitled.

25. We asked Jackie O’Sullivan, Executive Director of Communications, Advocacy & Activism at Mencap, why so many people did not sign up to the learning disability register. She suggested that in some cases it could be a lack of awareness or an assumption that a child would automatically go on the register if they had an education, health and care (EHC) plan in place, which does not happen. Mencap also noted that given ethnicity is a significant predictor of death at an early age, it is likely that many people from minority ethnic backgrounds were also absent from the register.

26. The Department for Health and Social Care acknowledged that not everyone with a learning

disability was on the register. It said work was “underway to address this issue, including work nationally and regionally to encourage children and young people to join the register at age 14 and access annual health checks”. However, even people who were aware of the learning disability register have struggled to access it because their requests were either delayed or denied. Jackie O’Sullivan noted people had been incorrectly refused access to the register:

The GP forms were very complex, in some instances running to 80 pages, and required diagnoses that leant on syndromes and recognisable learning disabilities.

I think there is an issue, and an education piece to be done, with people such as GP receptionists. We hear anecdotally about people being told, “You can’t go on the register because that’s just for people with cerebral palsy.”

27. When we put those concerns to the Government, David Nuttall, Deputy Director of Neurodiversity, Diversity and Learning Disability at the Department for Health and Social Care, advised people who disagreed with their GP's decision to take it up with their practice in the first instance and, if unresolved, raise a complaint with the relevant integrated care board (ICB). Ciara Lawrence told us it took her three years of persistently asking to finally get added to her GP's register:

I had to fight to get it. I had to really argue my way and fight for it. I had to battle for it with my local NHS trust. I am finally on the register—we finally cracked it recently—and I was able to have my first annual health check. However, it took a media interview, with me on TV, for someone from my local NHS trust to contact me to say, “Now we're going to help you.” It took things getting that far for me to get it.

28. Ciara's experience was not the only one. At our engagement event at the Hamelin Trust a young man told us he was only given access to his GP's learning disability register after taking his local MP along to the practice. Ciara told us she was lucky that she had both the knowledge, from her career at Mencap, and the confidence to speak up for her rights. She noted that many people with a learning disability lacked that voice.

29. The learning disability register is vital for people with a learning disability to receive important, life-saving annual health checks and reasonable adjustments. Yet around 75% of people with a learning disability are not registered. We heard from people who struggled to convince their GP to put them on the register and only achieved success once the media and politicians were involved. They should not have to reach that point, and not everyone will feel empowered to argue their case or have access to such

advocacy to assist them. The system has to work better to ensure all people with a learning disability have access to good healthcare.

30. As an immediate priority, the Department for Health and Social Care and NHS England should work with national and local learning disability organisations and charities and the Royal College of General Practitioners to investigate why eligible people are not on the learning disability register and take appropriate action to increase registration. That work should include an assessment of the reasons why eligible people who have applied to be on the register have been denied access to it and a review of the existing guidance for GPs to ensure it captures all those who are eligible for registration. We also recommend that, by the end of 2024:

- ***The Government should develop and launch an awareness raising campaign to encourage people to ask their GP to be put on the learning disability register; the campaign should be appropriately tailored to deliver increased registration among underrepresented communities;***
- ***All GPs should ensure staff are using existing guidance on registration correctly to ensure eligible people are not being denied access to the register before even seeing a GP.***

Autism assessments

31. The National Autistic Society told us that reducing the current waiting time for an autism diagnosis was a crucial element of tackling health inequalities for autistic people. The National Institute for Health and Care Excellence (NICE) Quality Standard on autism, which covers health and social care services

for autistic adults, young people and children, states that autism diagnostic assessments should begin within three months of a referral. In the months from April to December 2023, the median waiting time ranged between 218 and 306 days.

32. The Government has acknowledged that NICE's recommended timeframe is not being met, pointing to contributing factors such as increasing demand on services due to growing public awareness of autism; the impact of the covid-19 pandemic, which resulted in a pause or delay in assessments; and blockages within diagnostic pathways due to the diagnostic models being used and workforce pressures. We note that in the last quarter before the covid pandemic, Q4 2019–20, 60% of referrals waited longer than 13 weeks for an assessment with an average waiting time of 312 days. This is not a new issue.

As part of the *National strategy for autistic children, young people and adults: 2021 to 2026*, published in July 2021, the Government pledged to invest an additional £13 million in the first year to “begin reducing diagnosis waiting times for children and young people, as well as adults”. It said the funding would be used to “test different diagnostic pathways and post-diagnostic pathways, as well as to explore ways to reduce diagnosis waiting times and address backlogs of people waiting for assessments made worse by the pandemic”. That funding is in addition to core allocations to ICBs for learning disability and autism services. The Department told us that “A specific assessment of the adequacy of funding in meeting the National Institute for Health and Care Excellence’s waiting time standard for autism assessments has not been made.” The Minister for Mental Health and Women’s Health Strategy, Maria

Caulfield MP, explained it would take time to reduce waiting times to NICE's recommended three month target.

Table 1: Total baseline expenditure in ICBs for learning disability and autism services over the last five years

	Learning disability	Autism services	Unseparated learning disability and autism services	Total
2021 -22	£85,800,000	£3,700,000	£2,268,300,000	£2,357,900,000
2022 -23	£625,800,000	£27,100,000	£1,928,800,000	£2,581,700,000
2023 -24	£926,000,000	£47,100,000	£1,928,800,000	£2,904,600,000

Source: PQ 23733, 1 May 2024

Table 2: Additional national funding allocated to ICBs by NHS England, over each of the last five years, to improve autism assessment waiting lists and pathways

	Service Development Funding via the NHS Long Term Plan Transformation Funding	Spending Review 2021 via the COVID-19 Recovery Fund	Total funding for autism assessment pathways
2020–12	n/a	n/a	n/a
2021–22	£2,500,000	£14,500,000	£17,000,000
2022–23	£5,000,000	n/a	£5,000,000
2023–24	£4,200,000	n/a	£4,200,000

	Service Development Funding via the NHS Long Term Plan Transformation Funding	Spending Review 2021 via the COVID-19 Recovery Fund	Total funding for autism assessment pathways
2024–25	£4,300,000	n/a	£4,300,000

Source: PQ 23733, 1 May 2024

Note:

1. the in-year pay uplift for 2023/24 is not reflected in the table;
2. the service development funding allocations shown in the table are in addition to the ICBs core funding allocations.

33. To help meet the Government's commitment to explore ways at reducing waiting times for a diagnosis, NHS England developed a national framework for Integrated Care Boards (ICB) "to deliver improved outcomes for all-age autism assessment pathways". The framework, published in April 2023 sets out "the principles that should underpin the planning, design and delivery of an autism assessment pathway that works for everyone". It notes that waiting lists have reached "unsustainable levels". On resources, it states:

We recognise that achieving these policy ambitions requires a multifaceted response, that should include increasing the supply of a specialist workforce, ensuring that resource allocation to autism assessment services is sufficient to close the demand-capacity gap, while adhering to best practice clinical guidelines and deploying existing resources as effectively and efficiently

as possible. Increasing workforce supply and resource allocation to autism assessment services are outside of the scope of this work but should remain a focus in efforts to achieve national policy ambitions.

34. The National Autistic Society has described the effect of such work as minimal. As of December 2023, the number of people in England waiting for an autism assessment was 172,022—a 47% increase on the previous year and fivefold rise since 2019. Of those, 85.5% (147,042) had been waiting for more than three months. Tim Nicholls, Head of Influencing & Research at the National Autistic Society, argued that without further funding from the Government to increase capacity within services, ICBs will continue to struggle with the backlog, adding:

Quite simply, you will not tackle the hugely long, unacceptable and

damaging waits that autistic people go through in order to get their diagnosis, unless there is more resource in the system.

35. To help facilitate earlier diagnoses of autism in children, the Government committed to expanding a school-based identification programme to over 100 schools over three years from 2021. The Minister for Mental Health and Women's Health Strategy explained that specialist mental health support teams in schools support teachers to identify pupils who may have been missed previously to ensure they receive a timely autism (or other special educational needs such as ADHD) diagnosis and appropriate interventions. She told us "we should be able to pick up those who need assessment much more quickly than happens at the moment". The Government was not able to tell us how many additional children had received a diagnosis of autism as a result of the Early Identification of Autism Project. It told

us that an evaluation would be published in due course. Parents at our engagement event at the Hamelin Trust noted that getting a child assessed and an Education, Health and Care (EHC) plan in place could take months if not years.

36. It took 14 months—which we heard was a relatively short period of time—for Maya Stretton, Young Ambassador at the National Autistic Society, to receive their diagnosis. Maya relied on their parents, especially their mother who had experience of the process through a previous job, to push for a diagnosis so Maya could get the support they needed. They noted that without that knowledge “it is going to take you significantly longer because you need to find out the information”. Maya told us of the stress that pursuing a diagnosis can cause autistic people:

Especially with anxiety and different mental health conditions being a co-

occurrence for autism a lot of the time, overall the procedure is very stressful and long and it causes a lot of people more stress, which makes people go, “I might not pursue a diagnosis. I have managed this far. I am not autistic enough.”

37. Too many people are waiting far too long to get their autism assessment and the backlog is getting worse. It is clear that current efforts to address the waiting list backlog are inadequate and that the additional funding that has been allocated is far short of what is required. *The Government needs to radically increase the funding allocated to reducing waiting times for an autism assessment.*

38. *People with autism who may find it difficult to advocate for themselves can struggle to navigate the diagnosis process. The Government should work with NHS*

Trusts to ensure that information about the autism assessment process is accessible and available to everyone going through it, from pre- to post-diagnosis.

Autism in women and girls

39. Women and girls are more likely to struggle to get an autism assessment than boys and men. This is often due to outdated stereotypes of autism and who can be autistic. Maya Stretton, who was diagnosed with autism aged 17, told us that it was more socially acceptable for boys and men to be seen as autistic than women and girls. Maya explained:

The traits are seen as different; it can present in different ways. If a boy is really interested in trains—immediately autistic. But women seem to be more interested in things such as music, books, animals and even bands because of how they are socialised. They go, “Oh, that is just being a teenage girl; that

is just the usual experience.” You do not see the social struggles, because a lot of the time they will back down, agree with other people in their group and let them take that role.

40. Autistic women and girls, Tim Nicholls explained, might spend their formative years ‘masking’—“a strategy used by some autistic people, consciously or unconsciously, to appear non-autistic”—before being diagnosed with autism in their late teens. Masking can often lead to complex mental health problems, such as anxiety and depression. Maya told us that masking was “definitely why I got my autism diagnosis later on”. The National Autistic Society observed that “in particular, autistic girls and women may be misdiagnosed with mental health conditions including personality disorders, further delaying access to the correct diagnosis and suitable support”. As we discuss later in this report, an increase in autistic inpatients

on mental health wards (see below) has been driven in part by increases in the number of autistic women in those settings.

41. The National Disability Strategy committed to putting in place an autism public understanding initiative by autumn 2021 with a trial evaluation by May 2022. It set out that the initiative would “emphasise the diversity of the autistic community”, including how autism presents in women and girls. However, the Government has since paused that policy while the Department for Health and Social Care seeks to update the Statutory Guidance on Autism—to help local authorities to deliver improved outcomes for autistic people—before considering next steps on a public understanding and awareness initiative. At the time of writing this commitment was still paused.

42. Women and girls with autism struggle to get diagnosed. Understanding of how autism presents in women and girls must

be improved so that they can receive the support they need before they reach crisis and to prevent misdiagnosis and inappropriate care. The Government acknowledged this need in the National Disability Strategy but has made no progress in delivering the promised autism public understanding initiative. *The Department for Health and Social Care should develop and trial an initiative aimed at improving public understanding of autism in women and girls by the end of 2024. In the meantime, the Government should set out what steps it is taking to improve the autism diagnosis process for women and girls.*

Overreliance on inpatient care

43. In 2011, the BBC's *Panorama* programme exposed patterns of abuse directed towards patients at Winterbourne View, a Bristol-based independent hospital for people with a learning disability and autistic people. The scandal

revealed the extent to which people with a learning disability and autistic people were inappropriately detained in hospital settings. The then Department of Health set a target to move those inpatients to community-based support no later than June 2014. That target was missed, as was another target set in 2015 under the Transforming Care programme. Since *Winterbourne View*, *Panorama* uncovered similar levels of abuse at Whorlton Hall while the Norfolk Safeguarding Adults Board found that significant failures in care at Cawston Park hospital led to the deaths of three adults with learning disabilities.

44. Those high-profile cases are not isolated incidents. A 2020 Care Quality Commission (CQC) report found “many examples of undignified and inhumane care, in hospital and care settings where people were seen not as individuals but as a condition or a collection of negative behaviours”. The Equality and Human Rights Commission (EHRC) has also

been concerned that many people with a learning disability and autistic people have been detained in hospital settings for long periods, often far from home, and subjected to long-term segregation, restraint and restrictive interventions. Methods of restraint might include physical, mechanical (such as a harness), and chemical (such as psychotropic medicines that affect a person's behaviour, mood, thoughts and perceptions).

45. In 2019, the NHS Long Term Plan pledged to halve the number of people with a learning disability and autistic people in mental health inpatient care by March 2024 compared to 2015 levels. The Government also promised to reform the Mental Health Act 1983 to reduce the inappropriate detention of people with a learning disability and autistic people in mental health hospitals in the long-term. However, despite pre-legislative scrutiny of a draft Mental Health

Bill concluding at the beginning of 2023, the Government did not include the Bill in the final King's Speech of this Parliament.

46. Latest figures show there were 2,045 people with a learning disability and/or autism in inpatient mental health hospitals at the end of March 2024—a 30% reduction since March 2015. Most of this reduction has been driven by a fall in the number of inpatients with a learning disability only—over the same period the number of autistic people in mental health settings has increased from 1,115 to 1,380, including an increase in the number of women from 390 to approximately 500 over the last five years. The Minister for Mental Health and Women's Health Strategy acknowledged that many of the people the Government was seeking to discharge from hospitals had been there for many years and had complex needs. 52% of inpatients have experienced a total length of stay of over two years as of March 2024.

47. Several stakeholders observed that an underfunded social care sector meant people with a learning disability and autistic people were not getting the support they needed in the community. They noted that people were missing out on early interventions before spiralling into crisis and ending up in hospital. A lack of available services in the community has been a consistent reason why targets to reduce inpatient numbers have been consistently missed. We note that in its consideration of limiting the detention of people with learning disabilities and/or autism, the Joint Committee on the draft Mental Health Bill also raised concerns around a lack of community alternatives for people diverted away from hospital. In their recent report on the UK, the UN's Committee on the Rights of Persons with Disabilities stated they were "deeply concerned" about the "institutionalisation of disabled people,

including disabled people living in secure psychiatric facilities due to a lack of community-based support.”

48. The Minister told us she was personally meeting with ICBs to look at who was being detained in hospitals and why they had not yet been discharged. She said in most cases the problems “were not necessarily about packages of care in terms of getting people out of wherever they are placed; it is often about housing”. The Government’s Building the Right Support Action Plan, published in 2022, reaffirmed the NHS’s commitment to halve the number of inpatient stays in hospitals and improve community support, including the provision of supported housing for people with a learning disability and autistic people. A Delivery Board, meetings of which the Minister chairs, is responsible for bringing together local government, such as county councils and district councils, to implement the action plan.

49. The Government has fallen short on its commitment to halve the number of people with a learning disability and autistic people inappropriately detained in mental health hospitals. Promises to bring forward a new Mental Health Bill to help address this concern have gone unmet. Meanwhile, the number of autistic people in mental health settings and exposed to the harm that those settings can present is increasing.

50. The Government must make more progress in reducing the number of people with learning disabilities and/or autism detained in mental health settings. To achieve this the Government needs to learn from previous failings and increase support for community-based alternatives to detention and do more to stop people reaching crisis in the first instance.

51. *In response to this report, the Government should set out:*

- ***The reasons why the number of autistic people detained in mental health hospitals has increased; and how it plans to reduce that number, and by when.***
- ***The steps it will take to improve access to and availability of community-based alternatives to inpatient settings, including the additional resources it plans to allocate to support this; and***
- ***Its progress on discharging people with a learning disability and autistic people inappropriately detained in mental health hospitals, broken down by Integrated Care Board.***

Expertise by experience

52. We asked witnesses how the voices of lived experience—notably those with a learning disability, autistic people and families and carers—were being reflected in decisions

around health and social care policy. The Government said that it sought to involve people at all stages of policy development, including fora for people to engage on specific areas, including learning disabilities and autism. However, George Appleton, Head of Policy at Care England, told us those voices were “often lost in the conversation of bureaucracy, politics and what is doable within the financial constraints of government”. He argued it was important they were amplified through having central decision-making roles at local, regional and national level. Jim Blair argued that far too much power lay in the hands of professionals, few of whom had lived experience of a learning disability. He called for a “balance of power shift” at the national level and suggested the formation of a new panel “which gives a voice and real power to those with learning disabilities”.

53. We note that a National Learning Disability Board was established in 2013 to improve the health and wellbeing of people with

learning disabilities. It included people with a learning disability, family carers and other key stakeholders to provide “expertise by experience”. However the board was disbanded in 2016 following a “reorganisation and reprioritisation exercise within the Department” which saw its objectives integrated into “wider programmes and activities aimed at improving outcomes for this population”.

54. People with a learning disability and autistic people, and the people who care for them, are the real experts when it comes to their health and care needs. However, aside from the occasional opportunity to feed into consultations, their voices are often missing when it comes to decision making at both a local and national level. Their lived experience should be better reflected throughout efforts to reduce the health inequalities discussed in this report.

55. The Government should reestablish a national board with a focus on improving health inequalities for people with a learning disability and autistic people across all health and social care services. That board should include, and be led by, people with a learning disability and autistic people, people with parental and caring experience and health and social care professionals. Ministers should grant the board the responsibility and accountability necessary to drive change in health outcomes.

Access to employment

56. In 2022, the Government stated it had met its disability employment target five years early—set in 2017, the target was for an additional 1 million disabled people to be in work by 2027. However, as the Government itself has noted, the increase in absolute numbers cannot be attributed directly to any particular cause, including its policies or programmes: other factors, such as an overall rise in employment levels and the number of people reporting that they have a disability, have contributed to the increase. The disability employment gap, arguably a clearer measure of Government progress in supporting disabled people into work, remains wide. Official statistics show that 54% of working age disabled people were in employment as of June 2023 compared to 83% of non-disabled working age people. The disability pay gap also continues to widen,

nearly 69% of disabled workers earn less than £15 per hour and are more likely to work in precarious employment.

57. The data suggest the employment gap for people with a learning disability and autism as their main or secondary health condition is wider than for other disabilities. In 2022–23, just 30.8% of people with “severe or specific learning difficulties” and 30.6% of autistic people were employed. When looking at people accessing long term social care, only 5% of people with a learning disability were in paid work. Tim Nicholls called on the Government to set a new, ambitious target for reducing the disability employment gap with strategic actions behind it. The Secretary of State for Work and Pensions said in March 2023 that he would set a new disability employment goal. At the time of writing, the Government is yet to announce that new ambition.

58. Several Government measures are in place to help reduce the disability employment gap, including for people with a learning disability and autistic people. They include:

- Disability Confident, a government scheme to encourage employers to think differently about disability and health, and to take positive action to address the issues disabled employees face in the workplace;
- Access to Work grants to help towards extra costs of working beyond standard reasonable adjustments;
- A Local Supported Employment programme to support people with a learning disability and autistic people to find and retain work through intensive one-to-one support;
- Supported internships aimed at young people with a learning disability or autistic young people who have an Education, Health and Care (EHC) Plan;

- The Work and Health Programme which provides voluntary contracted employment support for disabled people and disadvantaged groups who are motivated to work and expect to find employment in the next 12 months; and
- A Universal Support offer to help inactive disabled people, people with health conditions and people with additional barriers to employment into sustained work.

59. In 2023, the Government commissioned the Buckland Review of Autism Employment—led by Rt Hon Robert Buckland KC MP—to support employers to recruit and retain autistic people and identify barriers. The report, published in February 2024, made several recommendations, most of which were aimed at changing employer behaviour. It noted the Government had already put developments in place, such as reviewing and strengthening Disability Confident and

improving Access to Work, but they would “require some steering to ensure the lived experience and needs of autistic people are fully taken into account”. It recognised that “the transformational change needed cannot be done all at once and everywhere” and that “it could take some years to follow through”. The report called for the creation of a task group to oversee the implementation of the report’s recommendations, with an independent chair who represents autistic people and their needs.

60. Notwithstanding Government support, witnesses living with a learning disability or autism told us of the barriers they encountered, either when seeking work or when employed. For example, the workplace can often lack what Maya Stretton termed a “neurodivergent-friendly environment” in which autistic people could feel comfortable and access reasonable adjustments, such as sensory aids. Maya told us they struggled with a former place of work to such an extent they were compelled

to leave and become self-employed to ensure their work environment suited their needs. We note that autistic people found the Access to Work application process difficult, and many also experienced delays of between three to six months in getting funding. Ciara Lawrence told us that applying for Access to Work was problematic for people with a learning disability, stating that it “is too difficult to use; it’s a really hard system”.

61. The disability charity Leonard Cheshire published a report in 2021 which found that, among employers, “ensuring the interview and application processes were accessible were seen as considerable barriers to employing disabled people”. The report argued that Disability Confident was not supporting employers to provide inclusive and accessible recruitment processes, a key commitment of the scheme. Mencap told us that Disability Confident had the right intentions but has made little impact on the employment rates of people

with a learning disability. Employers can gain the highest level of Disability Confident accreditation without employing a single disabled person. Maya Stretton noted that some employers demonstrated bias against autistic people and did not accommodate them during the recruitment process:

A lot of the time, CVs will be overlooked and disabilities will be seen as off-putting. It is disgusting that that is still happening. Once again, it is lack of understanding. Having an interview face to face might be too much. Maybe someone would prefer a phone call. Maybe a phone call is too overwhelming and too much sensory-wise. So there will always be that need to understand.

62. During our engagement event at the Hamelin Trust a participant with a learning disability told us they were scared to look for work because of the constant rejections they

received. One parent added that someone they knew with a learning disability had received 57 rejection letters. Ciara Lawrence told us she had filled in around 100 applications when looking for a job. She also commented on the difficulty she had in completing the forms, saying that “they were really hard, and my mum had to keep supporting me”. She added that if employers put in place, often small, reasonable adjustments—as they are legally obliged to do under the Equality Act 2010—people with learning disabilities could get work, do their jobs well, be promoted and enjoy successful careers. She added:

Employers need to know about reasonable adjustments, and they need to know where they can get support from. If they had that, they could employ people with learning disabilities, because they make brilliant employees. It is just about getting their foot on the ladder and knowing what the first stage is.

Apprenticeships

63. Mencap told us that apprenticeships and supported internships “will open pathways into long-term employment for many people with a learning disability”. However, as an apprenticeship provider itself, Mencap was aware of the flaws in the system. For example, it observed that the requirement for English and Maths was still a barrier for many people with a learning disability trying to access apprenticeships. Although there was some flexibility in the rules for young people with a learning disability, it said that apprenticeships were still often inaccessible to anyone without an Education, Health and Care (EHC) plan.

Supported employment

64. While in Oslo, Norway, we visited an organisation called Helt Med! which demonstrated a model for helping people with learning disabilities to find jobs in which they were interested. It involved the organisation

entering into agreements with municipalities and large and small companies to establish suitable workplaces. Positions are advertised as normal and people with learning disabilities are invited to apply. Helt Med! supports people with interview preparation and, if successful, provides follow-up with both the employee and the employer throughout the recruitment process and into the employment relationship. Following a four-week internship, some 80% of people on the programme were offered a full-time job. The programme demonstrated that once people with a learning disability had the opportunity to get into work, they thrived. We were told that previously people had been fearful about entering employment as they could lose some of their benefits and then have to go through the struggle of reapplying if the employment did not work out. To address those concerns, under the scheme people retain their benefits but the level of pay is adjusted.

65. In the UK, the Government has put in place a Local Supported Employment (LSE) initiative, until March 2025, specifically designed to help adults with a learning disability and/or autism move into “competitive employment”. The LSE provides grant funding to 28 local authority areas, with an estimated 2,000 adults with a learning disability and/or autism set to benefit from the scheme.

66. Other supported employment policies include the Work and Health programme which supports disabled people and disadvantaged people who expect to find work in the next 12 months. It provides up to 15 months pre-employment support and up to six-months of in-work support. As of November 2023, 300,000 participants had started on the Work and Health Programme, with 130,000 participants achieving first earnings from employment and 81,000 participants reaching the job outcome earnings threshold or six months of being in self-employment. The programme is set to

end in September 2024. As part of its plans to increase Jobcentre support for those who are economically inactive due to a long-term health condition or disability, the Government, in September 2023, announced a £53 million Universal Support programme. The programme is expected to help 25,000 people move towards employment by September 2024.

Jobcentres

67. Several witnesses noted it was important that Jobcentre staff, including work coaches responsible for referring people to employment support programmes, received adequate training to better help people with a learning disability and autistic people into work. Ciara Lawrence said it was the “attitudes of Jobcentre staff that really we have found very difficult”. She told us that staff needed “proper training about learning disability, because then they would know how to talk to people”. She told us:

I found it very hard; it was like banging my head on a table, going, “No, you need to talk to me in a clear way, please. It shouldn’t be this hard.”

Things have got better, but when we kept going back and saying, “Look, someone here needs to help us,” at the final hurdle—a year after we had first gone—we were told about the disability employment officer. Actually, had they told us when we first went that there was a disability job officer who could talk to me, we would have gone to her, but we were not told until a year later that she existed. She introduced me to Mencap, and the rest is history. But I had to struggle for so long. We did not get signposted to any support.

68. Working with the National Autistic Society, the Government developed a pilot accreditation scheme within Jobcentres to ensure all

staff—from security to disability employment advisers—were properly trained to provide services to autistic customers and those with other neurodiverse conditions. The pilot was successful in all 15 offices which tested the scheme. The Government said it would consider if the scheme could be rolled out nationally, something Tim Nicholls of the NAS was keen to see and who explained why that training was so important:

I heard from one person—a youngish guy—who found the harsh lights at the jobcentre overwhelming, so he went in with his hood up and headphones on. He did not hear the security guard on the door. The security guard then grabbed him, and he was incredibly sensitive to touch. That was a massive shock, and he had a meltdown. It meant he was not able to go to the appointment, and it meant he was

physically restrained. That was a terrible outcome for him. Training would solve that.

69. People with a learning disability and autistic people can and want to work and thrive when they get the opportunities to do so. However, they face the widest employment gap of all people with disabilities and find it difficult to get their foot in the door. *The Government should:*

- ***publish a new disability employment goal based on relative measures and set out how it plans to achieve it; that goal should include a specific target for people with a learning disability and autistic people;***
- ***ensure that work to improve Disability Confident and Access to Work includes reviewing the extent to which those***

policies are helping employers to recruit and support people with a learning disability and autistic people;

- ***simplify the Access to Work scheme for people with a learning disability and autistic people and tackle the delays in processing applications to that scheme;***
- ***extend the Work and Health programme for a further 12 months;***
- ***exempt people with a learning disability and autistic people who do not have an Education, Health and Care Plan from the Maths and English skills requirement for apprenticeships;***
- ***implement the recommendations of its Review of Autism Employment including, as a priority, the appointment of a task group to be chaired by someone independent of government who represents autistic people and their needs;***

- ***roll out the autism accreditation scheme in all Jobcentres; and***
- ***ensure all Jobcentre work coaches are trained in learning disability so they can effectively refer people to suitable employment support programmes.***

Annex: National Disability Strategy: Note of private informal meeting with people with lived experience

July 2024

Meeting between the Women and Equalities Committee and people living with or who are caring for young family members with learning disabilities and/or autism as well as other complex needs.

We would like to thank the Hamelin Trust and the Essex Carers Network for their support in organising the meeting and to the attendees for giving up their time to talk to us. All participants were aged over 18.

The following themes emerged during the discussion.

Transition from child services to adult services

‘Support falls off a cliff when a young person turns 16.’

Attendees outlined the challenges they had faced during their young person's transition from child to adult services at the age of 16.

One participant changed their job to support their son's transition to adulthood because 'support falls off a cliff' when a young person turns 16. They described the feeling of dropping them at a special school knowing they were safe, but that not being the case when dropping them at a mainstream college.

In healthcare, parents described how a young person under 16 can see a paediatrician for all their health needs but, after turning 16, will have to see a range of different clinicians for individual aspects of their care. They said that clinicians also want to speak directly to the patient, which can be a challenge when they have difficulty articulating their needs.

Everyone agreed that it was only the people who 'shout and shout loud' that get the services their young person needs. One attendee noted

that progress was possible, but carers needed to have the confidence to approach local representatives, such as councillors and their MP, to get things done.

Parent/carers discussed difficulties in getting Court of Protection Orders to make financial and/or welfare decisions on behalf of an adult who does not have the mental capacity to make those decisions for themselves. The process can be challenging, lengthy and expensive, taking between six months to two years and costing up to £3,000. Several attendees noted that Orders for a person's personal wellbeing were rarely authorised and difficult to obtain. Participants also spoke of the 'reams of paperwork' required to complete a successful application. Families felt like they were being treated as if they did not want the best for their child.

By contrast, some attendees told us that if the adult they care for has capacity, parents can

apply for Power of Attorney—a legal agreement between the person being cared for (the donor) and their caregiver (the attorney)—which was a relatively quick and inexpensive process.

Challenges within educational settings

‘Nothing has changed—you still have to fight for your child.’

One attendee suggested schools wanted students with learning disabilities because they received additional funding but noted that because that money sits in the school’s overall budget, it is not ringfenced for individual children. Everyone agreed that support for children with special educational needs and disabilities (SEND) often failed to materialise. For example, students with learning disabilities often did not get adequate one-to-one time due to a lack of resources, such as teaching assistants in classrooms.

A participant with a learning disability said their behavioural problems deteriorated while attending a mainstream school because there was no support in place. They were also bullied by their teachers. Once they moved to a specialist school, their behaviour improved, and they were able to get qualifications. They felt lucky that they could articulate their needs when other people with learning disabilities could not.

Participants discussed Education Health and Care Plans (EHCPs), formerly known as statements of special educational needs, highlighting some concerns.

- ‘Nothing has changed’ since EHCPs were introduced. Parents still have to fight for their child to get the support they need.
- Participants spoke of being overwhelmed by the amount of paperwork required to get an EHC assessment. The language and terminology can act as a barrier to a lot of

parents—some of whom may have learning difficulties or whose first language is not English.

- ‘No one knows what to put’ in certain sections of the forms—particularly the sections filled in by healthcare professionals. Some observed that those sections were little more than a list of diagnoses and a note saying they will be ‘reviewed by a clinician as needed’.
- The process can take years, and primary schools often do not want to put kids forward for an assessment because they know the amount of work involved. One participant resigned from their former role in which they were responsible for overseeing EHC applications in a school because they could not get applications through the system.

Participants highlighted travel for people with learning disabilities to and from educational settings as a particular barrier:

- As disability bus passes do not 'kick in' until 9.30am, some specialist colleges were forced to start later in the morning to accommodate students travelling independently.
- One parent/carer, whose child could not travel independently, had to wait for a taxi to collect their child in the mornings. As a result, they had to give up their job because they were unable to get to work on time.
- Applying for post-16 and post-19 travel was always 'a battle' and funding for transporting people from day centres to colleges to attend courses had disappeared due to reductions in local authority budgets.

Moving from education to employment

‘Give employers a chance to give the person a chance.’

Attendees agreed that working can build confidence. A person with a learning disability told us that most disabled people’s needs were simple: a home, friends and a job, but it was very difficult to find a job to fit around their care needs and benefits.

We heard that some people are so desperate for work that they end up applying for full time jobs, even though they know they won’t be able to work full time. An example was given of a person with learning disabilities who had received 57 rejection letters.

A participant with a learning disability said they were scared to look for work because ‘you fill out lots of forms, only for someone to say no to you’. The same participant could not apply by themselves and considered themselves lucky they had a very good Disability Employment

Advisor (DEA) at the Job Centre. However, there was consensus within the group that supportive DEAs were 'few and far between'.

Participants were asked what they thought would help change employers' attitudes to people with a learning disability and/or autism:

- Better training and understanding
- Time—encourage employers to give the person a chance
- Sharing good news stories of case studies where employing someone with a learning disability had been a success
- Understanding the skills people with learning disabilities have and finding roles that fit their skills so they can be productive
- Giving experience to young people so they understand different jobs in the workplace.

- Communicating the commercial benefits of employing people with specific skills. For example, some people with autism are exceptional at coding.
- Some industries cannot currently recruit enough people, so make them understand the benefits of employing people with learning disabilities

One person with a learning disability described the benefits system as 'hell'. For example, they had to tell an assessor about their worst day, which can be very upsetting and emotionally draining. Everyone agreed that many disabled people were worried about the impact that working can have on their benefits if the job does not work out.

Accessing healthcare

'Nothing for us without us.'

Everyone agreed that individual, person-centred support for people with complex needs was essential: it may be expensive, but money well spent at the right time would save money later.

An attendee with a learning disability spoke of the difficulties they had in getting their GP surgery to make the reasonable adjustments they required. The situation only changed after their local Member of Parliament became actively involved. They have since been added to their GP's Learning Disability Register and their experience of accessing primary healthcare has transformed. For example, the GP no longer wears clinical clothing for appointments (such as a white clinicians' coat) which triggered trauma from being sectioned, with appointments taking as long as they need. The same participant also highlighted the importance of clinicians speaking to the person directly, not just the carer accompanying them, and that clinicians should always assume the patient has capacity unless it has been proven otherwise.

The group said the standard of healthcare someone received was often a ‘postcode lottery’, even within the same county: people should have access to the screening and care they need.

Participants agreed that annual health checks for people with learning disabilities were important, but raised several concerns:

- They often felt like ‘tick box exercises.’
- Appointments were not always held in person, with clinicians opting to hold them over the phone. Examples were given of face-to-face appointments only agreed to once an advocate had become involved.
- Language was not tailored to individual needs. Someone gave an example of a patient being asked if they had trouble ‘passing water’ so, on the way home from that appointment, the patient changed his route home to walk past the river.

- One participant told us of clinicians ‘jumping to conclusions’ during appointments, immediately pursuing perceived safeguarding issues rather than dealing with the health issue at hand. For example, when they raised an issue relating to a person’s genitals, they were asked ‘why were you looking there?’.
- Despite rising awareness, most families were still not aware of annual health checks.

Living independently

‘I can’t do this forever; what happens when I’m not here?’

The biggest worry for parents is ensuring their children have a future pipeline of care. One attendee said that social services often assumed that a person with a learning disability wants to move out of the family home as soon as possible, but that this is not always the case.

The person is not always ready, and, in the meantime, they need support in building up the skills and confidence to live independently. However, there is little support in building those skills unless the parent pushes for it.

One participant spoke about moving from supported living accommodation to living independently in their own flat with a carer visiting several times a week to help where needed. They said that because of that support, they can engage with the things they are doing rather than worry about the logistics, such as how to get to and from somewhere. They spoke of how a person can become very dependent on their support worker, especially if, as in their case, they often felt lonely and isolated. They emphasised that extra support is vital for some people who do not have family members they can rely on to deliver the level of care they require.

Another parent/carer collaborated with other parents (of people with learning disabilities who attended the same day centre) to provide accommodation for their dependents to live together. The parents initiated the process themselves, and contacted local charities to see what support they could receive. The participant's son now lives in the house on weekdays and comes back to the family home at weekends. They told the group that while their son was 'not entirely happy yet', they were becoming used to independence.

Parent/carers said it is often assumed that, when allocating living placements to people with autism, they can live happily with other autistic people regardless of other personality traits and interests: they are being 'lumped together' because they all have autism. Parents worry about turning down a placement that does not feel right for their child because they might not get another one.

Support from social services

‘I haven’t seen a social worker since before the pandemic, and I don’t want to.’

The group felt that that social workers were always looking to reduce support and costs because of budget cuts. Some parent/carers spoke of being ‘terrified’ of speaking to social workers for fear that they will lose funded provisions.

Some families receive provision for a limited amount of overnight care. However, participants told us that some families were scared of using their allocation because if they did, and the parent/carer then became ill at a later date, there was no guarantee that a crisis room or bed would be available for the person they cared for. Families ‘hold on’ to some of their nights ‘just in case’, risking their allocation being reduced in subsequent years. Participants told us that respite beds are essential—they allow carers

who have had to go into hospital to relax and recover because they know their child is being cared for.

The risk of sectioning

‘If someone with a learning disability shouts or swears, they’re not labelled as having a bad day, they’re labelled as challenging. The spotlight is constantly on them.’

One carer told us that parents are ‘terrified’ to let their children live independently because they, as parents, will not always be there to calm them if they become distressed.

Participants told us that when a person with a learning disability turns 18, the default is for them to be sectioned if they become distressed and cannot regulate their own behaviour.

Patients are likely to be prescribed antipsychotic medications, as well as other medicines to combat the side effects. Attendees told us that clinicians were reluctant to take patients off

antipsychotics, because they are worried about their behaviour 'flaring up' again. One attendee described a vicious cycle of over-prescription, lack of therapeutic care, sectioning and hospital.

The issue of private hospitals lacking accountability was raised, as well as the apparent dehumanisation of patients in their care: one participant told us their son was referred to as a 'delivery' when being transferred between hospitals.

Personal challenges as a parent/carer of a person with learning disabilities

'It's easy to give other people advice but when it's your own child, you get lost in the fog.'

Many participants agreed that when they are giving other people advice, they can think logically, but when it is their own child, they get 'lost in the fog'. One participant said that they were 'so scared of doing something wrong'

because if the person they care for has a bad experience, the repercussions can last for months.

The group discussed the issue of divorce rates among couples who have a child with a learning disability, with one person describing it as “phenomenal”. Participants spoke about the inability to find the time to do anything together as a couple because they are “constantly exhausted”. The needs of siblings may also go unmet. One parent said that when couples have more than one child, “however hard you try, the child with the greatest needs gets the greatest care”.

Other examples were given of parents having to give up employment opportunities in order to support their child, and one participant said they would ‘never be able to retire’ because they did not have the opportunity to stay in employment long enough to build up a pension.

Final thoughts

‘Services know what support is needed, but there’s no one there to give it.’

We asked participants for their final thoughts on what would improve the lives of people with learning disabilities and autism:

- Timely response to prevent future crises. When someone says they need help, they need help now. However, things like moving someone out of accommodation that doesn’t work for them can take months.
- Put the money where it is needed and do not ‘reinvent the wheel’.
- Services need capacity to put the required support in place. Often people working in services know what support is needed, but there is no one available to give it.
- Provisions are being scaled back because there is no one to put them in place. For

example, children are not being properly supported in school, they are on long waiting lists for diagnoses (or diagnosed late) and receive minimal (physical and mental) therapy provision.

- If someone has a goal, such as improving social interaction or getting a job, they need someone to advocate on their behalf until they have capability.
- More attention should be paid to the pressures facing 'sandwich carers', who are caring both for a young person or child as well as their own, often elderly parents.

Conclusions and recommendations

C&R Sub heading

1. Health inequalities continue to be significant among people with learning disabilities and autism, including an unacceptable level of premature and avoidable deaths compared to the general population. Although some measures are now in place to monitor mortality, such as the annual Learning Disability and Mortality Review (LeDeR), and mandatory training on learning disability and autism, it is clear that more effort is required to improve health outcomes. Significant progress has been made in rolling out part one of the Oliver McGowan Mandatory Training on Learning Disability and Autism but the number of staff who have completed part two is low and availability is constrained while training capacity increases. (Paragraph 19)

2. *The Government should set out clear targets for the rollout of part two of the Oliver McGowan Mandatory Training on Learning Disability and Autism to help increase take up. The training should include elements tailored to specific health settings.* (Paragraph 20)
3. We welcome the commitment to train and recruit more learning disability nurses to help address some of the shortfall within the profession. *Alongside that commitment the Government should support more learning disability nurses to go into senior leadership roles within hospital and community health services to help drive the necessary improvements to health outcomes for people with a learning disability.* (Paragraph 21)
4. The learning disability register is vital for people with a learning disability to receive important, life-saving annual health checks and reasonable adjustments. Yet around

75% of people with a learning disability are not registered. We heard from people who struggled to convince their GP to put them on the register and only achieved success once the media and politicians were involved. They should not have to reach that point, and not everyone will feel empowered to argue their case or have access to such advocacy to assist them. The system has to work better to ensure all people with a learning disability have access to good healthcare. (Paragraph 29)

5. *As an immediate priority, the Department for Health and Social Care and NHS England should work with national and local learning disability organisations and charities and the Royal College of General Practitioners to investigate why eligible people are not on the learning disability register and take appropriate action to increase registration. That work should include an assessment of the reasons why eligible people who*

have applied to be on the register have been denied access to it and a review of the existing guidance for GPs to ensure it captures all those who are eligible for registration. We also recommend that, by the end of 2024:

- The Government should develop and launch an awareness raising campaign to encourage people to ask their GP to be put on the learning disability register; the campaign should be appropriately tailored to deliver increased registration among underrepresented communities;*
 - All GPs should ensure staff are using existing guidance on registration correctly to ensure eligible people are not being denied access to the register before even seeing a GP. (Paragraph 30)*
6. Too many people are waiting far too long to get their autism assessment and the backlog is getting worse. It is clear that current

efforts to address the waiting list backlog are inadequate and that the additional funding that has been allocated is far short of what is required. *The Government needs to radically increase the funding allocated to reducing waiting times for an autism assessment.* (Paragraph 37)

7. *People with autism who may find it difficult to advocate for themselves can struggle to navigate the diagnosis process. The Government should work with NHS Trusts to ensure that information about the autism assessment process is accessible and available to everyone going through it, from pre- to post-diagnosis.* (Paragraph 38)
8. Women and girls with autism struggle to get diagnosed. Understanding of how autism presents in women and girls must be improved so that they can receive the support they need before they reach crisis and to prevent misdiagnosis and

inappropriate care. The Government acknowledged this need in the National Disability Strategy but has made no progress in delivering the promised autism public understanding initiative. *The Department for Health and Social Care should develop and trial an initiative aimed at improving public understanding of autism in women and girls by the end of 2024. In the meantime, the Government should set out what steps it is taking to improve the autism diagnosis process for women and girls.* (Paragraph 42)

9. The Government has fallen short on its commitment to halve the number of people with a learning disability and autistic people inappropriately detained in mental health hospitals. Promises to bring forward a new Mental Health Bill to help address this concern have gone unmet. Meanwhile, the number of autistic people in mental health

settings and exposed to the harm that those settings can present is increasing. (Paragraph 49)

10. The Government must make more progress in reducing the number of people with learning disabilities and/or autism detained in mental health settings. To achieve this the Government needs to learn from previous failings and increase support for community-based alternatives to detention and do more to stop people reaching crisis in the first instance. (Paragraph 50)

11. *In response to this report, the Government should set out:*

- *The reasons why the number of autistic people detained in mental health hospitals has increased; and how it plans to reduce that number, and by when.*
- *The steps it will take to improve access to and availability of community-based*

alternatives to inpatient settings, including the additional resources it plans to allocate to support this; and

- *Its progress on discharging people with a learning disability and autistic people inappropriately detained in mental health hospitals, broken down by Integrated Care Board. (Paragraph 51)*

12. People with a learning disability and autistic people, and the people who care for them, are the real experts when it comes to their health and care needs. However, aside from the occasional opportunity to feed into consultations, their voices are often missing when it comes to decision making at both a local and national level. Their lived experience should be better reflected throughout efforts to reduce the health inequalities discussed in this report. (Paragraph 54)

13. *The Government should reestablish a national board with a focus on improving health inequalities for people with a learning disability and autistic people across all health and social care services. That board should include, and be led by, people with a learning disability and autistic people, people with parental and caring experience and health and social care professionals. Ministers should grant the board the responsibility and accountability necessary to drive change in health outcomes. (Paragraph 55)*

14. People with a learning disability and autistic people can and want to work and thrive when they get the opportunities to do so. However, they face the widest employment gap of all people with disabilities and find it difficult to get their foot in the door.

The Government should:

- *publish a new disability employment goal based on relative measures and set out*

how it plans to achieve it; that goal should include a specific target for people with a learning disability and autistic people;

- *ensure that work to improve Disability Confident and Access to Work includes reviewing the extent to which those policies are helping employers to recruit and support people with a learning disability and autistic people;*
- *simplify the Access to Work scheme for people with a learning disability and autistic people and tackle the delays in processing applications to that scheme;*
- *extend the Work and Health programme for a further 12 months;*
- *exempt people with a learning disability and autistic people who do not have an Education, Health and Care Plan from the Maths and English skills requirement for apprenticeships;*

- *implement the recommendations of its Review of Autism Employment including, as a priority, the appointment of a task group to be chaired by someone independent of government who represents autistic people and their needs;*
- *roll out the autism accreditation scheme in all Jobcentres; and*
- *ensure all Jobcentre work coaches are trained in learning disability so they can effectively refer people to suitable employment support programmes.*

(Paragraph 69)

Formal minutes

Wednesday 15 May

Members present:

Dame Jackie Doyle Price

Kate Osborne

Kirsten Oswald

Bell Ribiero-Addy

In the absence of the Chair, Kate Osborne was called to the chair.

Inequalities in healthcare and employment for people with a learning disability and autistic people

Draft Report (*Inequalities in healthcare and employment for people with a learning disability and autistic people*) proposed by the Chair, brought up and read.

Ordered, That the Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 69 read and agreed to.

Annex agreed to.

Summary agreed to.

Resolved, That the Report be the Sixth Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order No. 134.

Adjournment

Adjourned till Wednesday 22 May at 2.00pm

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the inquiry publications page of the Committee’s website.

Wednesday 29 March 2023

Fazilet Hadi, Head of Policy, Disability Rights UK; **Svetlana Kotova**, Director of Campaigns and Justice, Inclusion London; **Lord Shinkwin**, Chair (2020–2021), The Centre for Social Justice Disability Commission Q1–14

Martin McLean, Senior Policy Advisor, National Deaf Children’s Society; **Fran Springfield**, Co-Chair, Chronic Illness Inclusion; **Nil Guzelgun**, Policy and Campaigns Manager, MIND Q15–32

Wednesday 26 April 2023

Tim Nicholls, Head of Influencing & Research, National Autistic Society; **Maya Stretton**, Young Ambassador, National

Autistic Society; **Jackie O’Sullivan**, Executive Director of Communications, Advocacy & Activism, The Royal Mencap Society; **Ciara Lawrence**, Engagement Lead, The Royal Mencap Society Q33–59

George Appleton, Head of Policy, Care England; **Jim Blair**, Consultant Nurse and Associate Professor (Hon), Learning Disabilities Q60–79

Wednesday 17 May 2023

Angela Matthews, Head of Policy and Research, Business Disability Forum; **Tammy Jones**, Managing Director, Purple; **Eric Harris**, Director of Inclusive Research, Research Institute for Disabled Consumers; **Vivienne Francis**, Chief Social Change Officer, The Royal Institute of Blind People Q80–113

Wednesday 05 July 2023

Tom Pursglove MP, Minister for Disabled People, Health and Work, Department for Work and Pensions; **Maria Caulfield MP**, Minister for Mental Health and Women's Health Strategy, Department of Health and Social Care; **David Nuttall**, Deputy Director of Neurodiversity, Diversity and Learning Disability, Department of Health and Social Care; **Marcus Bell**, Director of the Equality Hub, Cabinet Office; **Jennifer Heigham**, Deputy Director for Strategy and Briefing for Work and Health Unit, Department for Work and Pensions

Q114–182

Published written evidence

The following written evidence was received and can be viewed on the inquiry publications page of the Committee's website.

NDS numbers are generated by the evidence processing system and so may not be complete.

- 1 Anonymised (NDS0009)
- 2 Anonymised (NDS0007)
- 3 Anonymised (NDS0008)
- 4 Anonymised (NDS0002)
- 5 Blair, Jim (NDS0043)
- 6 Bouhfadi , Mrs Vanessa (NDS0004)
- 7 British Psychological Society (NDS0016)
- 8 Business Disability Forum; and Scope (NDS0024)
- 9 Care England (NDS0014)
- 10 Central YMCA (NDS0031)
- 11 Cresswell-Plant, John (NDS0038)
- 12 Culverwell, Mrs Teresa (NDS0005)

- 13 Cystic Fibrosis Trust (NDS0025)
- 14 Dance Syndrome (NDS0042)
- 15 Disability Rights UK (NDS0021)
- 16 Equality and Human Rights Commission (NDS0039)
- 17 Family Fund (NDS0019)
- 18 Harris, Eric (NDS0044)
- 19 Healthwatch Solihull (NDS0006)
- 20 Inclusion Gloucestershire; and Barnwood Trust (NDS0029)
- 21 Inclusion London (NDS0030)
- 22 Liberation (NDS0034)
- 23 Mencap (NDS0027)
- 24 Muscular Dystrophy UK; and SMA UK (NDS0028)
- 25 National Association of Disabled Staff Networks (NADSN) (NDS0011)
- 26 National Autistic Society (NDS0022)

- 27 National Deaf Children's Society
(NDS0036, NDS0040)
- 28 Nethercot, Patrick (NDS0003)
- 29 New Bold Hope (NDS0045)
- 30 Pryer-Vaz, Mrs Rosie (NDS0018)
- 31 Royal National Institute of Blind People
(RNIB) (NDS0046)
- 32 Sharp (NDS0020)
- 33 Shaw Trust (NDS0015)
- 34 The British Toilet Association Ltd
(NDS0035)
- 35 The Challenging Behaviour Foundation
(NDS0037)
- 36 The Trades Union Congress (The TUC)
(NDS0017)
- 37 United Response (NDS0033)
- 38 Voluntary Organisations Disability Group
(VODG) (NDS0023)
- 39 Whizz-Kidz (NDS0010)

- 40 Working Together with Parents Network - University of Bristol (NDS0013)
- 41 Zeyen, Dr. Anica (Senior Lecturer in Entrepreneurship and Sustainability, Royal Holloway University of London); and Branzei, Professor Oana (Professor of Strategy, Ivey Business School) (NDS0026)

List of Reports from the Committee during the current Parliament

All publications from the Committee are available on the publications page of the Committee's website.

Session 2023–24

Number	Title	Reference
1st	The National Disability Strategy	HC 34
2nd	Misogyny in music	HC 129
3rd	Health barriers for girls and women in sport	HC 130
4th	Accessibility of products and services to disabled people	HC 605
5th	The prevalence of sexually transmitted infections in young people and other high risk groups	HC 463

1st Special	Attitudes towards women and girls in educational settings: Government, Ofsted and Office for Students responses to the Committee's Fifth Report of Session 2022–23	HC 258
2nd Special	The National Disability Strategy: Government Response to the Committee's First Report	HC 563
3rd special	Misogyny in music: Government, CIISA and Office for Students responses	HC 695

4th special	Health barriers for girls and women in sport: Government and Sport England responses to the Committee's Third Report	HC 752
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Session 2022–23

Number	Title	Reference
1st	Menopause and the Workplace	HC 91
2nd	The rights of cohabiting partners	HC 92
3rd	Black maternal health	HC 94
4th	Equality and the UK asylum process	HC 998
5th	Attitudes towards women and girls in educational settings	HC 331
6th	So-called honour- based abuse	HC 831

Number	Title	Reference
1st Special	Ethnicity pay gap reporting: Government response to the Committee's fourth report of session 2021–22	HC 110
2nd Special	Equality in the heart of democracy: A gender sensitive House of Commons: responses to the Committee's fifth report of session 2021–22	HC 417
3rd Special	The rights of cohabiting partners: Government response to the Committee's second report	HC 766

Number	Title	Reference
4th Special	Menopause and the workplace: Government response to the Committee's first report	HC 1060
5th Special	Black maternal health: Government Response to the Committee's Third Report	HC 1611
6th Special	So-called honour- based abuse: Government response to the Committee's Sixth Report	HC 1821
7th Special	Equality and the UK asylum process: Government response to the Committee's Fourth Report	HC 1825

Session 2021–22

Number	Title	Reference
1st	Levelling Up and equality: a new framework for change	HC 702
2nd	Appointment of the Chair of the Social Mobility Commission: Katharine Birbalsingh CBE	HC 782
3rd	Reform of the Gender Recognition Act	HC 977
4th	Ethnicity pay gap reporting	HC 998
5th	Equality in the heart of democracy: A gender sensitive House of Commons	HC 131

Session 2019–21

Number	Title	Reference
1st	Unequal impact? Coronavirus, disability and access to services: interim Report on temporary provisions in the Coronavirus Act	HC 386
2nd	Appointment of the Chair of the Equality and Human Rights Commission	HC 966
3rd	Unequal impact? Coronavirus and BAME people	HC 384
4th	Unequal impact? Coronavirus, disability and access to services: full Report	HC 1050

Number	Title	Reference
5th	Unequal impact? Coronavirus and the gendered economic impact	HC 385
6th	Changing the perfect picture: an inquiry into body image	HC 274