



# **‘Right to be heard’: The Government’s response to the consultation on learning disability and autism training for health and care staff**

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# Foreword by Caroline Dinénage

Among deep concerns about health inequalities and disproportionate numbers of potentially avoidable deaths of people with a learning disability, this government commissioned the Learning Disability Mortality Review (LeDeR) Programme. The findings from LeDeR reinforce just how much more Government, and our health and care system, need to do to give people with learning disabilities the good quality health and social care that they ought to expect as a right. Care that the LeDeR reports demonstrate is all too often denied them. This is simply not good enough.

A common theme in the deaths reviewed by the LeDeR programme was the need for better training and awareness of learning disability. The same is true of autism. In responding to the second annual report of the LeDeR programme, the Government set out a series of actions, including a commitment to consult on, and implement, mandatory learning disability and autism training.

The importance of this training was really brought home to me in October last year, when I responded to a debate in Parliament on learning disability and autism training for healthcare professionals. This was a response to Paula McGowan's petition calling for this training to be mandatory for all health and care staff. Hearing Paula's testimony, I was both moved and inspired by how she had turned the grief of losing her son, Oliver, into a powerful campaign highlighting the importance of a greater awareness of the needs of autistic people and people with learning disabilities. During the debate I heard very clearly how better understanding of learning disability and autism would have categorically changed his experience and could have resulted in an entirely different outcome for Oliver.

Sadly, Oliver's story is not unique, and I am both saddened and frustrated by other stories I have heard of tragic and potentially preventable deaths. Like that of Richard Handley, who may still be with us if staff had the appropriate skills and knowledge to better understand his needs. I was also struck by the case in the recent [Healthcare Safety Investigation Branch Bulletin](#), in which a young female patient died as a result of an undetected heart problem. The report highlighted that there is a lack of training and awareness within mainstream healthcare services on how to tailor care for patients with autism and learning disabilities. These stories, and too many more, emphasise the very urgent need to improve the experiences of people with learning disabilities and autistic people when accessing health and social care services.

In consulting on proposals for mandatory training for health and care staff, our aim has been to gain a better understanding of how to ensure that patients and service users receive safe, effective and dignified care and that those who provide care have the knowledge, skills and behaviours to support people with learning disabilities and autistic people.

I know that the proposed approach of making learning disability and autism training mandatory may seem a strong response and even, to some, an unnecessary step. However, we know from the LeDeR review process that people with a learning disability can experience hospitalisation, life-threatening illnesses, and even premature death when unable to access health services for even the most routine conditions or ailments. It remains a stark fact that people with learning disabilities die, on average, 20 years earlier than the general population, and that both they and autistic people continue to experience significant disparities in the quality of care and support they receive, as well as in the outcomes they can expect. As with earlier reports, from [Mencap](#) and many others, the LeDeR programme reinforces that a new approach is now desperately needed to give people with learning disabilities and autistic people the care they deserve.

I am pleased to be able to report on the outcome of our consultation and am grateful to all those individuals and organisations that have taken the time to contribute their views. We had over 5,000 responses, which is a testament to how important this issue is to people. I am also very pleased to say that support for the principle of mandatory training was overwhelmingly positive, with a clear recognition that an understanding of autism and learning disability is the cornerstone of good quality care and can make a real difference to hundreds of thousands of lives. I also recognise that we need to get this right to avoid turning any training effort into a box ticking exercise and to ensure its impact. Our proposed way forward takes this into account.

I am determined that everybody who has a learning disability, or is autistic, receives the high-quality care that meets their needs and their expectations. In life, Oliver, Richard and too many others had a right to be listened to and their needs understood but tragically this was not always the case. We owe it to their memory that people with learning disabilities and autistic people are supported to live healthy and happy lives. They deserve nothing less.



A handwritten signature in black ink, appearing to read 'Caroline Dinenage'.

**Caroline Dinenage**  
**Minister of State for Care, Department of Health and Social Care**

# Executive summary

1. This is the Government response to the consultation on proposals for introducing mandatory learning disability and autism training for health and social care staff, which was published on 13 February 2019 and closed on 26 April 2019. The Government received 5,155 responses to the consultation.
2. Consulting on proposals for mandatory learning disability and autism training was one of the commitments made in the Government's response to the second annual report of the [Learning Disability Mortality Review \(LeDeR\) Programme](#), which recommended that mandatory learning disability training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families.
3. This response sets out the views we heard from respondents to the consultation as well as the measures we intend to take to implement mandatory learning disability and autism training.

## What we heard

4. There was overwhelming support for the principle of mandatory training. A very small minority of respondents felt that mandating training would be bureaucratic and lead to a decline in learning motivation and engagement, thus limiting its success.
5. The consultation proposed that training should focus on understanding learning disability and autism, the legislative context and making reasonable adjustments. This was well supported by respondents, with valuable suggestions for other topics, which had a strong emphasis on ensuring that staff were fully aware of the hidden nature of someone's needs, and not making assumptions as to how they might be met.
6. The majority of respondents agreed that the training should reflect the [Core Capabilities Framework for Supporting People with a Learning Disability](#) and the new [Core Capabilities Framework for Supporting Autistic People](#). These frameworks identify the different levels of skills and knowledge staff need to support people with a learning disability and autism. Most respondents also agreed that employers should assess the level of training their staff need and ensure that their staff received this training. Where respondents disagreed with employers having responsibility for assessing training requirements, frequently cited concerns included the need for employer support and time and cost pressures potentially leading employers to opt for the most basic level of training.

7. Our proposal for staff to receive face to face training (as opposed to e-learning) only if they were in a role which meant they would be in regular contact with someone with a learning disability or autism received less support, with almost half of respondents who expressed a clear view saying that as many staff as possible should have face to face training.
8. There was very strong support for the idea that people with lived experience should be involved in the delivery of training and that they should be appropriately remunerated, either through receiving a salary or expenses.
9. The full analysis of responses to all the individual consultation questions is set out in this document in the sections that follow.

## **What we propose**

10. We received a strong positive response to the consultation, with clear recognition that health and social care staff must have a better understanding of how to support people with learning disabilities and autistic people more effectively.
11. We know that staff want learning disability and autism training and that training motivates them to change their practice. Mencap's survey for their ['Treat me well' campaign](#) found that almost half of staff responding thought that a lack of training on learning disability might be contributing to avoidable deaths and two thirds would like more training focussed on learning disability. Additionally, a benchmarking exercise for the learning disability improvement standards found that only around half of staff (53%) confirmed they had the necessary training to meet the requirements of the [learning disability standards](#) in terms of delivering care to people with learning disabilities, autism or both, in a way that takes into account their rights and needs. The NHS Long Term Plan sets out that over the next five years, national learning disability improvement standards will be implemented and will apply to all services funded by the NHS. These standards will promote greater consistency, addressing themes such as rights, the workforce, specialist care and working more effectively with people and their families.
12. Whilst the case for learning disability and autism training is clear, we also heard during the consultation about the practical challenges of implementing training at this scale. We need to ensure the training is meaningful and not just a box-ticking exercise. And that it is comprehensive, engaging and has the desired effect on attitudes and behaviours. We also need to be mindful of the impact of training on people's 'day jobs' and balancing this with their daily practice and activities. The training needs to be well designed.

13. Our proposals are ambitious yet proportionate, with the refreshed Core Capabilities Framework for Supporting People with a Learning Disability and the new Core Capabilities Framework for Supporting Autistic People at their heart. These Frameworks set out the core skills and knowledge that staff supporting people with learning disability and autistic people should have, depending on the nature and intensity of support and care that they give. The Frameworks also include expected learning outcomes for education and training, ensuring the quality and consistency of learning disabilities and autism training.
14. We want all training and development undertaken to be consistent with the Frameworks, so we have confidence that all staff, irrespective of setting or location, have the skills and knowledge that are appropriate to their role. Our vision is that the Frameworks are woven into all training opportunities - from the Care Certificate, which is an agreed set of standards that define the knowledge, skills and behaviours expected of specific job roles in the health and social care sectors, to apprenticeships and vocational training.
15. We are clear that to fully realise the benefits of training, all staff must do it and it must be proportionate to their role and the level and nature of contact they have with people with a learning disability and autistic people. We are equally clear that a phased approach, informed by trialling, is needed to ensure that the training achieves what is intended.

### **Pre-registration training**

16. Staff must have the skills, competence and knowledge to do their job well. We want to ensure that all new staff have already received a good grounding in the care of people with learning disabilities and autistic people before they begin their careers in health and social care. A focus on these aspects in pre-registration education and training is crucial to delivering the changes we want to see and ensuring that these are sustainable in the long-term.
17. We know that pre-registration training for most professions already covers some of the important elements. For instance, the General Medical Council's updated Outcomes for Graduates requires newly qualified doctors to be able to assess the needs of people with learning disabilities and the support required. Similarly, the Nursing and Midwifery Council's new educational standards of proficiency for all professions will ensure that, in future, nurses, midwives and nursing associates in England at the point of registration will be better equipped to deliver care for people with learning disabilities and autistic people.

## **Towards a common core curriculum**

18. Our vision is that in future all professionals will, before starting their career or through continuing professional development, undertake training which covers a 'common core curriculum' for learning disability and autism so that we can be confident that there is consistency across education and training curricula.
19. We are committing to work with all professional bodies and the Devolved Administrations to agree a common core curriculum in due course, based on the Core Capability Frameworks for Supporting People with a Learning Disability and Autistic People. We recognise that it will take time to ensure that all training is aligned with the Frameworks; with periodic updates to syllabuses and training requirements, but we will work with the regulators to ensure the closest possible alignment at the earliest opportunity.
20. Discussions with the professional bodies, regulators, employers and other organisations will be progressed to determine the best way to achieve a common core curriculum. Recent engagement has seen the Joint Academy of Medical Royal Colleges Training Forum discuss how to manage specific curricula items including learning disability and autism training. It will arrange a discussion with the regulator, the General Medical Council, on whether a small working group should be set up to discuss requests submitted by Government and Colleges, and, how to handle the arising issues. For nurses, midwives and nursing associates in England, the regulator the Nursing and Midwifery Council believe a common core curriculum could be used by education providers to provide added value to their own standards of proficiency. These standards focus on person centred care for people with cognitive, behavioural, mental and physical health needs, with an identified field of nursing in learning disabilities.

## **Developing and evaluating a training package**

21. As we outlined in the consultation, our vision is that all staff working in health and social care will, over time, receive learning disability and autism training relevant to their role. We do not underestimate the challenge of this, with over 1.2 million NHS staff and nearly 1.5 million adult social care staff in England.
22. In the consultation we heard very clearly that:
  - having a face to face component is important and how we build this in, in an appropriate way, will need to be considered as we develop and trial a training package;

- the training should involve people with lived experience, who are properly remunerated for their contribution in line with their preferences and local circumstances;
- training must be proportionate to the requirements of the role as determined by the employer.

23. To support implementation, we will develop tools and guidance for employers, as well as self-employed and independent practitioners, to help them assess the level of training needed. The capabilities (i.e. skills, knowledge and behaviours) described in the Core Capability Frameworks are defined at 3 tiers – from general awareness at Tier 1, through to those with a high degree of autonomy providing care in complex situations at Tier 3. Guidance for employers will help ensure that training is proportionate and appropriate for staff, taking into consideration their role and interactions with people with learning disabilities and autistic people. This means not all staff will require Tier 2 or 3 learning and we would expect for those at the highest tier, much is already a part of their existing training.
24. Health Education England are already developing an e-learning learning disability awareness training package for Tier 1 of the Core Capabilities Framework for Supporting People with a Learning Disability. This was a commitment made in response to the 2nd Annual report of the LeDeR programme in September 2018. This online resource is scheduled to be completed by the end of March 2020 and will be available on the Mind-Ed Platform; a free educational resource. This e-learning will be a resource which can be used prior to or as part of face to face training, or alongside workplace learning that a mentor, coach or supervisor may use.
25. Whilst there is no training offer that yet meets all the Tier 2 training requirements, there is some excellent best practice examples for elements of this, such as that offered by individual Trusts around the country and that trialled by Mencap, which we can draw on in developing a high-quality offer.
26. We want to ensure that any impacts arising from the introduction of mandatory training are properly tested and understood before implementation and a wider roll out, to better understand the costs as well as the enablers, benefits and barriers. There will be direct costs associated with delivering training but also impacts for staff of taking time out to do the training. We need to understand this fully.
27. We are therefore committing £1.4m to develop and test a learning disability and autism training package which can be deployed at scale. The development of the training will draw on existing best practice, as well as academic expertise. In recognition that mandatory training may present different challenges for different sectors of the health and care system, we will develop an approach which can be deployed in both the NHS and in social care. It will be trialled in both sectors and for different staff and service



types. Preparatory work with Health Education England is already underway, as well as work with Skills for Care to develop trials in social care settings, with the trial planned to run from April 2020 and reporting by March 2021.

28. The aim of mandatory training, and the training package, is to deliver improved outcomes. It must be impactful and not just a requirement to be fulfilled. Without good evaluation it will not be possible to establish that needs are being met, the methods of learning are effective, and that positive change is resulting from the training. We will undertake an evaluation of the training package, which will capture the views of people with lived experience and their families, as well as the staff undertaking the training. The evaluation, which will report before the end of 2020/21, will inform the final design of the training, a wider roll out and how we strengthen the requirements on employers, through regulation, to ensure that their staff have the skills and knowledge relevant to their role.
29. The training will draw on case studies to remind people why this training is being done. Stories like Oliver McGowan's capture exactly why NHS and social care staff need learning disability and autism training. We will therefore name the training package in Oliver's memory, in recognition of his story, his family's tireless campaigning for better training for staff, and to remember him and others whose lives were cut tragically short.
30. Findings from the evaluation will support us in considering the best approach ahead of the next Spending Review period. We will set out more detail at the end of 2020/21.

## **Making training mandatory**

31. Of those respondents expressing a clear view, there was very strong support for using secondary legislation to mandate training for staff engaged in regulated activities. We therefore propose to amend the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 to require all NHS and social care providers who carry out regulated activities to ensure that their staff have achieved the learning outcomes relevant to their role. Current plans are that these changes would come into force in April 2021.
32. Not all staff working in health and social care undertake regulated activities. For non-regulated staff working in the NHS, we will look at whether the provisions of the NHS Standard Contract should be strengthened, and/or whether separate guidance should be published, so that employers must ensure that all staff receive learning disability and autism training appropriate to their role. Changes to the NHS Standard Contract require consultation and we will ask NHS England to consider consulting in due course on appropriate changes that would come into effect from April 2021.

33. We will consider options for extending the scope to non-regulated staff in social care, taking account of the new burden's assessment test for Local Authority commissioned services, as well as the evidence from the trials we will undertake in social care settings. We will say more on this at the end of March 2021.
34. CQC inspections can provide a robust means of ensuring mandatory learning disability and autism training is happening. We will therefore work with CQC to agree with them how their regulatory approaches could be utilised to ensure that providers are requiring staff to have had mandatory training.
35. By introducing mandatory learning disability and autism training, we can deliver a real step change in culture and approach, making sure that staff have the right attitudes and the right competences to support people with learning disabilities and autistic people confidently and positively. Everyone deserves high quality, person-centred care that deliver the best possible outcomes, and we are confident that through implementing these proposals we will take an important step forward in delivering this.

## Action list

Action	By when
The Department of Health and Social Care will work with professional bodies and the Devolved Administrations to align pre-registration training as closely as possible with the Core Capability Frameworks for Supporting People with a Learning Disability and Autistic People and work towards a common core curriculum. We will report on progress next year.	March 2021
The Department for Health and Social Care, Health Education England and Skills for Care will begin development of a standardised training package, which will be trialled in both health and social care settings. This will cover tier 2 and examine blended learning approaches for tier 1.	March 2020
The Department of Health and Social Care will commission and publish an evaluation of the training package to inform a wider roll out of mandatory training.	March 2021
The Department of Health and Social Care will commission the development of tools and guidance for health and social care employers, self-employed and independent practitioners, to support them to assess the level of training needed and how best to record its completion, in line with the Core Capability Frameworks for Supporting People with a Learning Disability and Autistic People.	June 2020
The Department of Health and Social Care will commission the development of guidance for health and social care employers on the involvement of people with lived experience in the delivery of training, including remuneration.	June 2020
The Department of Health and Social Care propose amending the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 to mandate training for staff working in regulated activities.	April 2021
For non-regulated staff working in the NHS, the Department of Health and Social Care will work with NHS England to look at whether the provisions of the NHS Standard Contract should be strengthened, and/or whether separate guidance should be published, so that employers must ensure that all staff receive learning disability and autism training appropriate to their role.	April 2021
The Department of Health and Social Care will consider options for extending the scope to non-regulated staff in social care, informed by the trials in social care settings.	March 2021
The Department of Health and Social Care will work with the Care Quality Commission to agree with them how their regulatory approaches could be utilised to ensure that providers are requiring staff to have received mandatory training and are meeting the requirements of the learning disability standards.	June 2020

# Introduction

“The more people who have an awareness of learning disabilities and autism; the better chance there is of creating a society which is inclusive and supportive to people with these needs.”

**The Treloar Trust**

1. The second annual report of the [Learning Disability Mortality Review \(LeDeR\) Programme](#), published in May 2018 highlighted that, for a significant proportion of people with a learning disability whose death had been reviewed, their health had been affected by factors which could have been avoided. It recommended that mandatory learning disability training should be provided to all staff, delivered in conjunction with people with learning disabilities and their families. In its response to the [LeDeR report](#), published in September 2018, the Government accepted this recommendation and committed to consulting on and implementing such training, expanding the scope to include autism to reflect the similar challenges faced by autistic people.

## About the consultation

2. Earlier this year the Department of Health and Social Care (DHSC) conducted a public consultation. The purpose of '[Learning disability and autism training for health and care staff: a consultation](#)', was to gather views on how we can best ensure that health and social care staff have the right training to understand the needs of people with learning disabilities and autistic people and be able to make reasonable adjustments to support them. This publication provides an analysis of the responses received and sets out the Government's intentions.
3. The consultation document posed a series of questions about the Government's proposals, which covered the following areas:
  - planned content of the training;
  - staff roles and training;
  - how the training should be delivered;
  - how to involve people with learning disabilities and autistic people in training; and

- how the training should be mandated, monitored and evaluated in terms of its impact.
4. The consultation was launched on 13 February 2019, with an initial closing date of 12 April 2019. This was subsequently extended to 26 April 2019 at the request of stakeholders to ensure the highest possible rate of response.
  5. The consultation was published online, with an easy-read version also available on line and, by request, in hard copy. Organisations and members of the public were able to respond through an on-line portal, by email and by post. DHSC set up a dedicated mailbox to accept e-mailed responses and to answer questions about the consultation.

## **About respondents**

6. There were 5,155 responses to the consultation, including 4,956 responses submitted via the online portal, with others sent via the post or by e-mail. We received 147 responses in easy read format.
7. Of those responding online, 4,193 (85%) were responding as individuals – as health or social care professionals or people with lived experience of autism or learning disabilities, family members or carers. 606 (12%) were doing so on behalf of an organisation and 157 (3%) did not answer this question. The table below shows the range of organisations which responded. A list of organisations responding to the consultation is at Appendix A.

<b>Type</b>	<b>Number</b>	<b>%</b>
Academic	19	3
Voluntary	209	34
Provider	58	10
School	25	4
National body	5	1
NHS	179	30
Local authority	89	15
DWP	2	0 <sup>1</sup>
Other	6	1
Not stated	14	2

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<sup>1</sup> Rounded down.

<b>Type</b>	<b>Number</b>	<b>%</b>
Total	606	100

8. 3,225 (65%) of the online responses reported that they worked with people with learning disabilities or autistic people – either directly or responding on behalf of an organisation that does. 1,703 (34%) reported that they did not and 28 (1%) did not answer this question
9. Quotes have been extracted from responses to highlight the main themes that emerged. Respondents were asked whether they were content for this analysis to quote parts of their response. Only extracts where the respondent had given such permission have been quoted in the report. Some quotes remain anonymous at the respondent's request.

# Consultation analysis

## 1. The content of training

"Being a nice person who works in a person-centred way is as important as being a knowledgeable person".

### Question one:

**We have envisaged three main elements to learning disability and autism training: 1) understanding learning disability and autism, 2) legislation and rights; and 3) making reasonable adjustments. Do you agree? Should other elements be included?**

10. The broad approach was well supported: 4,387 (89%) of those responding to the question agreed, 187 (4%) did not agree with these proposals, 208 (4%) did not know if they agreed or disagreed with these proposals and 174 (3%) did not answer. The easy-read questionnaire asked respondents about five topics in the consultation, including the planned content of training. Of the easy read responses, 93% agreed with the planned content of training.
11. Our analysis shows that people responding on behalf of an organisation were more likely to disagree. Of the 187 who disagreed, 177 gave a reason for their response. Responses tended, however, to focus on concerns about practicalities rather than the scope of training.
12. Generally, people did agree with the proposals and often stated this was due to their negative experiences of care for either themselves as a person with a learning disability or as an autistic person, a family member, or someone they cared for with autism or learning disabilities.
13. In terms of practicalities, worries that the training would be time consuming, expensive, ineffective and of little benefit were raised. The idea of training being mandatory was also questioned as a small number of respondents, particularly those from professional organisations, remarked how healthcare staff are already subject to a comprehensive list of mandatory training requirements and expressed the view that adding to this list may make the training become a 'box ticking' exercise resented by staff and therefore reducing any positive impact of it.

“There is limited evidence that mandated training has the anticipated effect on the attitudes and behaviours. However, there is evidence that compelling adults to undertake training that they do not perceive as useful leads to a decline in learning motivation and engagement with the material. This will limit the success of any mandated training.”

### **The Royal College of General Practitioners**

14. In terms of delivery, some concerns were raised over the proposals being too vague and several people mentioned they would like more detail before they went ahead. Some respondents expressed concern about learning disabilities and autism being grouped together. The uniqueness of every individual with autism and/or learning disabilities was emphasised by many and the need to tailor the training to properly represent the possible differences between autism and learning disabilities and differences within the umbrella of learning disabilities was stressed. Suggested solutions included making better use of learning disability nurses and related teams to deliver training, as they already have the specialist training to better understand these nuances and ensure any training has a person-centred approach.
15. There were some valuable suggestions for topics which should be included within the training, with a strong emphasis on ensuring that staff were fully aware of the hidden nature of someone's needs, and not making assumptions as to how these might be met. Many respondents emphasised the need for training to support better communication, which are key elements of the Core Capability Frameworks for supporting autistic people and people with a learning disability.
16. Suggested topics for training:

#### **Understanding learning disability and autism**

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- Helping people understand autism.
  - Foetal alcohol syndrome disorder.
  - Neurodiversity, including conditions such as ADHD.
  - The challenges faced by people with learning disabilities or autistic people in the community, such as hate crime, exploitation etc.
  - The role of the family and carers.
  - Awareness of other conditions which often occur alongside autism: epilepsy, Obsessive Compulsive Disorder, social anxiety, dyspraxia, Pathological Demand Avoidance, Ehlers-Danlos
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## **Understanding learning disability and autism**

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Syndrome.

- Increased risk of suicide in an autistic person.
- Sensory processing issues - awareness of how light, sounds and the environment can overwhelm people. Touch sensitivity can often be an issue as people get touched a great deal in hospitals which can be painful or distressing

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## **Legislation and rights**

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- The Care Act 2014.
- The United Nations Convention on the Rights of Disabled People (UNCRPD)

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## **Making reasonable adjustments**

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- Focus on communication differences for autistic people with sensory sensitivities.
- The role of specific communication methods such as: Makaton, TECCH techniques, visual timelines, social stories, symbols, Applied Behaviour Analysis, Team TEACH.
- Awareness of issues autistic people may have with communication and practical advice on ways to communicate with autistic people.
- How to involve and make best use of the knowledge and expertise of the family member or carer.
- Potential differences in presentation (e.g. between males and females).

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“Stimming, overloads and meltdowns, sensory seeking, anxiety and depression and concurrent health conditions such as EDS.”

**Headspace projects and training**

“We believe this is a suitable basis. However, for dentists to be able to make the required reasonable adjustments they must be given access to patients Summary Care Record which they are routinely not.”

**British Dental Association**

“Currently many social care staff, managers and providers do not seem to fully understand issues around capacity and consent and the support needs of the person, but also the responsibility of support staff and care providers to make sure the person is able to live a healthy and happy life”.

**Cornwall Foundation Partnership Trust**

“SPELL is a framework for understanding and responding to autistic people's needs. It will allow you to develop better practice and use evidence-based strategies to support autistic children and adults.”

“Understanding the importance of being flexible in approach and that each person experiences autism in their own way and therefore the approach needs to be individualised.”

“There needs to be clear reference to the NHS England Accessible Information Standard, with specific reference to the right to be included in decisions about their lives and the right to be able to communicate in a means of their choice.”

17. Easy-read responses highlighted the following:

- the importance of covering the broad range of issues, particularly capturing the range of needs on the autistic spectrum;
- ensuring that training includes an appropriate focus on understanding sensory issues, and on communication, including use of easy-read;
- scepticism about the value of e-learning

**Question two:**

**Do you agree that awareness of how the Mental Capacity Act impacts on the way in which support is provided needs to be a significant part of training for all staff?**

18. The clear majority of respondents (86%), agreed that how the Mental Capacity Act (MCA) impacts on the support provided needed to be part of training. Only 2% of

respondents disagreed, with the remaining 12% either not sure or not answering the question.

"Qualified clinicians still struggle with MCA and therefore mandatory updates on this for all staff involved with vulnerable people must be high on the agenda."

**East Norfolk Community Learning Disabilities Team**

19. Some respondents agreed that it should be included but did not think that training on the MCA needed to be a 'significant' part of the training. There were also respondents who highlighted that training on the MCA was either already mandatory or included elsewhere in other training so did not think it would be a good use of time to include it in new training.
20. Similarly, some respondents highlighted that training on the MCA was more relevant for some groups of staff than others, such as medical staff, though this wasn't a common theme. Some respondents thought a specific focus on how to interpret the MCA with regards to working with people with learning disabilities and autistic people was needed.

"It is appropriate for the MCA to be covered, but this is already covered in other training. repeating it disproportionately could take up more time in a training session than is helpful. The deficits in using the MCA is not due to lack of awareness of it."

"Not all staff need MCA training only clinical decision-making staff"

21. A reoccurring theme was that a focus on legislation and legal aspects is not important for this training. Instead, what is important is focusing on training staff in how to treat autistic people and people with learning disabilities holistically or communicating effectively with patients with autism and learning disabilities.

"Rather than getting wrapped up in the specifics of this or that legislation, people need a more basic understanding of how difficulties lead to behaviours and how to stay kind."

22. Some respondents felt that the MCA was unfit for purpose or widely misused by medical staff. There were also respondents who felt that training on the MCA should be mandatory but should be kept separate from training about autism and learning disabilities. Some respondents also highlighted other Acts that they considered equally as important such as the Equality Act 2010. However, these were not common comments.

“Autism is not a mental health condition per se it is a neurological condition. Many adults with autism have capacity under the Mental Health Act but are denied support because they fall between the stools of provision and support.”

“I think MCA should be mandatory but not linked to LD training as it could give staff the incorrect impression that MCA only needs to be considered for people with LD.”

23. A number of respondents felt that the MCA is about helping those without capacity to make decisions about their care, and that it cannot or should not be assumed that autistic people or people with learning disabilities lack capacity to make such decisions. Some respondents went on to clarify that staff should be making sure they seek to communicate information in a suitable way, rather than assuming a lack of capacity in patients with autism or learning disabilities. Similarly, some respondents raised points about how far parents and carers should be included in communication and decisions about care. Overall, the consensus was that staff needed to be aware of the MCA, but not all roles would require in-depth training.

“Being autistic does not rob someone of the capacity to make decisions for themselves. Treating autism (and other hidden disabilities) as a mental health issue or people who have the condition like children is wrong and counterproductive.”

### **Question three:**

**Are there additional elements which need to be covered by training on awareness of autism and the needs of autistic people?**

24. Whilst respondents disagreed as to whether autism should be covered by separate training, most agreed that training needed to capture the different needs of autistic people, compared to people with a learning disability, and that training had to cover how autism may impact on someone’s health and care needs. Some highlighted the very important, and often overlooked issue, of the differences in how autism presents in men and women.

“We need to remove the stereotypes and the myths as this results in people thinking you can’t be autistic if you give eye contact for instance.”

## **What we propose**

25. Whilst the case for learning disability and autism training is clear, we recognise the practical challenges of implementing training at this scale. It is critical the training is meaningful and not a box-ticking exercise. It must be comprehensive, engaging and have the desired effect on attitudes and behaviours. We also need to be mindful of the impact of training on people's 'day jobs' and balancing this with their daily practice and activities.
26. Ensuring the training has the right content will be a vital part of ensuring this training is worthwhile. We will draw on existing best practice and academic expertise to develop a learning disability and autism training package that takes into account the views expressed on content through this consultation. More information on developing this package is set out at section 3.
27. This training package will be named in memory of Oliver McGowan, recognising his story, his family's tireless campaigning for better training for staff, and to remember him and others whose lives were cut tragically short.

## 2. Staff roles and training

### Question four:

**Do you agree that the different levels of training should reflect the Learning Disability Core Skills Education and Training Framework (and in due course, the Autism Framework)?**

28. The consultation proposed that training is organised to reflect the three tiers of staff needs in the Core Capabilities Framework for Supporting People with a Learning Disability (formerly known as the Learning Disability Core Skills Education and Training Framework) and, similarly, the new Core Capabilities Framework for Supporting Autistic People. Of those expressing a definite view, 3,646 (96%) agreed with this proposal.

“Yes. Mapping the core training across the Learning Disability Core skills framework and upcoming Autism Framework will provide clarity for organisations seeking the implement appropriate training.”

#### **Devon Sustainability and Transformation Partnership**

“The Autism Core Skills and Education Training Framework must be used by all employers and staff in health and social care to make an assessment of the level and knowledge needed to undertake a particular role. We believe it is crucial that employers know they must ensure that the training needed is undertaken, so there is no room for interpretation about their role and level responsibility in guaranteeing appropriate training is delivered.”

#### **National Autistic Society**

### Question five:

**We propose that individual employers should assess which level of training staff need and ensure that they get it. Do you agree?**

29. Of those respondents expressing a definite view, 3,054 (82%) agreed with this proposal. Where respondents disagreed and provided a reason for this, many felt that due to time or cost pressures employers may only opt for the most basic level of training. Among those agreeing with the proposal, many remarked on the flexibility this

would offer in terms of being able to better reflect the working practices and roles within individual organisations.

"Yes, with some additional safeguards built in to ensure that employers discharge their responsibilities in this regard – how will the DHSC monitor compliance with this requirement? Some employers (particularly smaller ones) may not feel confident to assess the necessary level of training for staff, so would need to refer to the appropriate framework. Staff should also be able to self-assess and refer based on their role/level of specialism. Involving people with LDD and autism in the recruitment process would help employers to gauge the level of existing understanding and training requirements in prospective staff members. This is an approach we take at OHC&AT and it has repeatedly proven its worth in terms of recruiting high calibre staff."

**Orchard Hill College & Academy Trust**

"The notion of employers is not helpful with regards to many dentists, being as they are, independent contractors to the NHS. As such, it would be more appropriate for the decision to be made by those who commission GDS services"

**British Dental Association**

**Question six:**

**What support might employers need in determining the appropriate level of training for a member of staff - e.g. a more detailed tool for assessment?**

30. 2,851 responded to this question. Among the most common themes raised were:

- Clear direction and guidelines, including regular updates. The need for the training to work in a tiered or graded way was expressed by many along with the thought that, dependent on an individual's specific job role, different levels of training would be appropriate for different people.
- Resources and tools to ensure the training does not become a one off 'tick box' exercise but rather is a continual process. The use of internal and external assessment tools was suggested by many as a means of certifying training was being conducted at the right level and renewed regularly.
- Input from experts by experience (autistic people, and people with a learning disability, people who regularly work with them and support them, and professional bodies and charities).

“They would need training themselves to understand what is required before being able to assess what someone else may need.”

“More detailed framework with exact mandatory requirements for each staff level e.g. support staff, team leader, care coordinator. An agreed assessment tools that all providers use.”

“People with autism and professionals highly trained in autism and learning disabilities should be involved in decision making using a standard tool for assessment.”

**Question seven:**

**We do not propose that all staff should have face to face training; just those with roles which mean they will be in regular contact with people with a learning disability or autistic people in Tiers 2 and 3. Do you agree?**

31. Of those providing a clear answer to the question, 2,001 (52%) agreed with the proposal and 1,819 (48%) disagreed. This reflects the strong concern that came out throughout the consultation that as many people as possible receive effective training, and the sense that face-to-face encounters with someone with a learning disability, or an autistic person, was the best means of developing understanding.

“We broadly agree assuming each service uses a systematic approach to determine the level of training their staff need. A needs assessment should be aided by the three tier definitions.

Blended learning that may include face-to-face delivery, simulation, digital, video and reflective learning interventions may also support those practitioners in primary and community settings who have a higher degree of contact with those who have learning and disability needs”

**Health Education England**

“e-learning can become a tick-box exercise, where large groups of staff are encouraged to demonstrate that they have accessed the training, without safeguards in place that they have given the training an appropriate level of attention”.

**Downs Syndrome Association**



"Training without any face-to-face elements will do nothing to challenge these stereotypes. Some members of staff will have only limited or occasional interaction with people with learning disabilities."

University of Birmingham Law School

**Question eight:**

**Should there be a standard form of documentation, to act as a training passport, portable between employers, indicating when and where training was undertaken, and documenting the specific skills developed?**

32. 3,741 people provided an answer to this question, although not all responses commented directly on whether there should be a standard training passport. 3,048 of those responses suggested that a training passport was a good idea (approximately 81%). Some respondents felt an electronic or mobile app version would be easier to manage. Some respondents specified that for a training passport to record the training would need to meet certain national standards.
33. Forty respondents thought a certificate upon completion of training would be better than a training passport whilst twenty thought an electronic register of people who had completed the training would be preferable.

"Training passports, accredited learning schemes and certificated achievements within a robust Learning Management System can certainly assist in monitoring the uptake of training. However, it is important to be clear as to whether the aim of any such system is to ensure that training has taken place or to ensure that learning has occurred. The former provides useful information as to uptake; the latter provides more critical evidence of likely impact and would typically demand some form of assessment to be conducted".

**Skills for Health**

"This will only work if everyone is offering similar training. I think a training passport should happen with all training we waste so much time if you change jobs having to retrain even if you have only just recently trained."

"Certificate of completion with a minimum threshold to confirm a minimum level has been attained (multiple choice questions with set % pass mark)."

“Not necessarily if standard training on tiers then a certificate to identify completed may be enough.”

34. A very small minority did not think a training passport was a good idea (74 people, roughly 2%). Those who did not think the training passport was a good idea mentioned issues such as the burden on employers, the potential for fraud, and the risk of it being a ‘tick box’ exercise and not measuring competency.
35. Some people expected it to already be covered, for example in HR systems or CPD logs. Others felt that existing processes could be adapted to include it, for example Care Certificates.

## **What we propose**

36. We recognise that not all staff will require the same level of training. Health Education England’s (HEE) new Core Capabilities Framework for Supporting Autistic People, which supports the development and planning of the workforce and informs the design of education and training programmes, already identifies recommended duration, frequency, and refresh periods for health, care and public facing workforces. HEE, Skills for Health, Skills for Care and NHS England have also worked together to issue the Core Capabilities Framework for Supporting People with a Learning Disability, which has updated the earlier Learning Disabilities Core Skills Education and Training Framework.
37. The capabilities (i.e. skills, knowledge and behaviours) described in the Core Capability Frameworks are defined at 3 tiers – from general awareness at Tier 1, through to those with a high degree of autonomy providing care in complex situations at Tier 3. This means not all staff will require Tier 2 or 3 learning. To be clear, the tier of training required is linked to the amount of contact that staff have with people with a learning disability or autistic people. Where contact is limited Tier 1 training may suffice. Equally, Tier 2 is not limited to higher skilled staff but anyone who is routinely caring for people with a learning disability or autistic people.
38. For those where Tier 1 learning is most appropriate, Health Education England are developing an e-learning learning disability awareness training package for Tier 1 of the Core Capabilities Framework for Supporting People with a Learning Disability. This online resource is scheduled to be completed by the end of March 2020 and will be available on the Mind-Ed Platform; a free educational resource. The impetus for this was the LeDeR reports, and recognition, that such e-learning can also be used prior to or as part of face to face training, or alongside workplace learning that a mentor, coach or supervisor may use.

39. In terms of Tier 2, there is not currently a training offer that meets all the requirements set out in the capability frameworks. However, there is some excellent best practice in training, which we can draw on in developing a high-quality offer.
40. To support implementation, we will develop tools and guidance for employers and the self-employed and independent practitioners to support them to assess the level of training needed. In relation to training passports, we will consider and provide guidance to employers on how to best record the training that has been undertaken.

### 3. Delivering training

#### Question nine:

**We propose that a common curriculum for the content of training in learning disability and autism for health and social care staff should be developed which could inform implementation of professional standards. Do you agree?**

41. Of those providing a definitive response, 3,485 (97%) agreed with our proposal for a common curriculum for the content of training in learning disability and autism, which could inform the implementation of professional standards. Only 3% disagreed.
42. That 28% of respondents (1,168) did not answer this question, or did not express a view either way, may indicate uncertainty as to how a curriculum would inform standards, and professional training.

“I am a student nurse and believe this education should form part of the nurse training curriculum. As students, we spend over 2000 hours on practice during our 3-year course, and many of us lack the skills and knowledge to effectively care for people with autism and learning disabilities. As a student nurse in the adult field of nursing, this training is vital.”

#### Question ten:

**What support are employers of health and social care staff likely to need to ensure their staff can have mandatory learning disability and autism training?**

43. 2,882 responded to this question. There was a very significant number of respondents (1,320 or 45%) who highlighted the need for training for employers, to ensure their staff can have mandatory learning disability and autism training, although this included both training for employers, and the central provision of training schemes and materials.
44. The key requirements highlighted were very much resources: the need for time, or investment, to support training. Ensuring staffing levels are adequate to allow for protected learning time was a theme and access to qualified individuals and experts in the field to assist with the design and implementation of the training was mentioned.

"We would like to see information about whether health and care professionals will be afforded protected time in order to fully engage with the training."

**Nursing and Midwifery Council**

"Small employers of health and social staff, or those using Personal Budgets/Direct Payments to employ their own staff will need to be able to access training via larger employers. A central repository would be needed holding details about courses and their availability to staff external to the agency that is hosting the training."

**University of Bristol, LeDeR Programme Steering Group**

"Support from local LD and Autism groups to co-deliver training. Also, the DHSC or NHSE should award a 'kite' mark to organisations that are LD and Autism friendly."

**Question eleven:**

**What best practice are you aware of in delivering training on learning disability or autism?**

45. Although many respondents were not aware of particular good practice in delivering training on learning disability, or autism, there was a consistent recognition of the importance of face-to-face training which involved autistic people and people with disabilities, and potentially, carers, and family members. In terms of training techniques, roleplays and case studies were recommended.

"Video simulation scenario-based assessments with the input of real patient experience."

**Registration Council of Clinical Physiologists**

46. Organisations such as Mencap, the National Autistic Society and the Autism Educational Trust were recommended for their training.

**Question twelve:**

**Who should be responsible for ensuring the promotion of best practice in how to support people with a learning disability or autistic people (e.g. through guidance or training for trainers)?**

47. There were divergent views on who should be responsible for ensuring the promotion of best practice on how to support people with a learning disability or autism (e.g. through guidance or training for trainers), with a range of organisations recommended by respondents, including some of the aforementioned voluntary sector organisations and national bodies, such as the Department of Health and Social Care, the Care Quality Commission and Health Education England. The breadth of suggestions indicated there could be some flexibility about how training could be championed (and there were a number of proposals for specific champion roles), provided it was of high quality and happened. Predominantly, people expected the Government, employers and managers to promote best practice.

“A mixture of people: “local champions”, through to the Chief executive/Medical Director/Lead clinician to demonstrate the commitment; also, the contribution and insight of employees with an LD or autism.”

“Driver from DHSC but don't forget HEE, DfE & DfWP across the board. Don't put LD and Autism into a box. Societal changes mean everyone responsible with really strong leadership.”

“Appropriate national charities would be best placed to promote best practice.”

“Everyone.”

**Question thirteen:**

**How quickly after taking up a post should new members of staff who have not previously received training have to complete training?**

48. A number of respondents did not feel able to specify a time frame, as they felt this would be dependent on role and the level of training required for that role, but when quantified, the broad categories were as follows:

<b>Timeframe</b>	<b>Number of people who said this</b>	<b>% of people who said this</b>
Immediately	302	25%
1 month	73	6%
3 months	419	34%

<b>Timeframe</b>	<b>Number of people who said this</b>	<b>% of people who said this</b>
6 months	410	33%
1 year	22	2%

## **What we propose**

49. Whilst the need for learning disability and autism training is clear, we understand concerns around feasibility and costs. To ensure that any impacts arising from the introduction of mandatory training are properly tested before implementation and a wider roll out, we will be rolling out a series of trials to better understand the costs as well as the enablers, benefits and barriers.
50. We are therefore committing £1.4m to develop and test a standardised training package as described in section 1 (paragraphs 25-27). This package will draw on existing best practice and academic expertise. We will develop an approach for the NHS and an equivalent for social care, recognising there may be different challenges for different sectors of the health and care system. Preparatory work with Health Education England is already underway, as well as with Skills for Care to develop trials in social care settings, with the trials planned to run from April 2020 and reporting by March 2021.
51. We will undertake an evaluation of the training, reporting before the end of 2020/21 which will capture the views of people with lived experience and their families. Without good evaluation it will not be possible to establish that needs are being met, the methods of learning are effective, and that positive change is resulting from the training. The evaluation will inform a wider of roll out and how we strengthen the requirements on employers, through regulation, to ensure that their staff have the skills and knowledge relevant to their role.
52. Findings from the evaluation will support us in considering the best approach ahead of the next Spending Review period. We will set out more detail on how this would be rolled out at the end of 2020/21.
53. In the future, we want to ensure that all new staff have already received a good grounding in the care of people with learning disabilities and autistic people before they begin their careers in health and social care. A focus on these aspects in pre-registration education and training is crucial to delivering the changes we want to see and ensuring that these are sustainable in the long-term.
54. We know that pre-registration training for most professions already covers some of the important elements. For instance, the General Medical Council's updated Outcomes

for Graduates requires newly qualified doctors to be able to assess the needs of people with learning disabilities and the support required. Similarly, the Nursing and Midwifery Council's ongoing review of its educational standards will ensure that, in future, nurses at the point of registration will be better equipped to deliver care for people with learning disabilities and autistic people.

55. Our vision is that in future all professionals will, before starting their career or through continuing professional development, undertake training which covers a 'common core curriculum' for learning disability and autism so that we can be confident that there is consistency across education and training curricula.
56. We are committing to work with all professional bodies and the Devolved Administrations to agree a common core curriculum based on the Core Capability Frameworks for Supporting People with a Learning Disability and Autistic People. We recognise that it will take time to ensure that all training is aligned with the Frameworks; with periodic updates to syllabuses and training requirements, but we will work with the regulators to ensure the closest possible alignment at the earliest opportunity.
57. We will continue working with the professional bodies, regulators, employers and other organisations to determine the best way to achieve a common core curriculum and alignment with the learning disability and autism competency frameworks. While recognising that changes can take time, we will find ways to achieve alignment wherever possible and as quickly as possible. Recent engagement has seen the Joint Academy of Medical Royal Colleges Training Forum discuss how to manage specific curricula items including learning disability and autism training. It will arrange a discussion with the regulator, the General Medical Council on whether a small working group should be set up to discuss requests submitted by Government and Colleges, and, how to handle the arising issues. For nurses, midwives and of nursing associates in England, the regulator the Nursing and Midwifery Council believe a common core curriculum could be used by education providers to provide added value to their own standards of proficiency.



## 4. Involving people with learning disabilities and autistic people

"Involvement' needs to be on an equal footing and not tokenistic. There needs to be adequate resources available to support people to develop and deliver training."

58. There was a very clear consensus in people's responses that it was essential to involve people with learning disabilities, or autistic people, in delivering training.

### Question fourteen:

**What are the barriers to involving people with a learning disability or autistic people in delivering training as proposed?**

59. 2,850 people submitted an answer to this question (58% of respondents). It is worth noting that there were respondents who did not feel there would be any barriers, or none that could not be easily overcome, but this was not an opinion shared by all.

60. Many respondents mentioned barriers that might be considered practical or logistical. This included things like the extra time it might take a person with a learning disability or an autistic person to prepare for or deliver training, flagging the need for reasonable adjustments both in the content of training, the methods of delivery, and physical accessibility of the training venue. There were also respondents who mentioned the likelihood of other disabilities or conditions that might make participation difficult, although this was not a common response.

61. Possible individual barriers cited included the communication skills of people with learning disabilities and autistic people, and different cognitive abilities and preferences. Some respondents were concerned that those delivering the training would not be able to make themselves understood, and some felt this could lead to negative feelings or reactions from the person with learning disabilities or autism.

"It can be difficult for autistic people to convey their needs via communication, even 'high-functioning' individuals."

"We do not always communicate and learn at the same speed as others. For me I can perceive things on a different level to others, but I can't physically communicate well."

62. Similarly, some respondents thought that the confidence or social skills of people with learning disabilities or autistic people could be a barrier to them delivering training. However, other respondents were keen to highlight that people with learning disabilities and autistic people are individuals and their conditions and challenges vary considerably, highlighting the need for flexibility in the content and delivery of training to make it suitable. Some respondents were concerned that those who participate in delivering training would most likely be people with mild needs and therefore would not meet the aim of representing all people with learning disabilities or autism accurately.

“For many autistic people, social skills deficits would be a barrier as would an inability to function as part of a group with unknown people”.

“There are no barriers if you make reasonable adjustments. You need to ensure involvement is tailored to specific communication needs of those involved. And pay them”

“Tendency for user-led sessions to predominantly feature people with mild learning disabilities and exclude people with more severe/profound learning disabilities. Training environments/scenarios may be difficult for people with autism without adjustments”.

“Difficult for many people with LD to fully understand their own situation, let alone that of others. People with severe LD will not have the understanding needed to be able to contribute at all.”

“Sensory issues, travel, public transport, change in routine, anxiety.”

“Where and when meetings are arranged and funding for carer/escort to take to and from meetings.”

“Uncertainty. Lighting. Noise. Communication barriers.”

“Ensuring they understand the process and being supported to give their opinion/be fully engaged, the setting (ensuring it is accessible according to individual needs), finding representatives from all areas of the target population.”

63. Another common view was that elements of the situation could cause anxiety for people with learning disabilities or autistic people that could be overwhelming. For instance, some people highlighted that large groups or unfamiliar surroundings could be a barrier and some respondents felt this could cause distress for the person with a learning disability or autistic person. A number of respondents also highlighted the need to be aware of potential sensory issues or the risk of sensory overload for trainers with learning disabilities or autism.

"Could be overwhelming need to consider any sensory issues or difficulties being in unfamiliar environments with unfamiliar people."

"May lead to high anxiety and feelings of being overwhelmed, unless well prepared and supported."

64. There were also some respondents who thought identifying and attracting enough people with learning disabilities or autistic people to take part may be problematic.

"Finding people who are both willing, and able. Some people may shy away from it due to anxiety; more forthright individuals may focus too much on their own experience; important to get the message across that no two people will have the same experience."

65. A further category of barriers identified by respondents were around cultural perceptions or understanding of learning disability and autism. Some respondents were concerned about the attitudes, perceptions or lack of understanding of those attending the training, with some responses considering that the prejudices exhibited by the audience would be a barrier. For example, some responses flagged the implicit assumption that people with learning disabilities could not deliver training or be professionals.

66. There were also respondents who felt that the attitudes or lack of understanding of those commissioning, designing or leading/co-delivering the training could be a barrier, and that there was a risk that they would not fully include people with learning disabilities and autistic people. Some were concerned that autistic people and those with learning disabilities would not be treated with respect.

"(i) Discriminatory practices, (ii) A we know them better than they know themselves thinking, (iii) equipment/adaptations required."

"Other people's ignorance and attitudes."

"Professionals being too patronising..... lack of strong trusted 'equal' relationships (e.g. through working on various service issues not just training)."

"Lack of knowledge/experience of those liaising with the individuals with a learning disability."

"Willingness of the trainers to involve them".

**Question fifteen:**

**What support or advice might be needed for people on how to best involve people with a learning disability or autistic people in developing training?**

**Question sixteen:**

**What support might be needed for people with a learning disability or autistic people to ensure they have the right skills to participate in training?**

67. 2,562 and 2,508 people respectively answered these questions. There was consensus that there would be a need for support and training for people with learning disabilities or autistic people to be able to meaningfully take part in the training. Some responses highlighted that there might be a need for practical support in helping the person deliver training or to get to the training venue. In a similar vein, a number of respondents highlighted their concerns that the involvement of the person with a learning disability or autism would be tokenistic, whereas what was needed was meaningful involvement. Related to this, some responses highlighted how people with learning disabilities and autistic people should be treated as professional and not as volunteers, and some suggested that the training needed to be co-produced.

“Some people may benefit from training around public speaking and facilitation, which can also be useful across other areas of life. Different autistic people and people with learning disabilities will have very different experiences and skills, so including a range of people is likely to be beneficial for a varied and widely useful training session.”

**Autistica**

“To ensure they do not involve individuals as a tokenistic measure; this needs to be meaningful and purposeful.”

“Listen to the autistic people, let them be fully involved in the planning, respect them as a great source of knowledge.”

“Preparation and planning, alongside the trainer. Extra visits to the venue beforehand; sensory audit of the venue. Identify a safe, quiet area to move to if required.”

68. Advocacy and mentoring were concepts which came up regularly, to help support people with a learning disability or autistic people in acting as trainers. Other people highlighted the need for extra time for people with autism or learning disabilities to

prepare. In addition, as above, the need to ensure an appropriate environment, either in general terms, or to take account of the specific environmental or sensory needs of an autistic person.

"There are many fabulous organisations that work as advocates for people with LD who should be involved - so much of this work is already being done, don't just start from scratch, make use of the amazing people out there who've been fighting for this!"

**Question seventeen:**

**How should people with a learning disability or autistic people be remunerated for participation in training to health and social care staff?**

69. There was unanimity that people with lived experience participating in training should be appropriately remunerated and there should be no distinction made because the person has a learning disability or autism. Some respondents suggested that expenses may be sufficient, particularly where there was a possibility that payment could affect any benefits a person might be receiving. Given this, some respondents felt the best approach was to ask them how they would prefer to be remunerated.
70. Vouchers or other forms of contribution in kind were suggested instead of paid remuneration. Certificates recognising their contribution were suggested less commonly.
71. There were also respondents who felt that it should be recognised that people with learning disability and autism are experts by experience people and who should be recognised as such.

"They should be compensated for their travel (in advance so they can actually attend) and be paid for their time just as any other speaker would be."

"As any other working person would be remunerated, as it is a job!"

"Depends on current benefits received & how payment might affect them contracted & invoice per session delivered."

"Account needs to be taken of the fact that they may be in receipt of benefits, but their expenses must be recognised, and their contribution valued."

"Payment in vouchers, so that there aren't any issues with benefits."

“Certificate for CVs offered free courses in further learning/interests, expenses for travel and food.”

## **What we propose**

72. While respondents were clear on the importance of involving people with lived experience, there was a range of opinions as to how best to do this in practical terms. Similarly, while there was consensus that there should be proper remuneration, how this should be achieved prompted different suggestions. We agree that the training would be much stronger if people with lived experience of learning disability or autism could be involved in its delivery. We also agree that they should be properly remunerated for this role. We will therefore reflect on learning from the trialling of the new training package and commission guidance on how to best involve people with learning disabilities and autistic people in the delivery of training, drawing on existing good practice.

## 5. Mandating training and monitoring the impact

### Question eighteen:

**Do you agree with our proposal to use the Health and Social Care Act 2008 (Regulated Activities Regulations) 2014 to place further requirements on service providers who carry on regulated activities within the meaning of the Health and Social Care Act 2008, with a view to ensuring that all staff whose role may involve interaction with people who have learning disabilities or autistic people have received appropriate training in learning disability and autism?**

### Question nineteen:

**Do you agree that we could use the NHS Standard Contract to place requirements on providers to ensure unregulated staff have received appropriate training in learning disability and autism?**

73. Our key proposal was to use the Health and Social Care Act (Regulated Activities) Regulations 2014 to place requirements on service providers who carry out regulated activities within the meaning of the Health and Social Care Act 2008, to ensure staff have the appropriate training. Our proposal to use the 2014 Regulations was supported by almost all (97%) of those that expressed a firm view on the question, that is those that either agreed or disagreed. The high number of people who did not respond to the question (1,774 or 36% of respondents), may be suggestive of respondents having less knowledge of how Regulations work and the extent to which they are effective.

"When there are so many competing demands on training time LD & autism drops down the list of priorities. In my own organisation I have struggled (& failed) to secure this; this proposal would provide the grip needed."

"If regulation specifies it will be done. However, we will need funding for this, we cannot expect not for profit providers to be able to do all this within budget."

74. There was a very similar pattern of responses in terms of the proposal to use the NHS Standard Contract to place requirements on providers to ensure unregulated staff have received appropriate training in learning disability and autism. Nearly half of respondents to the consultation did not know or did not answer the question. Of those that clearly responded, around 97% agreed.

75. Those that disagreed and provided further explanation highlighted a wide range of issues, although the most common was that the NHS Standard Contract would not cover all staff or all types of care (e.g. social care). Some who said no regulation was needed felt that to do so would place too much burden on providers.

“If it is not part of a contract, employers may find it easy to avoid ensuring all staff are adequately trained.”

“Social workers are not necessarily employed on an NHS Standard Contract, neither are those who are directly employed by the client or their carers.”

“Not all staff are governed by the NHS, need to incorporate voluntary, social care and private.”

“This might cause problems in employing bank staff and add additional cost to individuals”

“Be mindful to avoid over-legislating and therefore stopping companies being able to comply.”

**Daniel Ratcliffe, Member of Specialist Autism Services**

**Question twenty:**

**What do you think we should do to ensure that self-employed staff/lone practitioners/partners undertake training to an appropriate level?**

76. 2,533 people answered this question and suggestions for how we could ensure that self-employed staff/lone practitioners/partners could undertake training to an appropriate level included:

- creation of some form of register;
- certification;
- evidence mandated by a regulator;
- a contractual requirement to ensure training is undertaken (the most common response);
- ensuring access to training and opportunities to complete it are equal across all provision.



"To ensure that the independent practitioners who provide the majority of NHS dentistry are trained to an appropriate level the Department of Health and Social Care must link training to the commissioning of such services."

"We already have mechanisms for this so in the same way that practitioners have to show e.g. CPR refresher before working in a role."

"Some sort of regulated database."

"Ensure these are included in LA contracts with partners and private and 3rd sector linking in with curriculum developed so we have consistency across H&SC. Also ensure lone practitioners sign up to voluntary code which requires them to undertake training."

**Question twenty-one:**

**We envisage that CQC and Ofsted inspections can provide a robust means of ensuring mandatory learning disability and autism training is happening. Do you agree?**

77. Over half of respondents agreed with the use of CQC and Ofsted inspections as a potential means of ensuring mandatory learning disability and autism training was happening; whilst only 5% did not agree, more than 35% did not answer, suggesting again that this sort of logistical issue was of less immediate concern to respondents.

"Should encourage local monitoring as well through existing local contract management arrangements. This would need to be built into contract monitoring frameworks."

"KLOEs to ensure that providers are ensuring staff have had mandatory training in learning disability and autism."

"How will this actually happen in practice? Surely there are other measures than having a tick box for training? Having the training doesn't actually mean there's any difference culturally!"

**Question twenty-two:**

**How might people with a learning disability or autistic people be involved in assessing or monitoring mandatory training?**

78. 4,245 people responded to this question, offering a number of suggestions for how people with learning disabilities and autistic people could be involved in the assessing or monitoring of training. These included:

- having people with lived experience interview staff after training and then a few months later to see if they had made any sustained changes to their practice;
- mystery shopping to see if staff had implemented what they had learnt in training;
- include experts by experience on inspections as they understand what the barriers are and will know if they are still there;
- via user involvement groups/service user panels; and
- through the Equality Delivery System (EDS) tool for NHS Trusts.

“They could be offered the opportunity to train as Mandatory Learning Disability & Autism Training Consultants. This would open for certification & the possibility of consultants becoming economically self-sufficient.”

“Through existing local Quality Checking from inclusion organisations?”

**2gether NHS Foundation Trust**

“CQC already work with Experts by Experience in best practice, this should be extended and become mandatory.”

## **What we propose**

79. To mandate the training, we propose amending the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014 to require all NHS and social care providers who carry out regulated activities to ensure that their staff have achieved the learning outcomes relevant to their role as described in the Core Capabilities Framework for Supporting People with Learning Disability and the Core Capabilities Framework for supporting Autistic People. Regulated service providers would therefore have to satisfy themselves that an employee had received appropriate training prior to registration, or in previous employment, and if they had not, ensure that they undertake relevant training to achieve the learning outcomes required by their role. Current plans are that these changes would come into force in April 2021.

80. We recognise that not all staff working in health and social care undertake regulated activities. For non-regulated staff working in the NHS, we will look at whether the provisions of the NHS Standard Contract should be strengthened, and/or whether

separate guidance should be published, so that employers must ensure that all staff receive learning disability and autism training appropriate to their role. Changes to the NHS Standard Contract require consultation and we will ask NHS England to consider consulting in due course on appropriate changes that would come into effect from April 2021.

81. For social care, there is no standard contract, and a wide range of providers of different sizes. We will therefore consider options for extending the scope to non-regulated staff in social care, taking account of the new burden's assessment test for Local Authority commissioned services, as well as the evidence from the trials we will undertake in social care settings. We will say more on this at the end of March 2021.
82. Apprenticeships provide a key mechanism for developing skills and on the job training and we will work to develop specialist learning disability and autism options for health and social care apprenticeships. We will also take steps to ensure that the Care Certificate is wholly compliant with Tier 1 of the Core Capability Frameworks for Autism and Learning Disability.
83. CQC inspections can provide a robust means of ensuring mandatory learning disability and autism training is happening. We will therefore work with CQC to agree with them how their regulatory approaches could be utilised to ensure that providers are requiring staff to have had mandatory training.
84. The aim of introducing mandatory training is to deliver improved outcomes for people with a learning disability and autistic people and without good evaluation it will not be possible to establish that needs are being met, methods of learning are effective, and that positive change is resulting from the training. Following rollout of the training, we will commission an independent evaluation to assess its impact. This will capture the views of service users and families in terms of how their experience of care has changed, as well as reporting quantitative measures of improvement.

## 6. Costs and benefits

“Economic benefits are irrelevant for those who have LD or are autistic (or both). It is much more important than that as it impacts their lives and physical and mental well-being”

“I don't know. But there would be a lot of time saved, not having to put mistakes right and not having to find alternative providers for people whose support packages had broken down.”

**Question twenty-three:**

**What do you think are the likely costs of implementing mandatory training for health and care staff in learning disability and autism?**

**Question twenty-four:**

**What evidence is available on the economic benefits of mandatory training?**

**Question twenty-five:**

**What evidence can you provide on the current provision of learning disability and autism training around the country?**

85. There was limited evidence provided in response to the consultation on the costs of undertaking formal training in the way proposed. Whilst costs were not quantified, respondents recognised the impact on clinical time as well as the costs of sourcing and arranging the training. Many recognised that there could be disproportionate costs for smaller organisations and particular implications for independent and self-employed practitioners. In terms of those respondents who answered question twenty-four, there was unanimity that mandatory learning disability and autism training would have significant economic and other benefits though with views largely falling into the following themes:

- improved health and wellbeing outcomes due to increased engagement in services, reducing the likelihood of a deterioration in health; and

- improvements in patient safety, experience and satisfaction, resulting on in a reduction of complaints and litigation and compensation associated with poor quality care.

86. Of those responding to question twenty-five, most pointed to current provision being limited or of poor quality. Some specific examples of local good practice were cited.

## **What we propose**

87. Understanding the costs and benefits of this training will be important to ensuring a proportionate and effective roll out. As set out above, we have therefore committed £1.4m to develop and test a learning disability and autism training package which can be deployed at scale, as well as developing guidance for employers to support them in assessing what level of training staff require. This training will be fully evaluated to better understand the costs as well as the enablers, benefits and barriers. The evaluation will report by March 2021 to inform planning ahead of a wider roll out.

## 7. Easy Read responses

88. We received 147 responses which used the easy read template, sending hard copies via the post, and returning PDFs to the mailbox. 62 (42%) responded on behalf of an organisation, and many more were members of organisations.

89. The easy read questionnaire asked respondents about five topics in the consultation.

- the planned content of training;
- training about autism and whether it should be separate to learning disability training;
- deciding what training staff need;
- when to give training and what the Government should do to implement this;
- making sure people with learning disability/autistic people are involved in training and making sure that training works well.

90. For each topic, respondents were asked if they agreed with the approach described, with a choice of YES or NO, or NOT SURE, and a space for comments. Some respondents took the opportunity to provide comments throughout their response.

91. These responses were overwhelmingly positive; every topic scored at least an 82% approval rating. 136 (93%) agreed with the planned content of training.

92. Key concerns identified in the easy read responses included:

- the importance of covering the broad range of issues - particularly capturing the range of needs on the autistic spectrum;
- ensuring that training includes an appropriate focus on understanding sensory issues, and on communication, including use of easy-read;
- scepticism about the value of e-learning;
- differentiating between autism and learning disability (a few respondents wanted autism and learning disability training completely separate);
- ensuring all appropriate staff, including receptionists, opticians, are trained;

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- making best use of local self-advocacy groups, e.g. in delivering training, and -in reviewing and updating training – the use of people with lived experience was consistent and fundamental throughout responses;
- giving people the right support to deliver the training;
- using champions and gurus to promote training, and to ensure organisations carry it out.

# Appendix A: List of organisations responding to the consultation:

2gether NHS Foundation Trust  
3 Trees Community Support  
360 Degrees Healthcare and Rehabilitation  
able2achieve  
Achievement for All  
Achieving for Children  
ACSYL  
Action on Hearing Loss  
Adapt to Learn Ltd.  
ADHD Greenwich  
Affinity Trust  
Alfreton Park Community School  
Allied Healthcare  
Ambitious about Autism  
Area 51 Education Ltd  
Ashcroft Care Services  
Aspens Charities  
Aspirations  
Association of Anaesthetists  
Autism Bedfordshire  
Autism Plus  
Autism Teaching Company  
Autism Together  
Autism Wellbeing CIC  
Autism Wessex  
AUTISTICA  
Autistic Pride Reading  
Autizma  
Avocet Trust  
Balham Park Surgery  
Barking & Dagenham, Havering and Redbridge CCG  
Barking, Havering and Redbridge University Trust Hospitals  
Barnet Council  
Barnsley Healthcare Federation  
BBRaun Avitum  
BCC  
BCP Council  
Bedford Hospital NHS Trust  
Beechtree Day Services Ltd  
Belmont Special School  
Berkshire Health NHS Foundation Trust  
Betsi Cadwaladr University Health Board  
Bibic  
Birmingham Autism and ADHD Partnership Board  
Birmingham City Council



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Birmingham Community Healthcare NHS Foundation Trust  
Blackpool Council  
Blue Apple Theatre  
Boston Carers Group Learning Disabilities  
Brandon Trust  
Bright Opportunities  
Brighton and Hove Speak Out  
British Association of Childhood Disability  
British Association of Social Workers  
British Dental Association  
British Institute of Human Rights  
British Institute of Learning Disabilities  
British Psychological Society (BPS)  
Bromley Council  
Cambridgeshire County Council SEND Service  
Camden Learning Disability Service and Islington Learning Disability Partnership  
Cardiff People First  
Cardiff and Vale University Health Board  
Care England  
Care Horizons Ltd.  
Care Management Group  
The Carers Hub - Peopleplus  
The Castle School  
Caudwell Children  
C-Change Scotland, dates-n-mates  
Central and North West London NHS Foundation Trust  
The Centre for FASD  
CFHS  
The Challenging Behaviour Foundation  
CHANGE  
Change the World Class  
Cheshire and Wirral Partnership NHS Foundation Trust, Adult ASD service  
Cheshire and Wirral Partnership NHS Foundation Trust  
The Clatterbridge Cancer Centre NHS Foundation Trust  
College of Optometrists  
Community Transitions  
Corambaaf  
Cornwall Foundation Partnership Trust  
Cornwall Foundation Trust  
Coventry & Warwickshire Partnership NHS Trust  
CPCCG  
Creative Care  
Croydon CCG  
Croydon Health Services NHS Trust  
Croydon Mencap  
Cumbria County Council, Public Health  
Cumbria Parent Carer Forum  
Department for Work and Pensions  
Derby City Council, Preparing for Adulthood Team  
Derbyshire County Council

Devon County Council - Early Help & SEND Improvement Programme  
Devon Link Up  
Devon Partnership NHS Trust  
Devon Sustainability and Transformation Partnership  
Dimensions  
Discovery  
Disha Comprehensive Rehab Centre  
Dizz Kidz  
Doncaster Council, Learning Opportunities Children & Young People  
Doncaster Council Sensory Team  
Doncaster Metropolitan Borough Council  
Down's Syndrome Association  
Ealing Council  
East London NHS Foundation Trust  
East Norfolk Community Learning Disabilities Team  
Elborough Street Surgery  
Epilepsy Action  
Erya CIC  
Essex County Council  
Essex Partnership University NHS Foundation Trust  
Evelina London Children's Hospital  
Falcon Road Medical Centre  
Family Planning Association  
Family Voice Surrey  
FASD Network UK  
Freedom Support Ltd  
Fountain Loving Care Ltd  
Full of Life  
Future Home Care  
General Medical Council  
Gloucestershire Care Services  
Golden Lane Housing  
Greater Manchester Autism Consortium  
Green Lane Special School  
Greenwich Parent Voice  
Halow Project  
Hampshire Autism Voice  
Hampshire County Council  
Harrow Mencap  
HCT  
Headspace projects and training  
Health Education England  
Health Education England South Region, intellectual disability workforce programme  
Healthwatch Blackburn with Darwen  
Healthwatch Calderdale  
Healthwatch Hertfordshire  
Healthwatch Lewisham  
Hedgewood Special School  
Henshaws  
Hertfordshire IHCCT

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Highfield Scheme Ltd  
Home from Home Care Ltd  
Hounslow and Richmond Community Healthcare NHS Trust  
Hounslow Borough Council, Community Access Service  
Imagine, Act and Succeed  
Impact Advocacy Service  
The Inclusion Project  
Independence Matters  
In Di Go Dedicated Care and Support CIC  
Inklecomms  
Insight Training and Consultancy  
IPSEA  
The Island Project  
Isle of Wight Council  
Kent Autistic Trust  
KeyRing  
Kings College Hospital NHS Foundation Trust  
Kings Mill School  
Kingsley Specialist Services  
Kirklees Council  
Knightsbridge Care Services Ltd  
Knowsley MBC Children's Social Care  
Lancashire Care NHS Foundation Trust  
Langley Park School for Boys  
Lawnmowers Independent Theatre Company  
Learning Disability England  
Leeds Autism Services  
Leicester City Council  
Leonard Cheshire Disability  
London Borough of Havering  
London Borough of Hounslow  
London Borough of Sutton  
London Borough of Tower Hamlets  
Let Us Communicate  
Lewisham Nexus Service  
Lexden Springs  
Liaise Loddon Limited  
Lincolnshire Parent Carer Forum  
Linkability  
Luton CCG  
MacIntyre  
Magistrates Association  
Maidenhead Children's and Young People's Disability Service,  
Making Space  
Manchester University NHS Foundation Trust  
Marches Academy Trust- Education MAT  
Medical Needs Tuition Services  
Medical Schools Council  
Mencap  
Mercylink Care Services

Merseycare NHS Foundation Trust  
Milton Keynes Council  
Mind the Gap  
Minstead Trust  
Momentum Care  
Morrisso Health  
My Life My Choice  
My Options- Telford and Wrekin Council  
National Autistic Society  
National Autistic Taskforce  
National Network of Parent Carer Forums  
Newbridge Group MAT  
Newry & District Gateway Club  
NHS Bassetlaw CCG  
NHS Berkshire West CCG  
NHS England  
NHS Oldham CCG  
NHS West Cheshire CCG (in partnership with Cheshire West and Chester Council)  
NICE  
N-Lighten North East  
Norfolk Autism Partnership Board (hosted by Norfolk County Council)  
Norfolk Community Health and Care NHS Trust  
Norfolk County Council  
Norfolk and Suffolk NHS Foundation Trust  
North Bristol NHS Trust  
North Cumbria CCG  
North East London NHS Foundation Trust  
Northfield Surgery  
Northallerton and the Dales Mencap Society  
Northamptonshire County Council Learning Disability Service  
Northumberland CCG  
Northumberland County Council  
North West Boroughs Healthcare NHS Foundation Trust  
Nottingham Mencap  
Nottinghamshire County Council  
Nottingham University Hospitals NHS Trust  
Nursing and Midwifery Council  
Offender Health Research Network  
Openstorytellers  
Optical Confederation and Local Optical Committee Support Unit  
Options for Life  
Orchard Hill College & Academy Trust.  
Oxford Health NHS Foundation Trust  
Oxfordshire Children's Services, Special Educational Needs Disability Information and Support Service  
Oxleas NHS Foundation Trust  
Paddock School  
Parity for Disability  
Park Community Academy, Blackpool  
PDA Action UK

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PDA Society  
Pennine Care NHS Foundation Trust  
People Matter IW  
People's Choice Group  
Peterborough City Council  
Pioneering Independence Ltd.  
Poetry in Wood CIC  
Poole Borough Shared Lives Scheme  
Poole Hospital NHS Foundation Trust, Children's Therapy Services  
Portsmouth Down's Syndrome Association  
PossAbilities CIC  
Precious  
Professional Carers  
Project 49, Southend Care Ltd  
Project Art Works  
Provide CIC  
Purple Patch Arts  
Purple Star Strategy  
Reach Learning Disability  
The Registration Council of Clinical Physiologists  
Rehability UK  
Resources for Autism  
The Rose Road Association  
Roughcote Hall Ltd.  
Rowan  
Royal College of Anaesthetists  
Royal College of General Practitioners  
Royal College of Midwives  
Royal College of Nursing  
Royal College of Physicians, Faculty of Forensic and Legal Medicine  
Royal College of Physicians of Edinburgh  
Royal College of Speech & Language Therapists  
Royal Cornwall Hospital  
Royal Mencap Society  
Royal National Institute of Blind People  
Salford Integrated Care Organisation  
Salford Royal Foundation Trust  
SCIA  
SeeAbility  
Sense  
Shaftesbury High School  
Sheffield Children's NHS Foundation Trust  
Sheffield Hallam University  
Sheffield Health and Social Care NHS Foundation Trust  
The Sheiling Special Education Trust  
Signalong  
Skills for Health  
SMMA: The Courtyard  
SNACS  
Solihull MBC

Somerset CCG  
Somerset County Council  
Southend Council Children's Services  
South London and Maudsley NHS Foundation Trust  
Southport and Ormskirk Hospital NHS Trust  
South Warwickshire NHS Foundation Trust  
South West London Alliance of CCGs  
South West London & St George's Mental Health NHS Trust  
South Yorkshire & Bassetlaw Local Maternity System  
Space Inclusive Ltd.  
Speakup Self Advocacy  
Specialist Autism Services  
Springboard (The Springboard Project)  
Spot Opportunities  
Staffordshire Adults Autistic Society  
Staffordshire County Council  
St Anne's Community Services  
St Helens Council  
St Martins' Teaching School  
St Mary Magdalene Academy/The Courtyard  
St. Vincent's and St. George's Association  
Stockport Metropolitan Borough Council  
Sunderland Parent Carer Forum  
Support Asia Ltd.  
Supporting Independence Ltd.  
Surrey and Borders Partnership NHS Foundation Trust, LD division  
Surreychoices  
Sutton & Merton Mental Health and Learning Disabilities Team  
Talk 2 Us  
Tameside and Glossop NHS Foundation Trust, Learning Disability Team  
Target Autism  
Tavistock and Portman NHS Foundation Trust  
Tees, Esk and Wear Valleys NHS Foundation Trust  
Thorpe Nursery Pre-School  
Thriving Now Pty Ltd.  
Thurrock CCG  
Thurrock Coalition  
Together All Are Able  
Torbay Mencap  
Tourettes-Syndrome, inclusion in the community (T.I.C.)  
Transforming Care Board - Sussex  
Treloar Trust  
Turning Point  
United Lincolnshire Hospitals Trust  
United Kingdom Homecare Association  
United Response  
University of Birmingham Law School  
University of Bristol  
University Hospitals Leicester  
University of Nottingham

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University Plymouth NIC Trust  
University of Sunderland  
Us in a Bus  
VALUES Project, Voluntary Action Leicestershire  
Voluntary Organisations Disability Group  
Watergate School  
The Waterside Centre  
Ways into Work CIC/Disability is Our Ability CIC  
We can do it training CIC  
Well Connected  
West Hertfordshire Hospital NHS Trust  
West London NHS Trust  
West Sussex Carers Support  
Westminster Council  
Weston Area Health NHS Trust  
Widemarsh Ventures  
Wigan Council  
The Winford Centre for Children and Women  
Windward Day Services  
Wirral Mencap  
Wolverhampton Mencap  
Worcestershire Association of Carers (Right support for Carers)  
Worcestershire Health and Care NHS Trust  
Worcestershire Parent & Carers' Community  
Young NCB (NCB) and FLARE (Council for the Disabled Children).  
Your Choice Care Limited  
Your Healthcare CIC  
Yourway Support Services