

Learning Disability England
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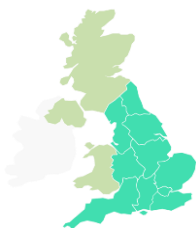
Prime Minister
10 Downing Street
London
SW1A 2AA

13th July 2026

Dear Prime Minister,



We are a group of people and organisations that care about the lives of people with learning disabilities.



In England there are 1.3 million people with a learning disability. There are also many people who support people with a learning disability.



We want the government to make a plan for the health of people with learning disabilities.



The plan should say what good healthcare looks like for people with learning disabilities.



This would help us and you make sure the NHS does a good job.



This letter tells you more about our reasons why.



There have been problems with the way people with learning disabilities are treated for many years.



People with learning disabilities are still dying years younger, from illnesses that could be stopped.



We recognise the work that is happening to tackle some of these problems.



The Oliver McGowan mandatory training in learning disability and autism is being rolled out.



And new guidance is coming in under the Mental Health Act and Down Syndrome Act.



But there is worry that things are not going to change enough.



There is only one mention of learning disability in the NHS 10 year plan.



Reports like the 'Learning Disability Mortality Review' known as 'LeDeR' have had problems and delays. People still die much younger.



There are 44% fewer learning disability nurses than 15 years ago.

DNACPR



Sometimes hospitals still use a person's learning disability as a reason not to resuscitate.



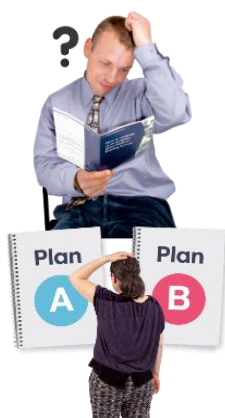
Most people with learning disabilities aren't covered by the Covid vaccine any more.



Hospitals are still homes for over 2000 people with learning disabilities and/or autism.



People with learning disabilities are finding it harder to get care as the NHS becomes more digital.



Now as the NHS changes it is even harder to find out who is responsible for improving the healthcare of people with learning disabilities.

We have noticed new NHS guidelines are missing actions to support people with learning disabilities.



Plans for Men's health, Women's health and Neighbourhood health don't say much at all.



Plans on inequalities and neurodiversity are important but can forget to talk about support for people with learning disabilities.



There is no plan to find out how many people with learning disabilities are waiting for care and if they are missing out.



The NHS changes might affect how many people get a good quality GP learning disability health check and have a health action plan.



There is chance to make things better. National strategies can help improve people's rights and inclusion.



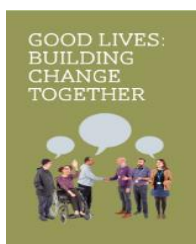
Twenty years ago, there were national programmes which brought people with learning disabilities together to make change happen.



The Department of Health had leaders with a learning disability to report on progress.



But there has been no national learning disability strategy since Valuing People Now in 2009. It means much of this progress has been lost.



In 2023 Learning Disability England brought people together to say what people with learning disabilities need for inclusive and equal lives. This was led by people with learning disabilities.



A new national strategy could use the 'Good Lives Framework' rather than starting from scratch.



What we are asking for in healthcare

We want you to establish a new national NHS programme for learning disabilities.



This should be co-led by a director with a learning disability and co-produced by people with learning disabilities.



We want this programme to have its own strategy, to put learning disability healthcare at the heart of the new NHS.

Some people have said this could be what the NHS calls a Modern Service Framework or Quality Strategy.



The important thing is what it should aim for.



The plan should aim for people to be living longer and healthier lives. It should prevent early deaths and help people live well.



Not just through NHS care but through healthy living, social care and family support.



It should have clear rules for how people with learning disabilities should expect to be cared for in the NHS.



The rules should be based on the best research.



There will be a list of things to do locally and nationally to make sure care is good. This will be reported on.



This plan would look at what extra workforce, training and services are needed for people with learning disabilities to be supported.



Each area should have a person in charge to make sure these improvements happen. This person should be easily identifiable and contactable.



We also want all health guidance and plans to have a focus on people with learning disabilities.



This includes when plans are published on different conditions or aims, such as cancer or health inequalities (known as Core20Plus5)



These ideas are a way to make positive change happen and for us not to be forgotten.

We hope you agree and look forward to hearing from you.

Yours sincerely,

175 Organisational Signatories

1. Access in Dudley	Anne Nicholls
2. Ace Anglia Ltd	Andrea Clark
3. Achieve together	Michael Fullerton
4. Active Prospects	Joel Hartfield
5. Advocacy for All	Advocacy for All
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7. Affinity Trust	Janine O'Regan
8. Age UK	Caroline Abrahams
9. All Brains Welcome	Nicola Maxfield
10. All Disabilities Matter Charity	Jaci Beddard
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12. Ategi	Kate Allen
13. Bede House Association - LD services	Carole Brady
14. bemix	Mollie Mattingly
15. Blade Education (Making Care Fair Campaign)	Beth Hooper
16. Brandon Trust	Rachael Sugden
17. Brighter Horizons	Dave King
18. British Institute of Human Rights	Sanchita Hosali
19. British Institute of Learning Disabilities (Bild)	Lindsey Allen
20. Bromley Well	Chetan Raval
21. Calm Futures	Mark Penney
22. Campaign for Disability Justice and Inclusion Barnet	Cat Whitehouse
23. Camphill Village Trust	Sharon Nicholson
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25. Care England	Fraser Rickatson
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27. Centre 404	Anna Lewis
28. Centre for Inclusive Futures	David Towell

29. Certitude	Aisling Duffy
30. Changing Our Lives	Jayne Leeson MBE
31. Choice for All Doncaster	Karen Imogen Senior
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33. CLASP	Deborah Corcoran
34. Cloverleaf Advocacy	Suzi Henderson
35. Community Integrated Care	Jim Kane
36. Cornwall Partners in Policy Making, Hearing Families	Brigid de Courcy
37. Cornwall People First	Fliss Hedge
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39. Dalesview Partnership Learning Disability Services	Michelle Baxter Registered Learning Disability Nurse
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44. Dimensions UK	Rachael Dodgson
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50. Dudley Voices for Choice	Sarah Offley
51. Every Body Needs Massage	Kay Morriss
52. Exclusively Inclusive	Katie Peacock
53. Fairoak Housing Association	Alison Barnes
54. Future Directions CIC	Paula Braynion
55. Generate Opportunities	Tony Boden

56. Getta life	Melanie Kerkeni
57. Gloucestershire Health and Care NHS Foundation Trust	Julia Kim Walters
58. Golden Lane Housing	John Verge
59. Grace Eyre Foundation	Cleo Dibb
60. Halton Speak Out self advocacy	Susan Jones
61. Healthwatch Southwark	Ruman Kallar
62. Include Me TOO	Parmi Dheensa
63. Inclusion East CIC	Joanne Hough, Matthew Howard and Sara Kent
64. Inclusion Gloucestershire	Emily Luckham
65. Inclusion North CIC	Hannah Tough
66. International Mixed Ability Sports	Mark Goodwin
67. Iris Care Group	Peter Kinsey
68. Kaleido-scope	Bridget Boakye
69. Kent, Surrey & Sussex Learning Disability Community of Practice	Michael Fullerton
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72. Kisimul Group Ltd	Anita Andrews
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76. Learning Disability Professional Senate	Ashok Roy
77. Learning Disability Today	Alison Bloomer
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79. Lewisham Speaking Up	Marsh Stitchman
80. Links Support Solutions Ltd	Elena De Lucia
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82.	Look Ahead	Chris Hampson
83.	Love Community CIC	Alex Roland
84.	MacIntyre	Sarah Burslem
85.	MAKE	Marshall Wilson
86.	Manchester People First	Andy Needle
87.	Midland Mencap	Dave Rogers
88.	Millennium Support Ltd	Jessica McGurk
89.	Moorview Care	Julie Wells-Colley
90.	My Life My Choice	Ady Chappell
91.	My Safe Home Limited	David Abbey
92.	National Care Forum	Professor Vic Rayner
93.	NDTi	Madeline Cooper
94.	New Directions Rugby Ltd	Paul Tolley (CEO)
95.	New Possibilities Ltd	Anna Geyer
96.	New Prospects Association	Annabel Miller
97.	One Fylde	Tracey Bush
98.	Orchard Trust	Tony Lafford
99.	Our House Waingroves Ltd	Sarah Wyatt
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101.	Oxfordshire Family Support Network	Gail Hanrahan
102.	PALS Ltd	
103.	PARCHMENT TRUST	Sara Whalley
104.	Pathways to Potential UK	Vincenza de Falco
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106.	PENNINE CARE NHS FOUNDATION TRUST	Wajiha Zia
107.	People First Dorset	Kerry Martin
108.	People in action	Alice Burford
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110.	People's Health Trust	John Hume
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112.	Plymouth Highbury Trust	John Knight
113.	PMLD LINK	Annie Fergusson

114. Positive Support For You CIC	David Barras
115. PossAbilities	Rachel Law
116. Primary Healthcare Darlington	Neil Bradbury
117. Priory Healthcare	Sharon Drake
118. Project Art- Hastings	Fairlane Villegas
119. Project Art Works	Wendy Matthews
120. Race Equality Foundation	Jabeer Butt
121. Reach Learning Disability	Steve Shatwell
122. Respect in Bexley self- advocacy group (Bexley Mencap)	Miss Jane Delyse Menzies
123. Rightful Lives	Julie Newcombe
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125. Rotherham Doncaster South Humberside NHS Trust	Tom Redding
126. RPR Services (NW) Ltd.	Cecilia Walsh
127. RWP (part of Progress Housing Group)	Annette Stevens
128. Salutem care and education	Julie Kelynack
129. SeeAbility	Lisa Hopkins, CEO
130. Self Directed Futures	Christopher Watson
131. Sense	James Watson- O'Neill
132. Sensory Soft Play	Lisa Henderson
133. Skills for people	Leanne Geritz
134. Social Benefits Consortium CIC	Sandra Beeton
135. Social Capital Ventures Ltd	Philip Coen
136. Social Care Institute for Excellence	Gerard Crofton- Martin
137. Somerset Foundation Trust	Katey Louise Davis
138. Soundabout	Holly Radford- James

139. South Tyneside Community Learning Disability Team	Laura Hyde
140. South Yorkshire ICB	Anita Winter
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142. Speech Therapy Systems Ltd	Mary Tondo
143. Spring into Action CIC	Lucy Hamlin
144. Stand for children with down syndrome(SCD)	Victoire Murekerende
145. Sunderland People First CIC	Lisa Clark
146. Support Horizons CIC	Teresa Lazzari
147. Survivor Sanctuary	Laura Fisher
148. The Advocacy People	Siobhan Hunt
149. The Advocacy Project	Katherine Shaw
150. The Challenging Behaviour Foundation	Jacqui Shurlock
151. The Durnford Society	Jenna Worley
152. The Essex Carers Network	Wendy Burt
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154. The Include Project	Alix Lewer
155. The L9ndon Buddy Scheme C.I.C.	Ashley Pearxe
156. The Lisieux Trust	Emma Hodges
157. The Lodge Trust CIO	Josiah Knight
158. The Makaton Charity	Zanna Finnerty
159. Thera Trust	Katie Winn
160. Through the Roof Charitable Trust	Annette Stuart
161. Tizard Centre, University of Kent	Dr Magali-Fleur Louise Barnoux
162. Together Matters	Christine Towers
163. Tricuro Ltd	Marianne Wanstall
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170. Volition- Leeds	Pip Goff
171. Voluntary Organisations Disability Group	Rhidian Hughes
172. West Norfolk Autism Group	Karan McKerrow
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174. Windward Day Services CIC	Becky Hamilton
175. Xhale Living	Tracy Hall

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- 547. Karen Berrow
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- 549. Karen DeSantis
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- 562. Kate Startup
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