



South Tyneside and Sunderland NHS Foundation Trust

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Paul Chrisp
Director for the Centre for Guidelines
National Institute for Health and Care Excellence
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11 June 2022

Dear Mr Chrisp,

Call for the National Institute for Health and Care Excellence to develop a Guideline on the identification of learning disability in children and young people

The Confidential Inquiry into Premature Deaths of People with Learning Disabilities (www.bristol.ac.uk/cipold/fullfinalreport.pdf) found that men and women with learning disabilities died 13 and 20 years earlier respectively than those in the general population.

The **NHS Long term plan** supports improved outcomes for people with a learning disability and autism:

Section 3.31: "Action will be taken to tackle the causes of morbidity and preventable deaths in people with a learning disability and for autistic people".

Section 3.32: "The whole NHS will improve its understanding of the needs of people with learning disabilities and autism, and work together to improve their health and wellbeing".

Section 3.34. "Children, young people and adults with a learning disability, autism or both, with the most complex needs, have the same rights to live fulfilling lives".

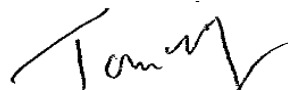
NICE published a clinical guideline CG128 in 2011, updated in 2017, to support the recognition, referral and diagnosis of autistic children under 19 years of age. This has influenced service provision within health teams for children and the development of clear pathways for the identification of autism, albeit with long waiting lists in many places, exacerbated by the pandemic. Children and young people with a learning disability have no such guidance in place to support care pathways to identify their needs. In many places, this has the consequence that young people grow up to adulthood without their learning disability having been identified. This means they miss out on services and reasonable adjustments to better meet their needs. Young people cannot begin to access their annual health checks with their general practice teams if their learning disability has not been identified in the first place.

We call on NICE to urgently develop a guideline **to support the identification of children and young people with a learning disability** so that they have the best life chances with the right information and support in place.

Yours faithfully,



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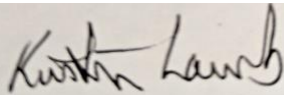
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**The Association
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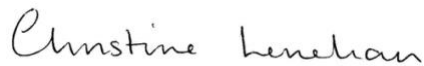


National Network of Parent Carer Forums
"Our Strength Is Our Shared Experience"

Tina Emery & Mrunal Sisodia OBE
Co-chairs
National Network of Parent Carer Forums



Amanda Allard
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Dame Christine Lenehan
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