

PRESS RELEASE

From: Rt. Hon. Sir Ed Davey, MP; Disability Law Service; National Autistic Society; Cerebra; University of Leeds

5th August 2020

41 Local Authorities are unlawfully discriminating against autistic children

According to a [report](#) published today by Disability Law Service, Leeds University, Cerebra and the BBC, at least 41 Councils across England have policies that prevent autistic children from accessing a care assessment. This is discrimination under the Equality Act. It is wholly unlawful behaviour.

The 41 Local Authorities have adopted policies that exclude autistic children from a Children's Act 1989 assessment by their Children with Disabilities team unless they have another disability or a formal diagnosis of autism (which can take many months or even years to receive).

This is unlawful. Local Authorities have a duty to provide services appropriate to an autistic child's needs under the Children Act 1989. Moreover, a policy that excludes children who are autistic from appropriate assessment and therefore from appropriate care constitutes discrimination under the Equality Act 2010.

Rt Hon Sir Ed Davey MP, a patron of Disability Law Service has today written an [open letter](#) calling on all Local Authorities in England to ensure that their policies are lawful. The campaign is not currently naming any individual local authority, but Sir Ed will be writing to the 41 authorities the study identified to highlight how their policies are in breach of the law, and to give them both a chance to respond and an opportunity to amend their policies.

Autism is a lifelong disability that affects how people communicate and interact with the world. All autistic people share difficulties around communication and social interaction but face varying challenges and need different levels of support. This can range from 24-hour care to clearer communication and a little longer to do things at work or school.

Sir Ed Davey said:

'It is shocking that at least 41 Local Authorities across England are breaking the law by discriminating against autistic children. While Government underfunding of Special Education Needs and Disabilities is severe, that is no excuse for discrimination. Most councils are abiding by the law. All councils should.'

"The law requires all disabled children to be given proper care, but many councils have adopted a policy that excludes many autistic children from an appropriate assessment. The case studies in this report are particularly heart-breaking – every child has one chance at childhood, and so many are being denied their chance."

"This new evidence and report from The Disability Law Service in partnership with Cerebra, the BBC and the School of Law at Leeds University demands a response from Ministers and councils: this injustice must be rectified as soon as possible.'

Priya Bahri of Disability Law Service, the lead author of the report, said:

'Without sufficient and adequate support in place, children and families are often pushed to breaking point because of the barriers presented to them. The Children Act 1998 provides that disabled children are entitled to services that meet their needs and therefore policies which prevent this from happening need to be urgently reviewed and changed. We hope that we can make positive change with this campaign to ensure that every disabled child has access to services and support that meets their needs.'

Jane Harris, Director of External Affairs at the National Autistic Society, said:

'This is a damning report, revealing how autistic children are routinely being failed by a social care system starved of investment. Parents tell us they're asking for help in desperate situations but too often they're being turned away.'

It is completely unacceptable for a council to deny a child an assessment simply because an autistic child does not have another condition. It is equally wrong for a council to withhold support from someone just because they do not have a formal diagnosis. Families are left struggling to support their children without training or funding. And without extra help (like short breaks) they can end up isolated and alone, struggling to cope day-to-day.'

Councils should make decisions about support based on a child's needs. Without this, autistic children will struggle at home and at school and could end up isolated. No one would accept this situation for their child. And we won't accept it for autistic children. The Government must make sure councils follow the law and have funding to support autistic children properly.'

Professor Luke Clements, Cerebra Professor of Law and Social Justice, Leeds University, said:

'There can be no justification for treating disabled children with autism and their families adversely compared to other disabled children. Discrimination of this kind is contrary to the Equality Act 2010 and unlawful. Those councils who have developed these policies need to take rapid action to end the serious harm these policies are causing.'

Beverley Hitchcock, Deputy Head of Research at Cerebra said:

'At Cerebra we were finding that there was an increase in referrals to our Legal Rights Service from families with a child with autism who had been refused an assessment on the basis that autism as a condition was not enough on its own, or that autism was not recognised as a medical condition or that the child had not, as yet, had a formal diagnosis. We feel that this practice is discriminatory and causing unnecessary stress and hardship for families who are often already at breaking point. We believe that this practice needs to be rectified as quickly as possible.'



Jordan

Jordan has Severe Autism Spectrum Disorder with Associated Severe Anxieties and Challenging Behaviours, Sleep difficulties, Mild Learning Difficulties (moderate in educational terms) and Severe Joint Hypermobility. He is now 14 years of age and recently had an ADHD (attention deficit hyperactivity disorder) assessment which found that he may also have sensory processing difficulties.

When Jordan was 8 years of age, he was refused an assessment by the Children with Disabilities team for his social care needs because he did not meet the Local Authority's eligibility criteria. In 2013, his council agreed to conduct an assessment and provision of an out of school activities club, for children with profound disability needs, was funded by Disabled Children & Young Person Services (DCYPS) pending its outcome. The assessment concluded that Jordan 'does not meet the threshold for DCS specialist services so this service cannot be funded.' Despite providing further medical evidence

over the following years Jordan's council refused to reassess him.

In 2019, following a threat of Judicial Review, Jordan's Council agreed to conduct a reassessment of his needs. However, they again decided that Jordan did not meet their criteria because 'his overall level of needs are assessed as low - therefore he is not eligible for support from DCYPS'. Despite this, Jordan was found to be a Child in Need by his Council and his parents were told that his needs can be met by mainstream services which only involved after school and holiday clubs. This decision was against the advice of NHS Learning Disability Service and subsequently his Special Needs School that he would require specialist service and 1:1 support accessing any services. Instead of providing specialist support, Jordan's council only offered his mother information on parenting groups and courses she could join.

Jordan's Council have recently told his parents that they will fund two sessions during the summer break, at the same out of school activities club provided in 2013. They have told them that they will review this provision but have not confirmed further provision or funding.

Jordan requires 1-1 personal care support because of the severity of his combined conditions. As a result of not having any support at all from his council he is socially isolated and his parents have been left to care for him without any support.

Jordan's mother, Natalie says: "I battled for 6 years and we have been passed from pillar to post, I am physically and mentally exhausted and my own health is now deteriorating".

Notes

Sir Ed Davey MP

Ed Davey was four when his Dad died, and he became a young carer for his mum aged 12 when she was diagnosed with terminal cancer. She died when Ed was 15. Now, with his wife Emily, they care for their son John who has an undiagnosed neurological condition that means he cannot walk and talk, and requires 24-hour care.

Disability Law Service

The Disability Law Service is a charity that has been providing free legal advice to disabled people and their carers since 1975. Our mission is to challenge the poverty and inequality faced by those with disabilities by securing for them access to justice. Our website is at: www.dls.org.uk.

We use our legal expertise to advocate changes in law and to ensure those that already exist are followed.

The National Autistic Society

- The National Autistic Society is the UK's leading charity for autistic people.
- We are here to transform lives, change attitudes and create a society that works for autistic people.
- Since 1962, we have been campaigning for autistic people's rights and providing support and advice to autistic people and their families.
- To find out more about autism or the charity, visit www.autism.org.uk.
- Follow the National Autistic Society on Twitter [@Autism](https://twitter.com/Autism) or [Facebook](https://www.facebook.com/autismuk).

What is autism?

- Autism is a lifelong disability which affects how people communicate and interact with the world.
- There are approximately 700,000 autistic adults and children in the UK.
- All autistic people have difficulties with communication and social interaction.
- Autism is a spectrum condition. This means autistic people have their own strengths and varying and complex needs, from 24-hour care to simply needing clearer communication and a little longer to do things at work and school.
- Although everyone is different, people on the autism spectrum may:
 - Be under or oversensitive to sounds, touch, tastes, smells, light or colours, which can make everyday life extremely difficult
 - be unable to or find it harder to speak, need longer to process information or find it hard to hold conversations
 - experience intense anxiety around unexpected change and in social situations
 - become so overwhelmed that they experience debilitating physical and emotional 'meltdowns' or 'shutdowns'.
- Without the right support or understanding, autistic people can miss out on an education, struggle to find work and become extremely isolated.

School of Law, University of Leeds

The Cerebra Legal Entitlements & Problem-Solving (LEaP) Research Project is an innovative problem-solving project that helps families of children with brain conditions cope with the legal barriers they face.

The research project is funded by Cerebra and is part of the School's wide ranging Community Engagement programme

Cerebra

Cerebra is a national charity helping children with brain conditions and their families to discover a better life together.

We work closely with our families to find out where help is most needed and then work with our university partners to fund the relevant research. Our research work across neurodevelopmental conditions gives us a unique perspective within the charity research sector.

Our aim is to provide research-driven, high-quality health and social care advice and support for the families of children with brain conditions from birth to the age of 16.

For further information or to discuss this campaign, please contact:

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