

# **Unlawful restrictions on the rights of disabled children with autism to social care needs assessments**

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**The Disability Law Service** is a charity that has been providing free legal advice to disabled people since 1975.

Specialising in Community Care, Employment, Housing and Welfare Benefits our mission is to provide free legal advice to disabled people and their carers to ensure that they have access to their rights and justice.

You can find out more by visiting <[www.dls.org.uk](http://www.dls.org.uk)>.

**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.

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

We listen to families and help them get the knowledge they need to access health, social care and other support services. We identify the common legal problems that prevent families getting access to services and we develop innovative ways of solving those problems. We aim to reach as many families as we can by sharing our solutions as widely as possible.

**School of Law Leeds University Community Engagement** is fundamental to the ethos of the School of Law at the University of Leeds. Students are given every encouragement and support to use their legal skills to benefit the local community. In doing this, students develop these skills and deepen their understanding of the role of the law in the real world: the central role of the law in fostering social justice. In furtherance of this aim the School supports (among other initiatives) a number of law clinics and the Cerebra LEaP project.

## A message from

Rt. Hon. Sir Edward Davey MP Patron of the Disability Law Service

'It is shocking that at least 41 Local Authorities across the UK are breaking the law by discriminating against autistic children.

The law requires all disabled children to be given proper care, but many councils have adopted a policy that excludes autistic children from an appropriate assessment unless they (for example) also have another disability. 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.'

Edward Davey

## A message from

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

'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, unable to function on a daily basis.

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.'

Jane Harris

## Forward

'It is concerning that those in control of providing the support disabled children are entitled to, are breaking the law by having policies in place that restrict access to those that need it. The figures and experiences we have come across are disheartening and show that this problem is widespread.

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 1989 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 are pleased to have identified this issue and with the support of our partners will work towards making a positive change, to ensure that every disabled child has access to services and support that meets their needs.

It is imperative for change to happen as social care is a fundamental service on which millions of disabled people depend every day.'

Priya Bahri (Lead Author and Trainee Solicitor, Disability Law Service).

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## Key Messages

The research underpinning this report considers the legality of restrictions put in place by some local authorities, that impede the rights of disabled children with autism to an assessment of their needs and to support required to meet those needs. The policies of 149 English local authorities were considered although only 93 were identified as having ‘functional’ eligibility policies for such support.

1. Of the policies that were considered as functional: 41 (44.08 per cent) made specific mention of autism when determining whether a child would be assessed by / or supported by their Children with Disabilities team (para 3.07). These authorities generally linked autism to an additional requirement (or requirements) – for example: that the child had another impairment or a formal diagnosis. These criteria are referred to as ‘autism plus’ policies.
2. ‘Autism plus’ policies of this kind constitute unlawful discrimination contrary to the Equality Act 2010. They indirectly discriminate against disabled children with autism compared to other disabled children (para 5.07).
3. ‘Autism plus’ policies of this kind which predicate support on the existence of a formal diagnosis of autism, would appear also to constitute unlawful discrimination contrary to the Equality Act 2010 on grounds of sex – as materially more young men have an autism diagnosis than young women (para 5.11).
4. It is arguable that ‘autism plus’ policies of this kind also constitute direct discrimination under the Equality Act 2010 (para 5.04).
5. The research questions (but makes no final determination on this issue) whether local authorities with ‘autism plus’ policies have had due regard to their Public Sector Equality Duty obligations under section 149 of the Equality Act 2010 (para 5.13).
6. Eligibility policies that require disabled children with autism to have had a formal diagnosis of autism before accessing disabled children’s assessment and support services constitute a non-statutory barrier to disabled children’s support services under the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970 and are in consequence unlawful.
7. The issue of access was a major concern of the research team. Local authorities are under a duty to publish their eligibility criteria for disabled children’s assessment and support services (para 6.01) as part of their ‘local offer’. In many cases the relevant criteria were not accessible and in many cases they were only identified after a prolonged period of searching or the use of information gained was from Freedom of Information requests. In relation to over a third of the 149 local authorities studied, the criteria proved to be: either inaccessible or so unfit for purpose as to be incapable of constituting ‘lawful’ eligibility criteria (para 6.02).

8. The systemic failure identified by this research calls for swift action by the local authorities that are children's social services authorities; the Government, the Equalities and Human Rights Commission and Parliament (para 6.07).
9. Relevant local authorities must take immediate steps to rectify failings in their eligibility criteria for the assessment and support of disabled children – and to ensure that these are published in a readily accessible form on (at the very least) their local offer web pages (para 6.08).
10. No reasonable Secretary of State reading this data could fail to take action: (1) to verify the findings; (2) to write to all authorities with 'autism plus' policies requiring that these be withdrawn (using his statutory powers to issue 'Directions'); (3) to issue urgent guidance requiring immediate action by local authorities; and (4) in due course to issue formal guidance as to the content of lawful eligibility criteria – possibly including a template scale of the type issued by the Department of Health for adults in 2002.<sup>1</sup> An alternative (or an addition) to the use of formal guidance would be for the Government to bring forward legislation / regulations to put eligibility criteria on a statutory footing – as has been done for (among others) disabled adults in England<sup>2</sup> and disabled children in Wales (para 6.09).<sup>3</sup>
11. As with the Secretary of State, the Equalities and Human Rights Commission should take urgent steps to verify the findings and subject there to, to write to all authorities with 'autism plus' policies requiring that these be withdrawn (and if this fails, to use its powers to bring about the necessary changes) – para 6.10.
12. Finally, Parliament should consider whether the facts disclosed by this report are such as to call for an investigation by a relevant Committee (for example the Health and Social Care Committee and / or the Women and Equalities Committee) (para 6.11).

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<sup>1</sup> Department of Health *Fair Access to Care Services policy guidance* (2002).

<sup>2</sup> The Care and Support (Eligibility Criteria) Regulations 2015 SI No 313.

<sup>3</sup> The Care and Support (Eligibility) (Wales) Regulations 2015 SI 1578 (W. 187).

# 1. Introduction

- 1.01 This report is concerned with the way that local authorities in England respond to the social care assessment and support needs of disabled children with autism.
- 1.02 The National Autistic Society (NAS) defines autism as a 'lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them'.<sup>4</sup> A more detailed definition is provided by the World Health Organisation, namely:

A type of pervasive developmental disorder that is defined by: (a) the presence of abnormal or impaired development that is manifest before the age of three years, and (b) the characteristic type of abnormal functioning in all the three areas of psychopathology: reciprocal social interaction, communication, and restricted, stereotyped, repetitive behaviour.

For the purposes of this report Asperger's Disorder is considered to be a type of autism.<sup>5</sup>

- 1.03 The symptoms experienced by people with autism vary greatly. Some people have a learning disability, but it appears that about a third do not<sup>6</sup> – and many are 'high functioning'. The NAS have highlighted the difficulty that many people with autism have processing everyday sensory information. Sensory difficulties of this kind may take the form of extreme likes and dislikes to some sounds, textures, tastes and objects.<sup>7</sup> These symptoms do not necessarily result in the person having challenging behaviour – they can, for example: result in the person becoming withdrawn, highly anxious and / or isolated.<sup>8</sup>

## 2017 Research by the Disability Law Service

- 1.04 In 2017 the [Disability Law Service \(DLS\)](#) Community Care team identified a significant problem concerning the way some local authorities were undertaking assessments of the needs of autistic children. These authorities had 'autism specific policies': policies that blocked such children from being assessed by (and receiving support from) their Children with Disabilities teams. Although the children were sometimes offered an assessment from the 'Children in Need'

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<sup>4</sup> NAS *What is autism?* <<https://www.autism.org.uk/about/what-is.aspx>> accessed 24 January 2020.

<sup>5</sup> American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders DSM-5* (5<sup>th</sup> ed. 2013) states that 'Individuals with a well-established DSM-IV diagnoses of autistic disorder, Asperger's disorder or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder'.

<sup>6</sup> It appears that about 40 per cent of persons with a learning disability have an ASD, while about 30 per cent of persons with ASD do not have a learning disability - see J L Matson and M Shoemaker *Intellectual disability and its relationship to autism spectrum disorders Research in Developmental Disabilities* 30 (2009) 1107–1114 at p. 1110.

<sup>7</sup> NAS *Sensory Differences* (2016) <<https://www.autism.org.uk/about/behaviour/sensory-world.aspx>> accessed 24 January 2020.

<sup>8</sup> See for example J Case-Smith, L L Weaver and M A Fristad 'A systematic review of sensory processing interventions for children with autism spectrum disorders' *Autism* (2015) Vol 19, Issue 2, pp. 133–148 and E Marco et al 'Sensory Processing in Autism: A Review of Neurophysiologic Findings' in *Pediatric Research* (2011) May; 69(5 Pt 2): 48R–54R.

team within Children's Services, their specific needs were still not being met and the support provided was not sufficient.

- 1.05 The DLS was concerned that this discriminatory treatment might be widespread. It undertook a desktop review to ascertain the prevalence of such policies within Children's Social Services Departments. This suggested that 69 English and Welsh councils had similar 'autism specific' restrictions on the availability of support from their Children with Disabilities teams. Over half of these councils policies expressly stated that an autistic child would only be able to access support from their Children with Disabilities team if they had an additional disability. Policies of this kind are referred to in this report as 'autism plus' policies.
- 1.06 As part of its review, the DLS also undertook a survey to gain an understanding of the experiences of families with autistic children who attempted to access social care support from their local authority. The survey was published on the DLS website, promoted on their social media platforms, and shared among their followers. It was open for a period of three months during which it attracted 142 responses. The survey comprised a series of 9 questions and was answered both by those with experience of the care system and those who had no idea they had the right to support.
- 1.07 The DLS survey findings included:
- 94 per cent of the respondents stated that their child had been denied an assessment of their child's needs by the Children and Disabilities team;
  - 80 per cent stated that their child had not been offered an alternative assessment;
  - 59 different English, Welsh and Scottish local authorities were identified by the respondents as having 'autism specific' restrictions in relation to their Children with Disabilities support services. On analysis, the published policies of 30 of these authorities made no mention of children with autism – suggesting that unwritten 'autism specific' restrictions operated in these authorities, notwithstanding that their formal policy appeared non-discriminatory.
- 1.08 Follow up questions with 18 of the families sought to identify their child's specific care and support needs and the adequacy of the local authority response in relation to these needs. These questions identified two principal concerns, namely: (1) the lack of local authority staff with an understanding of autism; and (2) that the necessary care and support services were only available from their Children with Disabilities team and children with autism were often automatically excluded from accessing support from these teams.
- 1.09 In response to a question that asked the families about their experience of 'local authority staffs understanding of autism', 78 per cent expressed their frustration in encountering staff that had no such understanding.
- 1.10 In response to a question about the forms of care and support that families considered as most needed: respite care, personal care, direct payments and

advice / guidance were the most commonly mentioned – with respite care given the greatest importance:

### *Respite care*

Respite care is a service that helps families with disabled children ‘lead lives which are as ordinary as possible’.<sup>9</sup> Local authorities are under a duty to provide support of this kind to enable families to continue to provide care for their disabled children ‘or to do so more effectively’.<sup>10</sup> Disabled children who have access to short breaks will benefit from new interests, relationships and activities; while their parents can attend to their physical and psychological wellbeing. In practice, however, respite care support is often the service that simply enables a parent to ‘cope’ – to stay on the right side of the ‘cliff edge’.<sup>11</sup> The relevant regulations list other benefits that should flow from such support including: enabling carers to undertake education, training or any regular leisure activity; to meet the needs of other children in the family more effectively; and / or to carry out day to day tasks which they must perform in order to run their household.<sup>12</sup>

### *Personal care*

Personal care involving paid carers supporting children with washing, dressing and toileting was a valued service highlighted by the respondents – but one not generally available to children with autism. The main reason given for this failure was that ‘non-Disabled Children’s Team’ staff lacked the necessary expertise and training to provide this level of care.

### *Direct Payments*

Some families considered that receipt of Direct Payments (to enable them to purchase the necessary care and support for their disabled child) would have been useful – but that this form of support was only accessible for Disabled Children’s Teams.

### *Advice and guidance*

Some families explained that the lack of advice and guidance meant that they often felt lost in knowing and understanding what was available to them.

## **Wider concerns**

- 1.11 During the same period, the [Legal Entitlements & Problem-Solving \(LEaP\) Project](#)<sup>13</sup> was also contacted by a number of families who had experienced similar difficulties in accessing support for a disabled child with autism from their local Children with Disabilities team. In several of the cases, families were told that support services (such as regular respite care or direct payments for personal assistance) could not be provided to families who had not been

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<sup>9</sup> Department for Education *Short breaks for carers of disabled children Departmental advice for local authorities* (2011) para 1.9

<sup>10</sup> Schedule 2, Paragraph 6(1)(c) Children Act 1989

<sup>11</sup> L Clements and S McCormack *Disabled Children and the Cost Effectiveness of Home Adaptations & Disabled Facilities Grants* (Cerebra 2017) para 5.08.

<sup>12</sup> The Breaks for Carers of Disabled Children Regulations 2011 reg 3(b)

<sup>13</sup> Details of the programme and past research outputs can be accessed at: <https://cerebra.org.uk/what-we-do/research/our-research-partners/university-of-leeds-school-of-law/> accessed 27 January 2020.

assessed by their Children with Disabilities team. An (anonymised) extract from a 2018 referral note stated:

It seems clear that there is a difference in treatment for young people with ASC (in this case Asperger's syndrome). They have to go through the 'children in need' process which has all sorts of 'safeguarding / inadequate parenting' connotations and is generally (as in this case) subject to targeted time limited interventions.

- 1.12 The Local Government and Social Care Ombudsman in a 2018 report<sup>14</sup> also expressed concern about policies that diverted some disabled children to generic 'children in need' teams (i.e. where staff were not specialist disabled children's social workers). In this case the council's child health and disability team considered that the family needed respite care as it was in imminent danger of a breakdown, but that the child was not sufficiently disabled to come within its remit and so recommended that support needed to come from another social care team – but this did not happen. In finding maladministration the ombudsman noted that (para 46) 'regardless of which team provided the care, the Council assessed the need and was under a duty to provide [the mother] with respite'.
- 1.13 In view of the evidence obtained by the DLS and the LEaP project it was decided to undertake methodologically rigorous research into the prevalence of such policies and their legality. The research programme has been greatly assisted by the BBC's 'Yorkshire Impact Team' which kindly took responsibility for the making of the Freedom of Information (FoI) requests to English Children's Social Services Departments, which are considered further at para 2.01 below.

## Context

- 1.14 The research programme takes place in the context of wider concerns about the health and social care support arrangements made by the statutory authorities for people with autism. Examples of these concerns include the following:
- 1.15 The Care Quality Commission's 'state of health care and adult social care in England 2018/19'<sup>15</sup>:
- described as a 'common picture' the situation where 'people with a learning disability or autism had not had access to the help they needed as children from health, care and education services [and when] they encountered a crisis in their lives, there was nothing available locally to avoid going into hospital'.<sup>16</sup>
  - noted that 'organisations that represent people who use services have told us about the barriers that people are coming up against when trying to get diagnoses and assessments, particularly for dementia, autism, mental health conditions and social care. These include long waiting times, the need to be persistent, eligibility for assessments and the timing of assessments'.<sup>17</sup>
  - listed as the first item (under the heading 'Key equality issues in health and social care'):

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<sup>14</sup> Complaint no 17 011 899 Poole Borough Council 26 October 2018.

<sup>15</sup> Care Quality Commission *The state of health care and adult social care in England 2018/19* HC 9 (House of Commons 2019).

<sup>16</sup> Ibid, p. 7.

<sup>17</sup> Ibid, p. 15.

People in equality groups can face greater barriers to accessing good health and social care services. They can experience difficulties because the pathways and models of care for people in some equality groups, such as people with a learning disability or autism, are not working well.<sup>18</sup>

- 1.16 The publication by the Local Government and Social Care Ombudsman of many reports expressing concern about the failure of local authorities to have sufficient (or indeed ‘any’) autism-trained staff able to undertake assessments; as well as a failure to undertake ‘general autism awareness training for all frontline staff’.<sup>19</sup>
- 1.17 Academic concern has been voiced about the fitness for purpose of the current Children Act 1989 assessment guidance – namely ‘Working Together’ 2018.<sup>20</sup> Broach and Clements<sup>21</sup> refer to it as ‘problematic’, noting that it is ‘primarily concerned with the duties to safeguard children from abuse and neglect and provides only limited practical advice concerning the provision of support to disabled children and their families’.
- 1.18 There would appear to be a need for disabled children specific guidance<sup>22</sup> that describes good practice in assessment and care planning and should not be predicated on the expectation of ‘interventions’<sup>23</sup> in a family’s life.
- 1.19 It is arguable, that the resource needs of disabled children’s services have been overshadowed by the ‘crisis in care’ caused by the spiralling costs of ‘looked after children’. In 2018 only 8.7 per cent of children’s services assessments related to disabled or ill children – compared to 53.2 per cent concerning children considered to be at risk of abuse or neglect; 23.9 per cent for children at risk due to family dysfunction / acute stress.<sup>24</sup> In 2018-19 it was expected that – as a consequence of the 84 per cent increase in children being supported on child protection plans (since 2009), that children’s social services authorities budgets would be overspent by almost £800m.<sup>25</sup>

### **Delay in obtaining autism diagnoses**

- 1.20 There is widespread concern about the lengthy delay many families encounter

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<sup>18</sup> Ibid, p. 84.

<sup>19</sup> See for example complaints no 19 002 111 against Salford City Council, 29 August 2019; 17 015 382 against Hertfordshire County Council, 21 August 2019; no 18 001 147 against London Borough of Lewisham, 19 June 2019 and no 18 013 498 against Norfolk County Council, 7 June 2019 – and see also L Haynes and M Samuel ‘Big drop in autism-specific training for staff carrying out Care Act assessments’ Community Care July 2019.

<sup>20</sup> HM Government, *Working Together to Safeguard Children: A guide to interagency working to safeguard and promote the welfare of children*, 3 July 2019.

<sup>21</sup> See generally S Broach and L Clements *Disabled children a legal handbook* 3<sup>rd</sup> edition Legal Action Group (2020) paras 3.33 – 3.34.

<sup>22</sup> Prior to the ‘Working Together’ guidance good practice guidance of this kind existed as ‘Department of Health *Assessing Children in Need and their Families: Practice Guidance* 2000’ chapter 3 ‘Assessing the needs of disabled children and their families’ (DoH 2000) pp 73-108.

<sup>23</sup> Working Together (2018) uses the words intervention / interventions on 10 occasions and in its 111 pages, devotes only two paragraphs (28 and 29) to the assessment of disabled children.

<sup>24</sup> Department for Education *Characteristics of children in need: 2017 - 2018 England* (2018) Figure O (there were 35,209 assessments that year).

<sup>25</sup> National Statistics *Ministry of Housing, Communities and Local Government Local Authority Revenue Expenditure and Financing: 2018-19 Provisional Outturn, England* (2019).

in obtaining an autism diagnosis for their child,<sup>26</sup> as well as dissatisfaction with the actual diagnosis process.<sup>27</sup> A 2018 Parliamentary report identified delays of up to four years in several parts of England – a situation it described as ‘scandalous’.<sup>28</sup>

- 1.21 Research in 2016 found that parents typically encounter a delay of over 4.5 years between first noting concerns about their child’s development and their child receiving a formal ASD diagnosis – and that the period between first contacting a healthcare professional and receiving a formal diagnosis was on average 3.5 years.<sup>29</sup> In 2019, a British Medical Association report ‘Failing a generation: delays in waiting times from referral to diagnostic assessment for autism spectrum disorder’<sup>30</sup> referred to the ‘alarming’ impact that a delayed diagnosis can have on a child’s educational and mental health as well as the consequential harm on their family and called for urgent Governmental action to address this problem.

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<sup>26</sup> L Crane, J Chester, L Goddard, LA Henry, LE Hill ‘Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom’ *Autism: The International Journal of Research and Practice* (2016) 20(2):153–162.

<sup>27</sup> L Crane, R Batty, H Adeyinka, L Goddard, LA Henry and EL Hill ‘Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals’ *Journal of Autism and Development Disorders*. 2018; 48(11): 3761–3772.

<sup>28</sup> N Lamb and All Party Parliamentary Group on Autism *The autism diagnosis crisis*. All Party Parliamentary Group on Autism (2018).

<sup>29</sup> L Crane, R Batty, H Adeyinka, L Goddard, LA Henry and EL Hill ‘Autism Diagnosis in the United Kingdom: Perspectives of Autistic Adults, Parents and Professionals’ *Journal of Autism and Development Disorders*. 2018; 48(11): 3761–3772.

<sup>30</sup> British Medical Association *Failing a generation: delays in waiting times from referral to diagnostic assessment for autism spectrum disorder* (BMA 2019).

## **2. Research project methodology**

- 2.01 Freedom of Information (Fol) requests were sent to 149 English Children's Social Services authorities' by the BBC in April and September 2019. The responses to these were forwarded to the LEaP Project research team at the School of Law at Leeds University. The team was led by Professor Luke Clements and Dr Ana Laura Aiello with the assistance of Damarie Kalonzo (a postgraduate researcher) and 35 volunteer students. A copy of the Fol request sent to each authority is at the final Appendix to this report.
- 2.02 For the purposes of this provisional report the analysis is limited to the contents of the first question, namely: 'Please provide a copy of your policy for dealing with assessments of disabled children by your Children with Disabilities team. The relevant department will be Children's Services or equivalent'.
- 2.03 The primary goal of this stage of the analysis is to ascertain whether there is indeed a widespread policy of treating disabled children with autism differently: of stereotyping this particular condition.
- 2.04 In addition to analysing the data in the Fol responses, the project team also searched the websites of all 149 authorities for information concerning their eligibility criteria for disabled children to access support from the relevant authority. As noted at para 6.01 below, there is a statutory duty on authorities to make this information available on their websites. The analysis of the websites and Fol responses by the project team took place between October and December 2019.
- 2.05 All but 14 of the 149 authorities who received a Fol request responded by the time the period of analysis came to an end. Unfortunately in many cases the information provided in the Fol response failed to provide the requested information. The result was that much time was expended by the research team searching the individual local authority websites for the relevant data.

### **3. Research findings**

- 3.01 This preliminary report focuses on the research findings relating to ‘autism specific’<sup>31</sup> restrictions in policies relating to local authorities and Children with Disabilities support services.
- 3.02 During the analysis of the data a series of problems were encountered: two were of particular significance.

#### **Inaccessible policies**

- 3.03 In relation to 23 authorities (15 per cent of English children’s social services authorities), the research team were simply unable to identify the criteria by which the eligibility of disabled children for assessment and support services were determined. In this context see para 2.05 above (concerning the research teams efforts to identify the relevant criteria) and para 6.01 concerning the legal duty on authorities to make this information available.

#### **Defective or ‘suspect’ policies**

- 3.04 In relation to a further 33 authorities, the research team had serious reservations about the ‘fitness for purpose’ of their published eligibility criteria. Although these policies contained no obvious ‘autism plus’ conditions, it was not possible to say with confidence that the 33 authorities were not in fact applying ‘autism plus’ criteria (in this context see para 1.05 above). In a number of cases the relevant local authority policies were not in fact capable of acting as functional criteria for determining eligibility. These 33 authorities have therefore been assigned a separate category – referred to below as the ‘suspect’ category. These criteria are only considered briefly in this provisional report. They have been placed in a separate category, as the likelihood exists that within these authorities there must be other operating eligibility criteria – either unwritten or unpublished.
- 3.05 Within the ‘suspect’ category, we include criteria that simply repeated the definition in section 17(11) of the 1989 Children Act. For example, excluded categories specified in section 17(11) were most commonly disabled children with a mental disorder, who required a ‘diagnosis of a disability.’ Authorities confused their obligations under the 1989 Children Act with those under the Equality Act 2010, or referred to repealed legislation: e.g. the Disability Discrimination Act 1995, or contained highly subjective criteria e.g. by requiring that the child had ‘severe’ autism or ‘seriously’ challenging behaviour<sup>32</sup> or were rationally ‘circular’: i.e. requiring that in order to be assessed, the disabled child had to have a need for ‘specialist social care services’ - but failing to explain how

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<sup>31</sup> This including Asperger’s Syndrome.

<sup>32</sup> For which it was assumed that there must be other criteria explaining how ‘severe’ or ‘seriously’ etc was measured.

the authority could identify that such a need existed without the child ever having been assessed.

3.06 As we note at para 6.02 below, the final research paper will contain a detailed analysis of these 33 'suspect' criteria.

### **'Autism plus' policies**

3.07 Of the 93 authorities for which we were able to identify intelligible eligibility criteria 41 (44.08 per cent) specified that children with autism would only be eligible for an assessment / support if they also met an additional requirement (or requirements). For example, that a child with autism could not access disabled children's support services unless they also had another impairment. Examples of these 'autism plus' policies include:

- 'Autism plus' a diagnosis of autism;
- 'Autism plus' a significant learning disability;
- 'Autism plus' a challenging behaviour.

3.08 Authorities with 'autism plus' policies also differed in the permutations of required additional factors: for example requiring (on occasions), not only: (1) autism; plus (2) learning disabilities – but also (3) a significant impact on the child's everyday living. Another example was that in order for a child to be referred to its Children with Disabilities service, he or she had to have (among other things) 'a permanent or long lasting disability (diagnosed by a doctor or consultant) and be severely or profoundly impaired' – and so on.

3.09 Table 1 below shows the relative prevalence of 'autism plus' in the research sample:

Table 1

<b>Requirements</b>	<b>Number of policies employing this approach</b>
'Autism plus' a learning disability	22 out of 41
'Autism plus' a diagnosis of autism	21 out of 41
'Autism plus' a challenging behaviour	5 out of 41

3.10 As the previous table demonstrates, most of those authorities with a criteria referring to autism - link it to a learning disability (see para 3.09 above). Two examples of policies of this nature are detailed below:

### **Local authority A<sup>33</sup>**

Children and young people are eligible for specialist social work assessments, social work support, family support and short break services from the specialist children's disability team, the Joint Service for Disabled Children (JSDC), if they are aged between 0 to 17 years inclusive, live in [XXX] and have:

- a severe physical, learning, mental impairment or severe sensory impairment, such as a severe visual or hearing impairment, which has a substantial and long term effect on their ability to carry out day-to-day activities
- autism and associated severe learning disabilities
- challenging behaviour as a result of their severe learning disability
- complex needs, including life-limiting or a life-threatening conditions

### **Local authority B<sup>34</sup>**

#### **2.2 Eligibility Criteria**

2.2.1 The eligibility criteria for on-going support from the Children's Disability Social Work teams are detailed below.

Children who have:

- Moderate/ Severe Learning Disability - i.e. the child is functioning at a substantially lower than expected level for his/ her chronological age
- and/ or substantial physical impairment - e.g. wheelchair user
- Autistic Spectrum Disorder but only with a moderate/ severe learning or physical disability
- Sensory impairment but only with one or more of the above

2.2.2 The Children's Disability social work teams, however, will not offer a service to children with any of the following unless they also have a moderate/ severe learning disability

- ADHD
- High functioning ASD
- Dyslexia
- Dyspraxia

2.2.3 If a child does not meet these criteria and a full social care assessment is appropriate, the assessment will be undertaken by the Children and Families Assessment team. If a child does not meet the criteria for services from the specialist Children's Disability Social Work team they may be eligible for support from the Family Solutions Service, either Early Help or Statutory.

3.11 The following policies are examples of criteria linking autism to a diagnosis of autism (local authority C) and to a challenging behaviour (local authority D):

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<sup>33</sup> The sources of reference for the various examples of policies have not been included in this report.

<sup>34</sup> Ibid.

**Local authority C<sup>35</sup>**

A child is eligible for a child and family assessment from the Children with Disabilities social work team, if he/she:

- Has a medical diagnosis of severe physical impairment, learning impairment or Autism; and
- Has a home address within [XXX]; and has needs arising from their impairment that cannot be met by services within universal or targeted children's services.

**Local authority D<sup>36</sup>**

We use the following statement and criteria to decide which children are eligible for specialist services. The child should also meet one or more of the following criteria:

- they use specialist equipment for mobility
- they require support for all basic self care functions when no longer age appropriate
- they need constant supervision throughout the day and for prolonged periods at night, when no longer age appropriate
- they have behaviour as a result of disability that is a serious risk to self and or others, including self harm
- they have communication needs which, without support, severely affects personal safety, i.e. is deaf, blind or without speech
- they have been assessed as having either of the following conditions, which results in significant risk of self harm or harm to others:
  - Profound and Multiple Learning Disability (PMLD)
  - Severe Learning Disability (SLD) and/or autism with challenging behaviour

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<sup>35</sup> Ibid.

<sup>36</sup> Ibid.

## 4. The legal context

### Introduction

- 4.01 This section of the report sets out the key duties that local authorities owe to children and young people with autism, and the protection against discrimination in the provision of these services provided by the Equality Act 2010 and the Human Rights Act 1998 and places this into the context of international human rights law.

### The Children Act 1989 and Chronically Sick and Disabled Persons Act 1970 duties

- 4.02 The Children Act (CA) 1989 s17(1) places a duty on local councils (social services authorities) to safeguard and promote the interests of children ‘in need’ and to provide them (and their families) with a wide range of support services. Such support includes, for example, personal care of the disabled child – to help the child dress, or feed, or to stay safe; to give the child’s parent(s) a break from caring (respite care during the day or overnight or during the school holidays) and so on.
- 4.03 CA 1989 s17(10) states that a child will be ‘in need’ if:
- (a) he is unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision for him of services by a local authority . . . ; or
  - (b) his health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or
  - (c) he is disabled.
- 4.04 CA 1989 s17(11) defines a ‘disabled child’ as one who:
- is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed; and ‘development’ means physical, intellectual, emotional, social or behavioural development; and ‘health’ means physical or mental health.
- 4.05 The definition in s17(11) adopts the terminology of the Mental Health Act 1983 s1 by using the phrase a ‘mental disorder of any kind’. This is a wide definition and includes, for example, children with autism or Asperger’s syndrome even if they have a high IQ and even if they do not have behaviour that may be described as ‘challenging’.
- 4.06 The Chronically Sick and Disabled Persons Act 1970 s2(4), places a specific duty on children’s social services authorities to provide a wide range of support

services for disabled children once they are satisfied that these are necessary.<sup>37</sup> The Act defines a 'disabled child' in the same way as does the CA 1989 and the services that it can provide include respite care, personal assistance, travel support, care within the child's home and in the community and so on.

### **The duty to assess under the 1970 and 1989 Acts**

- 4.07 Children's social services authorities have a duty to undertake assessments to decide if a disabled child is eligible for support under the 1989 Act.<sup>38</sup> Where a disabled child may have special educational needs, the Children and Families Act 2014<sup>39</sup> reinforces this obligation to assess their social care needs. The duty to undertake an assessment of a disabled child's needs under the 1970 Act arises in the same way as under the 1989 Act but it is triggered by a request by the disabled child or anyone who cares for them.<sup>40</sup>
- 4.08 Although an assessment of a disabled child's needs will not always give rise to a duty to meet their social care needs – it does require authorities to make a rational decision as to what, if any, support is necessary and appropriate.<sup>41</sup> This means – for example – that authorities cannot fetter this duty by having blanket exclusions as to what support can and can't be provided.<sup>42</sup>
- 4.09 The making of a rational decision as to whether a particular disabled child has a need for support under the 1970 or 1989 Acts requires that authorities have regard to some independent scale of eligibility: a scale that explains to the authority's staff which needs they should prioritise when deciding what support should be provided.
- 4.10 For adults 'in need' in England these eligibility criteria are detailed in regulations<sup>43</sup> but this is not the case for disabled children. This means that every children's social services authority must have its own criteria. The law however requires that every such authority must publish details of its criteria – by which it determines what 'must be satisfied before any provision or service' can be provided.<sup>44</sup> This information has to be made available as part of its 'local offer' obligations<sup>45</sup> – i.e. the range of support services it provides to meet its obligations to children who are disabled and / or who have special educational needs.

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<sup>37</sup> See generally S Broach and L Clements *Disabled children a legal handbook* 3<sup>rd</sup> edition Legal Action Group (2020) paras 3.66 – 3.78.

<sup>38</sup> *R (G) v Barnet LBC and others* [2003] UKHL 57; (2003) 6 CCLR 500 and see also *R (AC and SH) v Lambeth* [2017] EWHC 1796 (Admin); (2018) 21 CCL Rep 76.

<sup>39</sup> Children and Families Act 2014 s36 and the SEN and Disability Regulations 2014 regs 3-10.

<sup>40</sup> Disabled Persons (Services, Consultation and Representation) Act 1986 s4 and see Department of Health Circular Guidance LAC (87)6 para 4.

<sup>41</sup> *R (AC and SH) v Lambeth* [2017] EWHC 1796 (Admin); (2018) 21 CCL Rep 76 at [65].

<sup>42</sup> See in this context the report of the local government and social care ombudsman on complaint no 17 011 899 Poole Borough Council 26 October 2018.

<sup>43</sup> The Care and Support (Eligibility Criteria) Regulations 2015 SI No 313.

<sup>44</sup> The Special Educational Needs and Disability Regulations 2014 SI 1530 reg 53 and Schedule 2 para 18.

<sup>45</sup> Children and Families Act 2014 s30.

- 4.11 Concern has been expressed about the adequacy of the ‘local offer’ and the publication obligation that underpins it, including the observation of the House of Commons Education Committee in October 2019 that:<sup>46</sup>

The local offer’s aims and intentions appear to have moved away from the initial intentions, and in some cases have become unusable and useless ....

### **Relevant social security case law**

- 4.12 As has been noted above (see para 3.09), a number of local authorities have adopted eligibility policies that restrict autistic children’s right to disabled children’s services to those children who have had a formal ‘diagnosis’ of the condition.
- 4.13 In this context the case law concerning the interpretation of the word ‘disabled’ for the purposes of the Social Security Contributions and Benefits Act 1992<sup>47</sup> is of direct relevance.
- 4.14 In social security decision R(DLA) 3/06<sup>48</sup> a Tribunal of Commissioners held that ‘disability’ was conceptually distinct from ‘medical condition’ and that (para 35):

Disability is entirely concerned with a deficiency in functional ability, i.e. the physical and mental power to do things. Of course, a diagnosable medical condition may give rise to a disability. For example, a condition that inevitably involves the loss of a sense or a limb would give rise to an obvious diminution in functional capacity. But entitlement to DLA is dependent upon a claimant’s inability to cope with care and mobility without assistance and with his consequent reasonable care and mobility needs; and not upon the diagnosis of any medical condition.

- 4.15 The Tribunal accepted (para 37) the argument that had there been an intention to require proof of a diagnosed or diagnosable medical condition, then Parliament would have made this clear. The same logic would appear to apply to the wording used by Parliament when enacting the Chronically Sick and Disabled Persons Act 1970 and the Children Act 1989.<sup>49</sup>
- 4.16 The R(DLA) 3/06 finding was cited with approval in the Three-Judge Panel decision of *KM (on behalf of ZM) v Secretary of State for Work and Pensions* which held that the test (for social security purposes) was whether (para 18):

a claimant is disabled physically or mentally, it is whether the extent of the disablement is such that the claimant reasonably requires assistance with a bodily function which is fundamental, not the existence of a diagnosis.

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<sup>46</sup> House of Commons Education Committee ‘Special educational needs and disabilities’ HC 20 (House of Commons 2019) p.5

<sup>47</sup> Ss 72 and 73(1)(d) of the 1992 Act confer entitlement to disability living allowance care component / lower rate mobility component on a person who is “so severely disabled physically or mentally” that certain consequences follow (para 2 of judgment).

<sup>48</sup> (Tribunal of Commissioners) 29.4.05 Issue No. 6 [June 2006] 109 1.

<sup>49</sup> And aligning the CSDPA 1970 definition of a ‘disabled child’ to the 1989 Act.

## **The Equality Act 2010**

4.17 The Equality Act 2010 makes it unlawful to discriminate 'because of' a range of protected characteristics, including disability. Section 6 of the Act provides:

- (1) A person (P) has a disability if –
  - (a) P has a physical or mental impairment, and
  - (b) the impairment has a substantial and long-term adverse effect on P's ability to carry out normal day-to-day activities.

4.18 A 'mental impairment' includes Asperger's syndrome and autism.<sup>50</sup> An impairment is generally understood to be 'long term' if it is likely to last more than 12 months<sup>51</sup> and 'substantial adverse effect' is 'something which is more than a minor or trivial effect'.<sup>52</sup> Whether an individual meets this definition is decided on a case-by-case basis, but it would appear reasonable to presume that a young person with autism, whose care and support needs arising from their autism - are brought to the attention of a local authority, as they will be experiencing a substantial adverse effect as a result of their 'impairment'.

## **Direct Discrimination and the Equality Act**

4.19 Direct discrimination occurs when a person is treated less favourably than others because of a protected characteristic.<sup>53</sup> Direct discrimination applies to all protected characteristics and subject to certain exceptions, cannot be justified.

4.20 In the context of this research, the two relevant questions (which will be analysed further in section 5 below<sup>54</sup>) are:

1. whether there is less favourable treatment? and if so
2. is this treatment because of disability?

4.21 The 2010 Act makes clear that segregating people because of their race is, in itself, less favourable treatment.<sup>55</sup> Segregating disabled people can also amount to direct discrimination – but in such a case the Equality and Human Rights Commission considers that it is necessary to show that it also amounts to less favourable treatment.<sup>56</sup>

## **Indirect Discrimination and the Equality Act**

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<sup>50</sup> See for example *C & C v The Governing Body of a School and others* (SEN) [2018] UKUT 269 (AAC); Equality and Human Rights Commission What equality law means for you as an education provider – further and higher education (EHRC 2014) p.54 and John Wadham, David Ruebain, Anthony Robinson and Susie Uppal *Blackstone's Guide to the Equality Act 2010* (OUP 2016) p.15.

<sup>51</sup> Equality Act 2010 Sch 1 para 22(1).

<sup>52</sup> Equality Act 2010 s212(1).

<sup>53</sup> Equality Act 2010 s13(1).

<sup>54</sup> See para 5.01.

<sup>55</sup> Equality Act 2010 s13(5).

<sup>56</sup> Equality and Human Rights Commission *Services, public functions and associations Statutory Code of Practice* (Stationery Office 2011) para 4.10.

- 4.22 Indirect discrimination arises when an apparently neutral provision, criterion or practice (PCP) applied by (for example) a public body to people with autism, puts individuals with a particular protected characteristic (e.g. disability or sex) at a disadvantage compared with others.
- 4.23 A key difference between direct and indirect discrimination is that indirect discrimination is capable of being justified if it is a 'proportionate means of achieving a legitimate aim'.
- 4.24 Thus, in the context of this research, the relevant questions (which will be analysed further in section 5 below<sup>57</sup>) would appear to be:
- 4.25 Is the PCP that makes it more difficult for a person with autism to access support:
1. a 'neutral' policy applied to everyone; and if so –
  2. does it put people with a protected characteristic (e.g. disabled people who are autistic<sup>58</sup>) at a disadvantage compared with other people who do not share that characteristic (i.e. disabled people who are not autistic); and if so –
  3. can the public body justify this on the basis that it is a 'proportionate means of achieving a legitimate aim'?

### **Public Sector Equality Duty**

- 4.26 The Equality Act 2010 s149 contains what is referred to as the public sector equality duty. This requires public authorities to have (among other things) 'due regard to the need' to eliminate discrimination, to advance equality of opportunity between children with autism and children with other disabilities or who are not disabled.<sup>59</sup>
- 4.27 A local authority will need to be able to demonstrate that it met this duty when it developed its policies on assessing the care needs of disabled children and when it applies that policy. The Courts have set out a set of principles<sup>60</sup> on how the duty is to be met. Technical Guidance from the Equality and Human Rights Commission<sup>61</sup> summarises these principles under the following headings:
- knowledge of the duty
  - timeliness
  - real consideration
  - sufficient information
  - non-delegable

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<sup>57</sup> See para 5.01.

<sup>58</sup> As the Equality and Human Rights Commission (EHRC) explains 'It is important to be clear which protected characteristic is relevant. In the case of disability, this would not be disabled people as a whole but people with a particular disability – for example, with an equivalent visual impairment' – see EHRC *Services, public functions and associations Statutory Code of Practice* (Stationery Office 2011) para 5.17.

<sup>59</sup> S.149.

<sup>60</sup> See for example, *R (Brown) v Secretary of State for Work and Pensions* [2008] EWHC 3158 (Admin) at [84]–[96].

<sup>61</sup> Equality and Human Rights Commission *Technical Guidance on the Public Sector Equality Duty: England* (EHRC 2014).

- review, and
  - evidence of consideration
- 4.28 The Technical Guidance addresses the use of criteria to guide decision making in individual cases. It explains that the use of criteria does not remove the responsibility of the decision-maker to have due regard when making individual decisions, especially where they have discretion when doing so.
- 4.29 If there is evidence that decisions taken in accordance with the criteria ‘will have a detrimental impact upon or be disadvantageous to’ those protected under the Equality Act 2010, the Technical Guidance states that ‘the body will need to consider whether to review the policy’.<sup>62</sup>

### **The Human Rights Act 1998, international human rights standards and non-discrimination**

- 4.30 This preliminary report focuses on the extent to which ‘autism plus’ local authority eligibility criteria are lawful for the purposes of English social care and UK equality legislation. It should be noted however that such policies must also be lawful for the purposes of the Human Rights Act 1998, and that when domestic courts are called upon to interpret provisions in this Act and the Equality Act 2010, they can (where there is ambiguity) consider the provisions (and case law) of other international human rights conventions and covenants such as the UN Convention on the Rights of Persons with Disabilities.<sup>63</sup>
- 4.31 In the context of the Human Rights Act 1998, Article 14 of the European Convention on Human Rights (ECHR) prohibits discrimination in relation to any of the Convention’s substantive rights<sup>64</sup> including on the ‘status’ of disability. Where a difference in treatment in relation to a Convention right on the basis of a ‘status’ (such as a person’s disability<sup>65</sup>) engages Article 14, the onus is on the state to advance cogent reasons to justify the discriminatory treatment: that it pursues a legitimate aim; is proportionate; and is within the state’s margin of appreciation.
- 4.32 The European Committee of Social Rights in its decision on the *Autism Europe v France* complaint<sup>66</sup> which concerned (among other provisions) Article E of the

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<sup>62</sup> Paras 5.46 – 5.50.

<sup>63</sup> See for example *Burnip v Birmingham City Council* and *Gorry v Wiltshire CC* [2012] EWCA Civ 629.

<sup>64</sup> For example Article 8 the right to respect for private and family life, home and correspondence. In this context Commissioner Bratza (as he then was) observed in *Botta v Italy* (1998) 26 EHRR 241 that the Convention places a duty on States to take action to ‘the greatest extent feasible to ensure that [disabled people] have access to essential economic and social activities and to an appropriate range of recreational and cultural activities’ to ensure that their lives are not ‘so circumscribed and so isolated as to be deprived of the possibility of developing [their] personality’: such compensatory measures, as Judge Greve has observed, are fundamental to a disabled person’s rights (*Price v. UK* (2001) 34 EHRR 1285 para. 30).

<sup>65</sup> *Glor v. Switzerland* Applic No. 13444/04 30<sup>th</sup> April 2009.

<sup>66</sup> Complaint No. 13/2002 (7 November 2003).

European Social Charter,<sup>67</sup> noted that this provision was almost identical to the wording of Article 14 of the ECHR and that (para 52):

.... As the European Court of Human Rights has repeatedly stressed in interpreting Article 14 ... the principle of equality that is reflected therein means treating equals equally and unequals unequally<sup>68</sup> ... [and that the prohibition of discrimination applies also to] ... all forms of indirect discrimination. Such indirect discrimination may arise by failing to take due and positive account of all relevant differences or by failing to take adequate steps to ensure that the rights and collective advantages that are open to all are genuinely accessible by and to all.

- 4.33 The Committee further emphasised (at para 48) that the European Social Charter Article 15<sup>69</sup> applied to ‘all persons with disabilities regardless of the nature and origin of their disability and irrespective of their age’, and that (at para 49) Article 17<sup>70</sup> was predicated on the need to ensure that children and young persons grew up ‘in an environment which encourages the ‘full development of their personality and of their physical and mental capacities’.<sup>71</sup>

### **Relevant UN Human Rights provisions**

- 4.34 The United Nations has separately expressed concern about the discriminatory treatment experienced by people with autism. In 2015,<sup>72</sup> the Special Rapporteurs on the rights of persons with disabilities and on the right to health, referred to the widespread ‘discrimination against autistic children and adults’ and to their lack of access to support services ‘on an equal basis with others’.

### ***UN Convention on the Rights of Persons with Disabilities***

- 4.35 The UN Committee on the Rights of Persons with Disabilities (the ‘CRPD Committee’), has also expressed concern about the adverse treatment of young people with autism in the context of equal access to (and participation in) education,<sup>73</sup> and stressed that equality under the law, requires states to take positive action to facilitate the enjoyment by persons with disabilities on an equal basis of the rights guaranteed under legislation.<sup>74</sup> In 2018, the Committee

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<sup>67</sup> Part V Article E – the non-discrimination provision of the Charter.

<sup>68</sup> Citing *Thlimmenos c. Greece* [GC], no 34369/97, CEDH 2000-IV, § 44.

<sup>69</sup> The right of disabled people to community living: similar in terms to the right to independent living in Article 9 UN Convention on the Rights of Persons with Disabilities.

<sup>70</sup> The right of children and young persons to social, legal and economic protection.

<sup>71</sup> See also the subsequent decision of the Committee (*European Action of the Disabled (AEH) v. France* Complaint No. 81/2012 (4 October 2013) where it was held that the limited funds in the French social budget for the education of children and adolescents with autism constituted a violation of the Charter.

<sup>72</sup> See Office of the High Commissioner on Human Rights Press Statement ‘Discrimination against autistic persons, the rule rather than the exception – UN rights experts’ on World Autism Awareness Day - Thursday 2 April 2015 at <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=15787> accessed 27 January 2020.

<sup>73</sup> General comment No 4 on the right to inclusive education para 35.

<sup>74</sup> General comment No. 6 (2018) on equality and non-discrimination para 16.

highlighted its concern (in the context of an inquiry concerning the situation in Spain<sup>75</sup>) that people with autism spectrum disorders (among other conditions) experienced adverse treatment in relation to access to education and other opportunities (para 46).

4.36 Analysis of the 94 concluding observations made by the CRPD Committee (prior to 2020), revealed that in 13 country reports the Committee expressed its concern about the disparate treatment of people with autism over a range of CRPD rights. For example it has expressed concern about:

- the absence of protection for girls with autism in relation to intersectional forms of discrimination (Nepal 2018);
- the lack of progress in implementing accessibility measures for (among others) persons with autism (Spain 2019);
- the lack of access to early intervention services for children with autism (Croatia 2011, para 39).
- the lack of services for families that have members with disabilities, particularly persons with autistic spectrum disorders, with the consequence that this 'places an undue burden on families, especially single female-headed families, increasing their risk of poverty and social exclusion' (Moldova 2017).

4.37 The CRPD Committee has made many statements in its country reports of relevance to this research, including expressions of concerns about:

- the failure of domestic legal systems to protect all persons with disabilities;<sup>76</sup>
- legal systems adopting a medicalised approach to definitions of disability;<sup>77</sup>
- the importance of providing 'all children with disabilities, regardless of their impairment, with sufficient early childhood intervention and development services';<sup>78</sup> and
- the failure of states to allocate sufficient financial resources to ensure the inclusion of all children with disabilities in basic public services and support.<sup>79</sup>

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<sup>75</sup> UN Committee on the Rights of Persons with Disabilities *Inquiry concerning Spain carried out by the Committee under article 6 of the Optional Protocol to the Convention: 18th session 2017* (2018) RPD/C/18/R.4.

<sup>76</sup> See for example the reports concerning Spain (2011); New Zealand (2014 para 18); Germany (2015); and Canada (2017).

<sup>77</sup> See for example reports concerning Korea (2014 para 8); Portugal (2016); Latvia (2017); and Croatia 2011.

<sup>78</sup> Montenegro (2017) and see also Korea (2014) which refers to the need for 'welfare services and personal assistance be extended to all persons with disabilities' (at para 9).

<sup>79</sup> See for example the report concerning India (2019).

## **5. Analysis of findings and the law**

### **‘Autism plus’ policies for assessment and support under the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970**

- 5.01 As noted in chapter 3 many local authority policies single out disabled children with autism for different treatment – stating that they will only be assessed as disabled children if they have (for example) a diagnosis, a severe learning disability, or severe challenging behaviour (see para 3.09 above).
- 5.02 From the data set out above it appears that there are various possible consequences to such a policy, including:
- It may result in an autistic child who is a disabled child for the purposes of the 1970 and 1989 Acts, not receiving support as a disabled child and thereby the policy being unlawful for the purposes of these two Acts.
  - It may result in disabled children with autism being provided with an assessment and / or support of a different nature or quality to other children entitled to support under the 1970 and 1989 Acts. The child could, for example, be assessed by a social worker who lacks experience as to: how a disabled child should be assessed for the purposes of the two Acts; what constitute lawful and unlawful eligibility criteria for the purposes of accessing the support entitlements of disabled children under these Acts; and what duties and powers are owed to disabled children under these two Acts.
  - It may result in disabled children and young people with autism not being assessed under the 1970 and 1989 Acts at all.

### **Diagnosis as a requirement for assessment and support**

- 5.03 As noted in chapter 3 above, a number of the local authority policies require that children with autism have a formal diagnosis of autism before they can be assessed as disabled children for the purposes of the 1970 and 1989 Acts. This is a policy that does not apply to any other impairments or conditions and ‘diagnosis’ is not a requirement of either Act (see para 4.15 above). Policies of this nature, not only insert an additional (unlawful) non-statutory condition that disabled children with autism have to satisfy before they can access their statutory rights under these Acts. They are also unlawful in themselves as both the 1970 and 1989 Acts have non-medical ‘disability’ focused definitions.

### **Direct discrimination**

- 5.04 Although, as noted below (para 5.07), there appears to be little doubt that ‘autism plus’ policies of the kind considered in this report constitute unlawful indirect discrimination. It is at least arguable that they also constitute direct discrimination on the ground of disability.

- 5.05 Put simply: the label of ‘autism’ is used to separate and limit entitlement to an assessment and to appropriate support. Through the application of this policy all people with autism (including all those who come within the ambit of the Equality Act 2010 section 6) - are the subject of direct discrimination. For them there is a clear indication by the authority of restricted entitlement: an indication that is not applied to any other condition.
- 5.06 The research evidence suggests that in a number of local authority areas all children and disabled young people with autism are experiencing less favourable treatment in many ways, including:
- the requirement (not applied to other disabled people) of a clinical diagnosis and / or the presence of another impairment such as a severe learning disability before an assessment of need will be undertaken;
  - their default diversion into a ‘children in need’ / safeguarding service rather than into their council’s disabled children’s service. Such ‘default segregation’ results in them being treated less favourably - for example: as a consequence of the routine delay in obtaining a diagnosis (para 5.08 below) - as well as receiving services that are less able to meet their needs (see para 1.06). In this context, it has already been noted (see para 4.21 above) that segregation linked disability may constitute direct discrimination where it amounts to less favourable treatment.<sup>80</sup> As noted above, the evidence suggests that policies of this nature do subject disabled children with autism to less favourable treatment.

### **Indirect discrimination**

- 5.07 The research demonstrates that a number of councils have ‘autism plus’ policies. These clearly come within the ambit of being a ‘provision, criterion or practice’ (PCP). These PCPs apply to children with autism many of whom share a protected characteristic namely ‘disability’. The evidence suggests that these PCPs put such disabled children at a ‘particular disadvantage’ compared with those who do not have that characteristic – i.e. disabled children who are not autistic.
- 5.08 The research evidence suggests that many children have substantial difficulty in obtaining a referral for a diagnosis and that even when referred, delay is often a major problem.<sup>81</sup> As already noted (see para 1.03 above), many children with

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<sup>80</sup> Equality and Human Rights Commission *Services, public functions and associations Statutory Code of Practice* (Stationery Office 2011) para 4.10.

<sup>81</sup> See for example British Medical Association *Failing a generation: delays in waiting times from referral to diagnostic assessment for autism spectrum disorder* (BMA 2019) and N Lamb and All Party Parliamentary Group on Autism *The autism diagnosis crisis*. London: All Party Parliamentary Group on Autism (2018) which identified delays in diagnosing autism in children of up to four years in several parts of England – a situation it described as ‘scandalous’.

autism, even if they have a formal diagnosis, don't have 'seriously challenging behaviour' or a learning disability.<sup>82</sup>

- 5.09 The insertion of additional non-statutory barriers that impede access to assessment and support rights under these Acts, is adverse treatment – for which it is difficult to envisage a justification. Available evidence indicates that the provision of early support for children and young people with autism 'can make a massive difference to people's life chances'<sup>83</sup> and that providing appropriate support can save money in the wider public sector. In 2009 the National Audit Office estimated that even a modest increase in the provision of support to people with autism had the potential to save the public purse £67 million per annum.<sup>84</sup>
- 5.10 'Autism plus' policies of this kind amount to indirect discrimination contrary to the Equality Act 2010 on the grounds of disability - for which there appears no reason to believe that it is capable of being justified.

### **Sex discrimination under the Equality Act?**

- 5.11 The requirement for a clinical diagnosis may also have a disproportionate adverse impact on young women. The research evidence suggests that far more young men are diagnosed with autism than young women<sup>85</sup> and there is no clear consensus as to why this may be. It is possibly due to the simple fact that early autism research focussed heavily on young men.<sup>86</sup>
- 5.12 It follows that 'autism plus' policies (that require an autism diagnosis), amount to indirect discrimination contrary to the Equality Act 2010 on the grounds of sex for which there appears no reason to believe that it is capable of being justified.

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<sup>82</sup> It appears that about 40 per cent of persons with a learning disability have an ASD, while about 30 percent of persons with ASD do not have a learning disability - see J L. Matson and M Shoemaker Intellectual disability and its relationship to autism spectrum disorders *Research in Developmental Disabilities* 30 (2009) 1107–1114 at 1110.

<sup>83</sup> N Lamb and All Party Parliamentary Group on Autism *The autism diagnosis crisis*. London: All Party Parliamentary Group on Autism (2018).

<sup>84</sup> National Audit Office Supporting people with autism through adulthood (The Stationery Office 2009) para 4.25 and see also Jo Cox MP House of Commons Hansard Column 59WH 8 March 2016 volume 607 Autism Diagnosis Waiting Times.

<sup>85</sup> See for example S Goldman 'Opinion: Sex, Gender and the Diagnosis of Autism — A Biosocial View of the Male Preponderance' *Research in Autism Spectrum Disorders*. 2013 June; 7(6): 675–679; S Bargiela S et al 'The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype' *Journal of Autism and Developmental Disorders* (2016) 46; and Fombonne E. 'Epidemiology of pervasive developmental disorders'. *Pediatric Research*. 2009;65(6):591–598 which suggested that males were four times more likely to be diagnosed with autism than women.

<sup>86</sup> W Mandy, R Chilvers, and U Chowdhury 'Sex differences in autism spectrum disorder: evidence from a large sample of children and adolescents' *Journal of Autism and Developmental Disorders* (2012) 42(7): 1304–1313.

### **Public Sector Equality Duty (PSED)**

- 5.13 It is not clear from the data available, which (if any) local authorities have considered their public sector equality duty when developing their 'autism plus' policies and / or criteria for assessing the needs of children with autism. Given that the research:

- (1) finds clear evidence 'autism plus' policies place disabled children with autism at a significant disadvantage compared to disabled children without autism;
- (2) that such policies are unlawful for the purposes of the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970; and
- (3) that policies of this nature are likely to have an adverse impact on the public purse.

It is difficult to envisage how any council that had had 'due regard' to its obligations under section 149 of the 2010 Act, when developing its 'autism plus' policy, could have reached a decision that it was nevertheless lawful.

- 5.14 Local authority compliance with their PSED duty when compiling their disabled children's assessment and support eligibility criteria, was not a specific question in the FoI requests (see para 2.01 above). Nevertheless, there appears to be good reason to believe that those authorities who have adopted 'autism plus' policies, have probably failed to have due regard to their obligations under section 149 of the 2010 Act.

## **6. Other issues that emerge from the research**

### **Access**

- 6.01 Inaccessibility is a significant issue to emerge from the research. Despite the legal duty on local authorities to publish their children's services eligibility criteria<sup>87</sup>, many such policies were difficult to access or inaccessible. The research team were unable to locate the eligibility criteria in the case of 23 authorities (15 per cent of English social services authorities). For a further 33 authorities, the criteria found by the research team were problematic (see para 3.04 above). Even for the 93 authorities with intelligible eligibility criteria which could be found, in many cases, the research team had to overcome several barriers and spend considerable periods of time, in order to access the information. In this respect the findings echo the comments made by the of Commons Education Committee cited at para 4.11 above.

### **The 33 'suspect' policies**

- 6.02 As noted above (see para 3.03) the research team were simply unable to identify the relevant criteria of 23 authorities. The criteria for a further 33 authorities were not considered to be 'fit for purpose': essentially incapable of bearing the label 'lawful eligibility criteria'. This finding may go some way to explaining the discrepancy noted in the pilot research by the Disability Law Service (DLS) (see para 1.05 above), between what was stated in a local authority policy and what families actually experienced in practice.
- 6.03 Although this failing is one that might call for further research, the reality is that action has to be taken without delay to address the failings identified in this research. 97 English authorities (65 per cent of the 149 studied) had policies that were either, inaccessible, problematic (at best) or contained unlawful 'autism plus' criteria.

### **Safeguarding**

- 6.04 A factor identified by many families with disabled children who approach local authorities for help, concerns the frequent references to 'safeguarding' in the conversations they have with officers and in the emails and letters they receive.
- 6.05 In part, this problem stems from the shortcomings of the 'Working Together' guidance (noted at para 1.17 above), but it is also perceived by a number of families as 'chilling': feedback from families with whom the Disability Law Service (DLS) and the Cerebra LEaP project have had contact with.

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<sup>87</sup> The Special Educational Needs and Disability Regulations 2014 SI 1530 and Schedule 2 para 18 (see para 4.10 above). The importance of the publication obligation is given additional weight by the requirements of Article 9 of the Convention on the Rights of Persons with Disabilities which provides for the right of disabled people to access (among other things) relevant information.

## **Stereotyping**

- 6.06 A not insignificant question emerges from this study: a question that would benefit from further research. It is simply “Why do local authorities feel able to stereotype and create additional hurdles for disabled children with autism?” It is not unreasonable to assume that there will be equality and diversity officers in all the local authorities that have been shown to have ‘autism plus’ policies; not unreasonable to assume that they have legal departments who are well versed in the requirements and prohibitions in the Equality Act 2010; and not unreasonable to assume that those actually applying these criteria are familiar with their professional codes concerning non-discriminatory practice. Why then has a systemic failure of these proportions been able to occur?

## **Action that needs to be taken**

- 6.07 The systemic failure identified by this research calls for swift action by the local authorities that are children’s social services authorities; the Government, the Equalities and Human Rights Commission and Parliament.
- 6.08 Relevant local authorities must take immediate steps to rectify failings in their eligibility criteria for the assessment and support of disabled children – and to ensure that these are published in a readily accessible form on (at the very least) their local offer web pages.
- 6.09 No reasonable Secretary of State reading this data could fail to take action: (1) to verify the findings; (2) to write to all authorities with ‘autism plus’ policies requiring that these be withdrawn (using his statutory powers to issue ‘Directions’); (3) to issue urgent guidance requiring immediate action by local authorities; and (4) in due course to issue formal guidance as to the content of lawful eligibility criteria – possibly including a template scale of the type issued by the Department of Health for adults in 2002.<sup>88</sup> An alternative (or an addition) to the use of formal guidance would be for the Government to bring forward legislation / regulations to put eligibility criteria on a statutory footing – as has been done for (among others) disabled adults in England<sup>89</sup> and disabled children in Wales.<sup>90</sup>
- 6.10 As with the Secretary of State, the Equalities and Human Rights Commission should take urgent steps to verify the findings and subject there to, to write to all authorities with ‘autism plus’ policies requiring that these be withdrawn (and if this fails - to use its powers to bring about the necessary changes).
- 6.11 **Finally**, Parliament should consider whether the facts disclosed by this report are such as to call for an investigation by a relevant Committee (for example the

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<sup>88</sup> Department of Health *Fair Access to Care Services policy guidance* (2002).

<sup>89</sup> The Care and Support (Eligibility Criteria) Regulations 2015 SI No 313.

<sup>90</sup> The Care and Support (Eligibility) (Wales) Regulations 2015 SI 1578 (W. 187).

Health and Social Care Committee and / or the Women and Equalities Committee).

## 7. Case studies: Matthew, Grace, Jack, Alex, Nicola and Blake

### 7.01 Matthew

“My son, Matthew was diagnosed with autism when he was 4 years old. Our Local Authority’s Children with Disability team refused to assess him because he did not meet their eligibility criteria, and because his IQ had to be lower than 70 which was not on the checklist. The Council did not refer Matthew for an alternative assessment and his needs were completely ignored.

As a mother, I just want my son to have the support services in place that he is entitled to, so that we can best manage his needs. He is isolated as a result of this policy in place, and we as a family do not know how to go on.

The strain on my family has led to all children being put on child in need because of my son’s continuing violent behaviour. Social services are quick to criticise but say they don’t offer respite, or any other solutions. However, if we were with disabled children’s services then maybe we would have much more understanding, support and maybe respite!

I want my family to be successful together, not driven apart. I love my son with all my heart. I just need help to make my family safe and successful”.

**Matthew’s Mother**

### 7.02 Grace<sup>91</sup>



“My daughter Grace who is 15 years old has a diagnosis of Pathological Demand Avoidance which is considered to be part of the autistic spectrum.

I asked the Council for an assessment of her social care needs but was refused because her condition was not even recognised as a disability within their criteria.

Grace has high anxiety and feels extremely isolated.

I have a younger son with autism & a learning disability who too has been refused an assessment.

I feel we have been gravely let down by the system and we have to fight for everything”.

**Grace’s Mother**

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<sup>91</sup> We have permission from families to use their child’s photographs for the purpose of this report.

### 7.03 Jack

When Jack was 8 years old he was refused an assessment by the Children with Disabilities team for his social care needs because he did not meet the eligibility criteria. He is now 12 years old and as well as autism has, ADHD, moderate learning difficulties and severe joint hypermobility.

A number of referrals were made specifically to the disabled children's service by a number of professionals, due to the prevention service and children and families service not being able to meet his needs. He still has not had an assessment by the disabled children's service to determine his level of care because the council have told his parents that this particular team only assess children with profound difficulties. His parents were told that his needs can be met by universal services which involved after school and holiday clubs. The Council also offered Jack's mother information on a parenting group on how to deal with children with challenging behaviour.

Jack requires 1-1 personal care support because of how severe his conditions are. As a result of not having any support at all from the Council, he is socially isolated, and his care needs are left to his parents to cover 24 hours a day, 7 days a week.

"I battled for 4 years and we have been passed from pillar to post, I am physically and mentally exhausted and my own health is now deteriorating".

**Jack's Mother**

### 7.04 Alex



"My son Alex was 5 years old when we requested an assessment for his social care needs. We were told that he did not meet the eligibility criteria for the Children with Disabilities team. He was not even referred to a different team and our case was closed. Not being able to access services such as respite care affected my own mental health as I have been unable to get out of the house without him. We are still fighting for support and feel as if this is never ending battle".

**Alex's Mother**

### 7.05 **Nicola**

“My daughter Nicola was diagnosed with autism when she was 7 years old. She also has selective mutism which is a severe and enduring communication disorder. Nicola is now 9 years old, and we have been battling with the Council to assess her social care needs for the past two years. She has been refused because she does not meet their criteria.

I asked for her to be referred to another team as long as someone had knowledge of autism. I was told that I could have a joint assessment with someone from the children’s disability team, but a referral would need to come from a professional. I sent all the relevant reports but was still told Nicola does not meet their criteria.

Nicola is isolated as a result of the lack of support and does not leave the house unless she goes to special school. As a family, we do not go anywhere, cannot access respite and are unable to properly support our other children.

If the Council looked holistically at us as a family and the dynamics of our family situation, they will see the support that Nicola needs, as well as us. We feel very let down by the Council and feel as if this is a never-ending fight”.

**Nicola’s Mother**

### 7.06. **Blake**



“I started asking for support from the Council when Blake was 2 years old. He is now 5 and we still receive no help despite there being a huge need.

I have no family who are around to help and I also have a second child with unmet needs. I feel that as a family we have been failed by the Council.

The mental stress and general health impact on myself has been massive. My mental state has deteriorated over the years.

Most Councils offer an extra pot of funding each year to assist carers. If I had this, I could use it to help us move to better accommodation or fund activities for Blake to increase his confidence and give myself some breathing space”.

**Blake’s Mother**

## 8. Appendix: Template of Freedom of Information (Fol) request

**From:** Hayley Brewer [...]

**Sent:** 23 April 2019 16:15

**To:** [...]

**Subject:** An FOI Request from the BBC - Autism and Councils

Hi,

I'm emailing to submit the following request under the Freedom of Information Act.

- *Please provide a copy of your policy for dealing with assessments of disabled children by your children with disabilities team. The relevant department will be Children's Services or equivalent.*
- *How do you assess and support children who are autistic but have no other disability? Please provide a copy of any policies you have for assessing and supporting children who are autistic but who have no other disability.*
- *For the financial years (start of April to end of March) 2014-15, 2015-16, 2016-17, 2017-18 and 2018-19, please provide the number of children with autism who have been:*
  - *declined an assessment by your children with disabilities team;*
  - *referred to another team within Children's services for an assessment;*
  - and*
  - *declined any assessment whatsoever in each of the financial years detailed above.*

I understand that under the Act I am entitled to a response within 20 working days of your receipt of this request. Some parts of the request may be easier to answer than others. Should this be the case, I request that you release information as soon as possible.

If my request is denied in whole or in part, I ask that you justify all deletions by reference to specific exemptions of the Act. I will also expect you to release all non-exempt material. I reserve the right to appeal your decision to withhold any information or to charge excessive fees.

If you require any clarification, please contact me in accordance with your duty under Section 16 to provide advice and assistance if you find any aspect of this FOI request problematic.

Please acknowledge receipt of this request by email. I look forward to receiving the information in the near future.

Yours faithfully,

Hayley Brewer

Producer

BBC Yorkshire Impact Team

[...]