

Institutionalising parent carer blame

*The experiences of families with disabled children in their interactions with
English local authority children's services departments*

Authors

Luke Clements and Ana Laura Aiello.

Student researchers:

Elizabeth Adeyemo; Haadiya Akhtar; Olivia Ashcroft; Zsombor Auber; Line Berg; Leah Brough; Sam Sam Chua; Aaron Dcunha; Marianna De Toma; Isobelle Dean; Yasemin Dogan; Madelaine Fazari; Lucy Fletcher; Kiara Giddings; Maame Ama Hammond; Kate Henderson; Chloe Ho; Anthony Howell; Harriet Hudson-Brightmore; Molly Hulme; Allan Huynh; Eva Ihezue; Vasil Ivanov; Ruby Ives; Waleed Jamshid; Oliver Keane; Surriya Khan; Yi Kwan Jocelyn Kwok; Ria Leatham; Jia Ling Lee; Joanna Lim; Lewis Lockwood; Jocelyne Louis; Sana Mahmood; Rohith Mayanatt; Hannah Metcalfe; Mariel Moinjil; Amelia Platon; Alina Pringle; Ellie Pugh; Isobel Reed; Lennart Schiek; Mami Seck; Jalila Tariq; Natasha Waller; Mohamed Wanza; Harry Winkley; Courteney Young.

Special thanks to:

Colleagues who have contributed to the training and support of the student volunteers – namely, Derek Spinks, Beverley Hitchcock, Carys Hughes, Derek Tilley and Sophie Champion (Cerebra); Priya Bahri (Disability Law Service) and Hayley Brewer (BBC), and especial thanks to the parents who provided video / webinar support to the research team. Finally, our thanks to colleagues who have read and provided feedback on earlier drafts of this report.

Expert Proof Reading by Marie Fitzgerald MA.

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.

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.

The LEaP project comprises Cerebra's in-house research team (which provides guidance and signposting information for families) and the research team at the School of Law, Leeds University. The in-house research team listens to families and helps them get the knowledge they need to access health, social care and other support services. Through this continuous contact with families, the LEaP project is able to identify common legal problems that prevent them from gaining access to care and support services and we then seek to 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.

The 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

I am very concerned to hear of the continued problems with the way many Children's Services Departments in England are treating parents for disabled children: a problem that was highlighted in a Disability Law Service report last year.

The current report points to defective Department for Education guidance as a root cause of this problem, which is leading to parents being blamed when they ask for care for their disabled children, instead of receiving the help and support they deserve. I call upon the Education Secretary to address this issue as a matter of urgency.

Edward Davey

A message from

Tracy Elliott, Head of Research and Information, Cerebra

It is of great concern to Cerebra that national and local social care policies in England create a default position that assumes parental failings when assessing the needs of disabled children. It is an approach that ignores the fact that disabled children often have complex medical, educational and social support needs and face many barriers to their participation in society. It places blame within the family, ignoring the wider societal barriers these children, and families, encounter. Assessment should be about helping disabled children to fulfil their greatest potential, to do that assessors must understand the full range of needs and the barriers to participation. They need to work with parents, support them, not blame them.

Tracy Elliot

CONTENTS

| | PAGE |
|---|-------------|
| Key messages | 4 |
| 1. Introduction | 6 |
| 2. The legal and policy context | 10 |
| 3. Research project methodology | 23 |
| 4. Research findings | 25 |
| 5. Analysis of findings in the light of the law and policy | 36 |
| Appendix 1: | |
| Survey questionnaire of parent carer-led support groups | 51 |

Research overview note

Disabled children and their families are one of the most severely disadvantaged groups in the UK (para 1.02).

The research underpinning this report considers – from a legal perspective – the experiences of disabled children and their families of the process by which their needs for care and support are assessed by children’s services authorities in England.

The research involved the analysis of the assessment protocols of 143 English children’s services authorities (para 3.02) and a survey of 92 English parent carer-led support organisations (para 3.04).

Key messages

- National and local social care policies in England create a default position for those assessing disabled children, that assumes parental failings. This approach locates the problems associated with a child’s impairment in the family – a phenomenon referred to in this report as ‘institutionalising parent carer blame’ (para 1.04).
- The national guidance that directs the process by which disabled children are assessed by English children’s services departments ‘Working Together 2018’¹ is not fit for purpose and arguably unlawful. Its focus is on safeguarding children from parental neglect and abuse and fails to address the distinct assessment and support needs of disabled children for whom there is no evidence of neglect or abuse (para 5.23).
- Unlike the national guidance concerning the assessment of disabled adults, ‘Working Together 2018’ contains no requirement that those assessing the needs of disabled children have any expertise or experience in a particular condition, so that the needs of the disabled child are accurately identified (para 5.25).

Of the 143 local authority assessment protocols identified:

- None contained a clear explanation that a different approach should be taken concerning the assessment of the needs of disabled children where the referral was not accompanied by evidence of neglect or abuse;
- 80 per cent required the assessor to confirm if the ‘child’s bedroom has been seen’ (para 4.18) regardless of whether there was any evidence to suspect that the child was being neglected or abused;
- 87 per cent referred to the need of seeing (or communicating with) the children alone (para 4.19) regardless of whether there was any evidence to suspect that the child was being neglected or abused;
- None gave guidance to assessors concerning the need for cogent grounds to exist before seeking to see a child’s bedroom or seeking to interview a child in the absence of their parent.

¹ Department for Education *Working Together to Safeguard Children* (2018).

Policies of this nature interfere with the fundamental rights of families to respect for their private and family lives and their home (para 5.40) and are discriminatory in that they treat disabled people and their families in the same way as people whose circumstances are materially different (para 5.34).

- Local authorities are routinely denying disabled children and their families the right to have their eligibility for statutory support services assessed. Services such as: parent carer's needs assessments, direct payments and long-term support packages including, for example, respite care (para 2.04).
- 86 per cent of the parent carer-led support groups who responded to the research survey (para 4.07) considered the assessment process that parents and their disabled children experienced to be extremely unsatisfactory and intrusive, highlighting:
 - Assessors' lack of training, experience and understanding concerning the disability related challenges that disabled children and their families encountered (para 4.10);
 - The intimidating nature of the assessment process: a process that focussed on safeguarding / child protection matters and parental 'fitness' rather than addressing the additional support needs that resulted from their child's impairment (para 4.11);
 - The intrusive nature of the process, with families reporting that assessment visits could take place with little (or no) notice and that they were often placed in impossible positions. For example, feeling that they had no real choice about whether the assessor inspected their child's bedroom and interviewed their children in their absence (para 4.12).

Urgent action required to address the research findings

- Separate statutory guidance needs to be issued to address the specific needs of disabled children and their families in the assessment, eligibility and care support planning process – as 'Working Together 2018' is not fit for purpose in relation to their needs.
- The new statutory guidance should require that assessments of disabled children and their families be undertaken by assessors who, through training and experience, have the necessary knowledge and skills of the particular condition (such as autism, learning disabilities, sensory impairments mental health needs or other conditions).
- There is a strong case – in the short term at least – for local assessment protocols to be abandoned and replaced by new statutory guidance. In any event, these protocols should cease to apply to disabled children and their families (for which there is no cogent evidence of neglect or abuse).

1. Introduction

- 1.01 This report concerns the way that English children’s services authorities respond to the support needs of disabled children and their families. It is based on research that commenced in 2017 as a result of families making contact with the [Disability Law Service](#) (DLS)² and the [Cerebra LEaP programme](#).³ Many of these families described their interactions with children’s services as profoundly unhelpful, humiliating and intimidating.
- 1.02 Disabled children and their families are one of the most severely disadvantaged groups in the UK.⁴ They are ‘significantly more likely to live under conditions that have been shown to impede development, educational attainment and adjustment to and increase the risk of poor health, additional impairment and social exclusion’.⁵ As Broach *et al* note⁶ ‘on almost every measure of material deprivation, disabled children are more likely than other children to live in households which are unable to afford things that are generally regarded as important and ordinary for children in the twenty first century’.
- 1.03 A 2017 scoping study by the DLS,⁷ found that many disabled children with autism were being denied support by specialist disabled children’s social work teams with materially adverse consequences for them and their families. These findings were tested in broader, more methodologically rigorous research that resulted in a 2020 report published jointly by the DLS and the Cerebra LEaP programme.⁸ The report identified multiple problems with the policies and practices of many English children’s services authorities and identified 41 that had eligibility criteria that were discriminatory.
- 1.04 Throughout the research programme, the LEaP programme has continued to receive reports from families with disabled children concerning their negative interactions with children’s services authorities. Not untypically, these concern parents who have approached their local authority for help in order to address the additional barriers they encounter as a result of their child’s impairment – only to find that (from the outset) they are treated in a manner that suggests to them that they are considered to be neglectful and/or abusive parents. Interactions that convey the strong impression that the default position for children’s services departments in such cases is to locate the problems families

² Disability Law Service is a unique charity that has been providing free legal advice and representation for disabled people since 1975.

³ A research project that combines the expertise of the in-house research team at Cerebra and the research team at the School of Law, Leeds University – see page 1 above.

⁴ See generally S Broach and L Clements *Disabled Children : a legal handbook* (Legal Action 3rd 2020) paras 1.31 – 1.55 for a critical overview of the multiple levels of disadvantage such families experience.

⁵ *Ibid* at para 1.31; see also (for example) Department for Work and Pensions, *Fulfilling potential. Building a deeper understanding of disability in the UK Today*, 2013; and Contact a Family *Counting the Costs* 2014.

⁶ S Broach and L Clements *Disabled Children : a legal handbook* (Legal Action 3rd 2020) para 1.35.

⁷ The findings of the DLS Scoping Study are summarised at paras 1.04 - 1.10 in P Bahri, L Clements, AL Aiello and T Hutchinson *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (Cerebra 2020).

⁸ P Bahri, L Clements, AL Aiello and T Hutchinson *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (Cerebra 2020).

face in parental failings and not in the lack of support that they require in order to overcome the many barriers that confront them as a consequence of their child's impairment. This approach is referred to as a 'parent carer blame' policy in this report.

- 1.05 As this report demonstrates, it is an approach mandated by key Central Government statutory guidance,⁹ embedded in core local authority practice by their assessment protocols and most probably reinforced by the auditing regime by which authorities are judged.
- 1.06 Parents describe the power imbalance that exists in such cases; the fear that they are being 'judged'; the fear that resistance to assessor 'requests' risks being treated as evidence of parental awkwardness – as of the parent having something to hide.
- 1.07 Parents describe how social work visits may take place with little notice (and occasionally unannounced) and at inconvenient times (for example by occurring early in the morning or by conflicting with school runs or dental appointments).¹⁰ Assessors would state that they were required to interview each of the family's children alone and that they were required to inspect the child's bedroom.
- 1.08 The research underpinning this report has sought to identify the nature and prevalence of these experiences through a more extensive and systematic investigation and the reasons why authorities require their assessors to act in this way.
- 1.09 This report analyses these interactions and experiences through the lens of the law. Human rights law requires, for example, that States deal differently with people whose situations are different and that States show respect for people's private and family lives and for their homes; that States ensure that their agents are fully aware of the seriousness of acting in a way that improperly interferes with these fundamental civil and political rights.
- 1.10 During the research programme, we have come to understand that concerns about inappropriate action of this kind are not isolated. They have been raised on many occasions by many individuals and organisations, including in two official studies published shortly before the release of this report.
- 1.11 The first, a 2021 Department of Health and Social Care report compiled by the Chief Social Workers for Adults and the Chief Social Worker for Children and Families,¹¹ noted (among other things):
 - Even where the sole reason for contact with children's social care was because of the social care needs of an autistic child, there was a tendency to use the social work assessment as an opportunity to judge parenting capacity through a child protection lens rather than through a lens of social care need. This has long been a complaint of families caring for disabled children.

⁹ HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (HM Government 2018).

¹⁰ See for example Local Government and Social Care Ombudsman report on complaint [no 20 007 812 against Wiltshire Council](#), 17 May 2021 which concerns action of this kind.

¹¹ Chief Social Workers for Adults and the Chief Social Worker for Children and Families *A spectrum of opportunity: an exploratory study of social work practice with autistic young adults and their families* (Department of Health and Social Care 2021).

- We were also particularly troubled by reports we received from families who had been brought into the child protection process because of disagreements with practitioners about how their child's behaviour could best be managed within the home setting ... this is a repeated concern that we hear from parents and carers outside of this study in the course of our ongoing communications with families over the years both in our roles as Chief Social Workers and during our many years in practice leadership roles.
- Fear of being labelled a bad parent or concerns about being blamed for failing as a parent may limit a family's willingness to seek help.

1.12 The second, an independent review of children's social care¹² (referred to below as the 'MacAlister review') commissioned by the Secretary of State for Education, in 2021 that noted (among other things):

- that 'a consistent theme in what the review has heard' was that families with disabled children felt 'that they are navigating a system that is set up for child protection, not support' (page 29);
- that review had heard 'from care-experienced parents who describe the undignified position of being subject to child protection investigations if they seek help, which in turn stops them asking for the support they need' (page 30); and
- that 'the system appears to be disproportionately spent on assessing and investigating families instead of providing support' (page 30).

1.13 There are, as this report records, families with disabled children who get excellent support from their children's services department. The research findings suggest, however, that these are generally where the families have been allocated an assessor, who has both the expertise and practice experience of supporting the specific needs of disabled children and their families. These also have the power to sign off / authorise the provision of care and support services that can materially improve their lives.

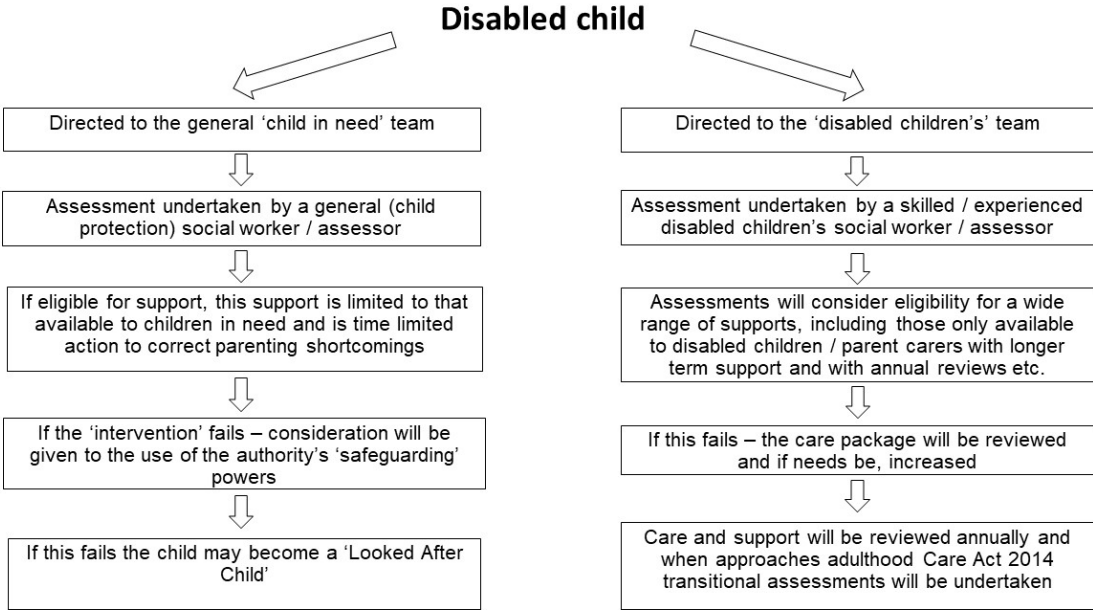
1.14 Disabled children who do not benefit from such support are (as this research suggests), generally assigned to generic assessors who lack disability expertise and are located in 'children in need' teams. Their terms of reference only permit them to provide, at best, short term support: support frequently focused on addressing perceived parental failings. Disabled children and their families who are directed down the 'children in need' assessment route (as opposed to the 'disabled children's' assessment and care planning route), also find themselves denied the possibility of support such as direct payments, longer-term respite / replacement care,¹³ parent carer needs assessments and other statutory support services. The net effect of this disparate treatment is that many families find themselves at a mental, emotional, physical, sleep deprived and financial breaking point – and it is only once they reach 'crisis point' (as the 'MacAlister review' notes), that support is offered.¹⁴ The graphic

¹² An independent review of children's social care (chaired by Josh MacAlister) *The Case for change* (2021) [announced by the Secretary of State for Education](#) on the 15th January 2021.

¹³ See for example, complaint no 17 011 899 Poole Borough Council 26 October 2018.

¹⁴ An independent review of children's social care (chaired by Josh MacAlister) *The Case for change* (2021) p.29 – see para 1.12 above.

below illustrates these two distinct assessment routes and their common consequences:



Graphic 1

1.15 This report is structured as follows. Chapter 2 considers the legal and policy context – including the domestic legal context (the Children Act 1989 and the Human Rights Act 1998 for example). The policy context, highlighting the way that councils have developed complex screening matrixes that conflict with their legal obligations - and relevant international Human Rights standards. Chapter 3 addresses the research project methodology (explaining the quantitative and qualitative methods employed). Chapter 4 presents the research findings, primarily resulting from: (a) a survey of parent carer-led support organisations; (b) the identification of local authority assessment protocols; and (c) discussions held by parents and carers on social media. Chapter 5 provides an analysis of the findings together with suggestions for action that needs to be taken. Appendix 1 contains a copy of the survey questionnaire that parent carer-led support organisations were invited to complete.

2. The Legal and Policy Context

Introduction

2.01 This section of the report sets out the key duties that English children's services authorities owe to disabled children and their families – with principal focus on the duties under the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970. In analysing how these duties should be discharged, it further considers the obligations created by the Human Rights Act 1998, international treaties which the UK has ratified and the key policy guidance issued by HM Government, 'Working Together to Safeguard Children' (2018)¹⁵ - referred to in this report as 'Working Together 2018'.

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

2.02 The Children Act (CA) 1989 s17(1) places a duty on English children's services authorities 'to safeguard and promote the welfare of children within their area who are in need' and to do so 'by providing a range and level of services appropriate to those children's needs'.

2.03 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.

2.04 Although the Act defines a broad range of children as 'children in need', it places additional duties on authorities in relation to the needs of disabled children and their families. Families with disabled children are, for example, entitled to receive support by way of 'direct payments'.¹⁶ Local authorities are under a duty to assess the support needs of parents of disabled children and to identify the extent to which there are parent carers within their area who have needs for support.¹⁷ Local authorities are under a duty to provide a range of services designed to minimise the effect on disabled children of their disabilities, to enable them to have the opportunity to lead lives which are as normal as possible and to provide their carers with 'breaks from caring';¹⁸ and so on.

¹⁵ HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (July 2018).

¹⁶ Children Act 1989 section 17A.

¹⁷ Children Act 1989 section 17ZD.

¹⁸ Children Act 1989 Schedule 2 Part 1 para 6.

2.05 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 permanently¹⁹ 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.

2.06 The definition of a ‘disabled child’ 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’.

2.07 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.²⁰ The Act defines a ‘disabled child’ in the same way as does the CA 1989 and the services that are mandated by the Act include practical assistance in the home (e.g. respite care), community based services, travel support and so on. The relationship between the 1970 Act and the CA 1989 has its complexities, but – put simply – when a children’s services authority determines that it is necessary to provide support under the 1970 Act, it is deemed at law to be providing this support under section 17 of the 1989 Act.

The duty to assess for disability specific support services under the 1989 and 1970 Acts

2.08 Children’s services authorities have a duty to undertake assessments to decide if a disabled child is eligible for support under the 1989²¹ and 1970²² Acts. Where a disabled child may have special educational needs, the Children and Families Act 2014²³ reinforces this obligation to assess their social care needs.

2.09 Although an assessment of a disabled child’s needs will not always give rise to a duty to meet their social care needs – authorities are obliged to make rational decisions as to what, if any, support is necessary and appropriate.²⁴ This means that they must focus on the child’s and their family’s specific impairment related needs. It follows that authorities cannot, for example, develop policies that deny disabled children (i.e. children who come within the definition provided by section 17(11) of the 1989 Act) their rights to be assessed for the disability specific support services detailed under the 1989 and 1970 Acts.

¹⁹ The requirement that a child’s impairment be substantial and permanent does not apply to children who ‘suffer’ from a mental disorder.

²⁰ See generally S Broach and L Clements *Disabled children a legal handbook* 3rd edition Legal Action Group (2020) paras 3.66 – 3.78.

²¹ *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.

²² Disabled Persons (Services, Consultation and Representation) Act 1986 s4 and see Department of Health Circular Guidance LAC (87)6 para 4.

²³ Children and Families Act 2014 s36 and the SEN and Disability Regulations 2014 regs 3-10.

²⁴ *R (AC and SH) v Lambeth* [2017] EWHC 1796 (Admin); (2018) 21 CCL Rep 76 at [65].

Policies of this kind would amount to an unlawful fettering of their statutory duties.²⁵

Local authority duty to assess under CA 1989 s47

- 2.10 Children's services authorities have extensive powers and duties to intervene in the lives of families, where they have reasonable cause to suspect that a child is suffering, or is likely to suffer significant harm. The basic duty in this respect is found in section 47 of the 1989 Act – the 'duty to investigate'. Where an authority has 'reasonable cause' to suspect that harm of this kind may be occurring, it is under a duty to ensure that enquiries are made to enable it to decide whether any action to safeguard or promote the child's welfare needs to be taken.
- 2.11 The statutory guidance 'Working Together 2018' details the actual procedures to be followed when taking action to safeguard children from harm. This guidance emphasises that social workers should lead section 47 assessments with support from the police, health practitioners, teachers, school staff and other relevant practitioners in undertaking relevant enquiries.²⁶ The general safeguarding principles in the statutory guidance are also supplemented by specific practice guidance concerning disabled children.²⁷

CA 1989 duties to parent (and other family) carers

- 2.12 Where a children's services authority is aware of a parent providing care for a disabled child within its area, who may have needs for support, then CA 1989 s17ZD places a duty on that authority to assess the nature and extent of these support needs. For the purposes of section 17ZD, a parent carer 'means a person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility' (s17ZD(2)).
- 2.13 'Parent carer needs assessments' (PCNAs) also feed into the strategic duty on children's services authorities to 'take reasonable steps to identify the extent to which there are parent carers within their area who have needs for support' (under s17ZD(14)).
- 2.14 Where a carer is providing (or intending to provide) substantial and regular unpaid care for a disabled child, the Carers (Recognition and Services) Act 1995 s1(2) places a duty on children's services authorities (when so requested) to assess the carer's ability to provide and to continue to provide care. The

²⁵ 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.

²⁶ The Statutory Guidance HM Government *Working Together to Safeguard Children* (HM Government 2018) Chapter 1 para 85 'Initiating section 47 enquiries' [the iteration of this on-line guidance as at the 1st May 2021].

²⁷ Department for Children, Schools and Families *Safeguarding disabled children – Practice Guidance* (DCSF 2009): para 1.11 explains that it is 'supplementary to, and should be used in conjunction with, the Government's statutory guidance Working Together to Safeguard Children' and para 1.12, that it is 'intended to provide a framework within which Local Safeguarding Children Boards, agencies and professionals at local level – individually and jointly – draw up and agree detailed ways of working together to safeguard disabled children'.

duty is of relevance since it applies to all such carers – regardless of whether they have parental responsibility for the child in question.

Policy and practice guidance

- 2.15 Regulations, statutory guidance²⁸ and practice guidance issued by Central Government, fulfil a vital role in determining the way in which the care and support needs of disabled people and unpaid carers are assessed and – if deemed eligible for support – how their care and support needs are met. In relation to disabled adults and carers, for example, assessment regulations²⁹ and extensive statutory guidance³⁰ have been issued.
- 2.16 In 2009, when referring to the importance of guidance concerning the determination of eligibility for disabled children’s social care services in *R (JL) v Islington LBC*³¹ Black J (as she then was) observed:

Without question, the use of eligibility criteria in determining provision for children is a very complex area. It is not possible in a judgment of this type to provide comprehensive guidance for local authorities generally as to when, precisely, it is acceptable to use eligibility criteria and as to the form they should take. The FACS guidance³² seeks to fulfil that role in relation to adult services and there is no doubt that there is a pressing need for guidance in relation to children’s services.

Since that time, no such ‘comprehensive guidance’ has been issued.

2000 policy and practice guidance

- 2.17 In 2000 detailed statutory guidance was published by the Department of Health concerning the principles to be followed when local authorities assessed the needs of disabled children and their families for the support that they required under the 1989 and 1970 Acts³³ (referred to in the following pages as the ‘2000 policy guidance’) emphasised a number of key principles of direct relevance to the ‘equality’ obligations on public bodies concerning the provision of care and support for children in need and their families, including:

Ensuring Equality of Opportunity

1.42 The Children Act 1989 is built on the premise that ‘children and young people and their parents should all be considered as individuals with particular needs and potentialities’ ... that differences in bringing up children due to family structures, religion, culture and ethnic origins should be respected and understood and that

²⁸ Sometimes referred to as ‘binding guidance’ and in the context of this report, it is guidance issued under section 7 Local Authority Social Services Act 1970, (and often other statutory provisions – for example Children Act 2004 s16).

²⁹ The Care and Support (Assessment) Regulations 2014 SI No. 2827.

³⁰ Department of Health and Social Care *Statutory guidance: Care and support statutory guidance* (at the time of publication the current iteration being that at 21 April 2021).

³¹ [2009] EWHC 458 (Admin) at [125].

³² ‘Fair Access to Care Services’ which comprised statutory guidance – Department of Health *Fair Access to Care Services Guidance on Eligibility Criteria for Adult Social Care* LAC (2002)¹³ and practice guidance – Department of Health *Fair Access to Care Services Practice Guidance* (2003).

³³ Department of Health *Framework for the Assessment of Children in Need and their Families* (The Stationery Office 2000).

those children with 'specific social needs arising out of disability or a health condition' have their assessed needs met and reviewed Ensuring that all children who are assessed as in need have the opportunity to achieve optimal development, according to their circumstances and age, is an important principle. Furthermore, since discrimination of all kinds is an everyday reality in many children's lives, every effort must be made to ensure that agencies' responses do not reflect or reinforce that experience and indeed, should counteract it. Some vulnerable children may have been particularly disadvantaged in their access to important opportunities, such as those who have suffered multiple family disruptions or prolonged maltreatment by abuse or neglect and are subsequently looked [after] by the local authority. Their health and educational needs will require particular attention in order to optimise their long term outcomes in young adulthood.

1.43 Ensuring equality of opportunity does not mean that all children are treated the same. It does mean understanding and working sensitively and knowledgeably with diversity to identify the particular issues for a child and his/her family, taking account of experiences and family context. This is further elaborated in the chapters in the accompanying practice guidance on working with disabled children and with black children.

2.18 Practice guidance³⁴ accompanied the 2000 policy guidance which contained a 30-page chapter³⁵ that addressed the specific skills required when authorities assessed the needs of disabled children and their families. It made a number of points and in the context of this research, the following extract is particularly apposite:

3.3 In the past, disabled children have often been excluded from or marginalised within mainstream services, and many standard assessment frameworks and approaches have been developed with only non-disabled children in mind. The Children Act 1989 emphasises disabled children are 'children first' and the Assessment Framework is based on this principle of inclusion. However, recognising disabled children as children first does not imply denial of a child's particular needs: 'Ensuring equality of opportunity does not mean that all children are treated the same. It does mean understanding and working sensitively and knowledgeably with diversity'³⁶ ...

3.6 ... While disabled children's basic needs are the same as all children's needs, impairments may create additional needs. Disabled children are also likely to face additional disabling barriers which inhibit or prevent their inclusion in society. The assessment of a disabled child must address the needs of the parent carers. Recognising the needs of parent carers is a core component in agreeing services which will promote the welfare of the disabled child. The main part of this chapter considers the needs and barriers in relation to each of the dimensions of the Assessment Framework.

3.10 This guidance is informed by an understanding of the 'social model' of disability, which uses the term disability not to refer to impairment (functional limitations) but rather to describe the effects of prejudice and discrimination: the social factors which create barriers, deny opportunities, and thereby dis-able people Children's impairments can of course create genuine difficulties in their lives. However, many of the problems faced by disabled children are not caused by

³⁴ Department of Health *Assessing Children in Need and their Families: Practice Guidance* (The Stationery Office 2000).

³⁵ Chapter 3: 'Assessing the needs of disabled children and their families'.

³⁶ Citing the 2000 Assessment Framework para 1.43.

their conditions or impairments, but by societal values, service structures, or adult behaviour ... : a major problem for disabled children is that they live in a society which views childhood impairment as deeply problematic

3.11 Effective assessment of a disabled child must consider: the direct impact of a child's impairment; any disabling barriers that the child faces; and how to overcome such barriers.

'Working Together' guidance

- 2.19 In 2006 the English Government published separate statutory guidance³⁷ entitled 'Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children'. The guidance, as its name implies, had a focus on child protection and was in part a response to the findings of the statutory inquiry into the death of Victoria Climbié (2003).³⁸ The guidance was quite distinct from the assessment guidance in the 2000 Assessment Framework – and stated (at page xv) that the 'Assessment of Children in Need and their Families (2000) should be followed when undertaking assessments on children in need and their families'. The 2006 'Working Together' statutory guidance was updated in 2010³⁹ and this revision (which had the same name as the 2006 guidance) again stated explicitly (at page 15) that the 'Framework for the Assessment of Children in Need and their Families (2000) should be followed when undertaking assessments of children in need and their families'.
- 2.20 In 2013 a much briefer⁴⁰ version of the 'Working Together' statutory guidance was published which not only repealed the 2010 version of 'Working Together' but it also cancelled the 2000 guidance (page 5) and in its place required (at paras 62 – 63) that local authorities and their 'partners, should develop and publish local protocols for assessment'. This requirement continued with the 2015 version of the 'Working Together' guidance⁴¹ and remains in the current iteration of the 2018 'Working Together' guidance⁴² which states:

³⁷ HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (HM Government 2006).

³⁸ This noted at page ix of the guidance – and see also HM Government *Keeping Children Safe – the Government's response to the Victoria Climbié Inquiry Report and Joint Chief Inspectors Report: Safeguarding Children* CM 5861 (The Stationery Office 2003).

³⁹ HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* replaced by *Working Together* (HM Government 2010). The revision was deemed necessary in order to take account of Lord Laming's report, *The Protection of Children in England: A Progress Report*, HC 330 (The Stationery Office 2009) which resulted, in part from another tragedy, the case of 'Baby P'.

⁴⁰ The 2013 Guidance runs to 97 pages compared to the 393 pages of the 2010 'Working Together' guidance: it also repealed the 2000 Assessment Framework which ran to 109 pages and the 2000 practice guidance which ran to 141 pages.

⁴¹ HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (HM Government 2015), at paras 65 – 67.

⁴² HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (HM Government 2018). As at the 1 May 2021, the 2018 on-line guidance has been amended on three occasions, namely: on the 1 August 2018, by correction of a small error in chapter 5, footnote 99; on the 21 February 2019 with the updating 'to reflect how local authorities should notify the Child Safeguarding Panel' and on the 9 December 2020 with 'factual changes in relation to information sharing, homelessness duty and references to

Local protocols for assessment

46. Local authorities, with their partners, should develop and publish local protocols for assessment. A local protocol should set out clear arrangements for how cases will be managed once a child is referred into local authority children's social care and be consistent with the requirements of this statutory guidance. The detail of each protocol will be led by the local authority in discussion and agreement with the safeguarding partners and relevant agencies where appropriate.

47. The local authority is publicly accountable for this protocol and all organisations and agencies have a responsibility to understand their local protocol.

48. The local protocol should reflect where assessments for some children will require particular care. This is especially so for young carers, children with special educational needs (including to inform and be informed by Education, Health and Care Plans), unborn children where there are concerns, children in hospital, children in mental health inpatient settings, children with specific communication needs, asylum seeking children, children considered at risk of gang activity and association with organised crime groups, children at risk of female genital mutilation, children who are in the youth justice system, and children returning home.

49. Where a child has other assessments, it is important that these are co-ordinated so that the child does not become lost between the different organisational procedures. There should be clear procedures for how these organisations and agencies will communicate with the child and family, and the local protocol for assessment should clarify how organisations and agencies and practitioners undertaking assessments and providing services can make contributions.

50. The local protocol for assessment should set out the process for challenge by children and families by publishing the complaints procedures.⁴³

2.21 The principles of assessment in the 2000 Framework and practice guidance (running to 250 pages) have, therefore, been replaced by these 5 paragraphs of guidance: guidance that transferred to local councils responsibility concerning the critical process of assessing the care and support needs of disabled children – not suspected of being neglected or abused.

Early Help

2.22 Working Together 2006⁴⁴ noted that the Laming Inquiry into the death of Victoria Climbié (2003)⁴⁵ 'revealed themes identified by past inquiries which resulted in a failure to intervene early enough'. The 2006 guidance

domestic abuse' and the removal of 'transitional guidance' – see HM Government note at www.gov.uk/government/publications/working-together-to-safeguard-children--2 accessed 1 May 2021.

⁴³ Including as specified under Section 26(3) of the Children Act 1989 and the Children Act 1989 Representations Procedure (England) Regulations 2006.

⁴⁴ HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (2006) para 1.6. and see also HM Government *Keeping Children Safe – the Government's response to the Victoria Climbié Inquiry Report and Joint Chief Inspectors Report: Safeguarding Children* CM 5861 (The Stationery Office 2003).

⁴⁵ Lord Laming *The Victoria Climbié Inquiry Report Of An Inquiry* CM 5730 (Secretary of State for Health and the Secretary of State for the Home Department 2003).

recommended that the ‘need for support needs to be considered at the first sign of difficulties as early support can prevent more serious problems developing’ (para 2.13).

- 2.23 The subsequent Munro Review⁴⁶ of child protection recommended that a duty be placed on local authorities ‘to secure the sufficient provision of local early help services for children, young people and families’.⁴⁷ The 432 pages of the Laming report contains no reference to ‘disabled / disability’ and the Munro Review is also – in effect – silent concerning the needs of disabled children.⁴⁸
- 2.24 The Government in its response to the Munro Review,⁴⁹ proposed a ‘local resourcing of the early help services for children, young people and families’. The response was silent on the needs of disabled children.
- 2.25 Working Together 2013⁵⁰ formalised the position of ‘Early Help’ as a local process by which authorities could ‘prevent needs escalating to a point where intervention would be needed via a statutory assessment’ (para 8). At para 18, the guidance referred to the relevant local interventions as those under sections 17, 47, 31 and 20 of the Children Act 1989. It made no mention of disabled children’s support services under the Chronically Sick and Disabled Persons Act 1970. The essential point to be grasped concerning ‘Early Help’ is that it is a mechanism designed to prevent children who may potentially fall into the neglect / abuse categories detailed in the Children Act 1989 sections 17(10)(a) and 17(10)(b) – from actually falling into one or other of these categories. Early Help cannot be a mechanism relevant to the needs of disabled children (i.e. children who fall within the definition of section 17(10)(c)) since they are already a ‘child in need’ by virtue of being disabled and therefore already entitled to a statutory assessment.⁵¹
- 2.26 Although ‘Working Together 2018’ (paras 35 – 36) now contains a reference to local authority duties under the 1970 Act (and to the rights of parent carers), an analysis of the statutory guidance and the official documentation underpinning the genesis of the ‘Early Help’ programme reinforces the argument that it is a programme that was not formulated or crafted to meet the needs of disabled children and their families. When describing the purpose of Early Help in 2015,

⁴⁶ E Munro *The Munro Review of Child Protection: Final Report* Cm 8062 (Department for Education 2011).

⁴⁷ Recommendation 10.

⁴⁸ In its 178 pages there are only seven references to ‘disability / disabled’ of which six are to parents with learning disabilities and the seventh (para 5.20) being a case study of a children’s centre where the panel referring families to the centre included ‘a Lead Officer for the special educational needs and Disabilities Integrated Services’.

⁴⁹ Department for Education *A child-centred system The Government’s response to the Munro review of child protection* (DfE 2011) paras 16 – 21. In 2011/12 a non-ring fenced Early Intervention Grant was paid to local authorities – replacing a number of previous grants to support services for children, young people and families - T Powell *Early Intervention* Number 7647 (House of Commons Library 2019) and see also the Local Government Association *Early help resource pack* (2019).

⁵⁰ HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (2013).

⁵¹ Problematically ‘Working Together’ 2018 is, itself, not entirely consistent in this respect. At page 14 para 6 it states that practitioners should ‘be alert to the potential need for early help for [a range of children including] a child who ‘is disabled and has specific additional needs’. While this statement may be using the phrase ‘early help’ to mean ‘provide support at an early stage’ rather than in its formal sense i.e. as the ‘Early Help’ mechanism – it is unfortunate.

Ofsted⁵² referred to ‘children whose family lives are affected by parental drug and alcohol dependency, domestic abuse and poor mental health’ and the Ministry of Housing Communities and Local Government in 2020⁵³ referred to it being a key ‘driver’ for the ‘Troubled Families Programme’.⁵⁴

- 2.27 A brief analysis of local Early Help policies also suggests that it is conceptualised as a short term intervention programme: as ‘swift action to prevent ... needs escalating’; as a ‘targeted service ... for three to six months’; as action to ‘prevent the need for prolonged support’; as action for ‘up to six months to bring about the changes needed with the whole family’; as support ‘provided for up to 12 weeks’; where a plan is developed with ‘goals or measures so that everyone involved knows what to look out for to see when things are getting better’ ... ‘When your goals have been achieved, we will hold one last Team Around the Family meeting to celebrate success’; and so on.
- 2.28 There appears to be a fundamental inappropriateness of conceptualising disability as a ‘problem’ that can be prevented or remedied by a short family intervention programme. It is an approach that appears to locate the problem of disability within the family and to suggest that the problem can be cured by setting families targets. It is a personal model of disability that appears to be some distance from the model envisioned by the UN Convention on the Rights of Persons with Disabilities.

Local ‘assessment’ and ‘eligibility’ policies

- 2.29 This report refers to two distinct local policies: (1) ‘local protocols for assessment’ (outlined above); and (2) ‘local eligibility criteria’. Many of the survey responses by parent carer-led support groups referred to difficulties disabled children and families experienced, that resulted from problems created by both these policies. It is important therefore to summarise the status and purported purposes of these two policies.
- 2.30 As already noted, the purported purpose of the ‘local protocols for assessment’ is to explain ‘how cases will be managed once a child is referred into local authority children’s social care’ (para 46) – including how assessments should be undertaken.
- 2.31 In theory ‘local eligibility criteria’ explain how a local authority decides whether a child in need (including a disabled child) is eligible for the statutory support services that they may be entitled to (once their needs have been ‘assessed’). The duty to develop and publish such criteria derives from the Children and Families Act 2014 s30(8) and regulations thereto⁵⁵ which require that local authorities publish information ‘about any criteria that must be satisfied before any provision or service set out in the local offer can be provided’.

⁵² Ofsted *Early Help: Whose Responsibility?* 2015 p.4.

⁵³ Ministry of Housing Communities and Local Government *Early Help System Guide A toolkit to assist local strategic partnerships responsible for their Early Help System* (2020).

⁵⁴ A programme focussing on families problems relating ‘to crime and antisocial behaviour, education, life chances, living standards, domestic abuse and mental and physical health’ – see P Loft *The Troubled Families Programme (England)* Briefing Paper Number 07585 (House of Commons Library 2020).

⁵⁵ The Special Educational Needs and Disability Regulations 2014 SI 1530 and Schedule 2 para 18.

2.32 As noted below (paras 5.05-5.06) a 2020 research study⁵⁶ endeavoured to identify and critically analyse one component of these ‘local eligibility criteria’ policies.

The Human Rights Act 1998

2.33 It is unlawful for a public authority to act in a way that is incompatible with (among others) Articles 8 and 14 of the European Convention on Human Rights (ECHR).⁵⁷

Article 8 ECHR.

2.34 Article 8 of the Convention protects the rights of individuals to respect for their private and family life, their home and correspondence. Any state sanctioned interference with this right must (among other things) be strictly necessary and pursue a legitimate aim (for example the protection of a child). There is an extensive body of European Court of Human Rights case law concerning the fundamental importance of States providing adequate safeguards to ensure that an individual’s Article 8 rights are respected. In the context of this report, positive measures would include an obligation to ensure that children are only interviewed on their own or have their bedrooms inspected when there is cogent evidence in relation to that particular child or family that makes such action ‘strictly necessary’. Positive measures of this kind would include assessors being trained as to their obligations under Article 8 and the existence of clear national guidelines as to how assessors determine when an interference with a family’s rights under Article 8 is – and is not - justified.⁵⁸

2.35 Interferences of this nature are not excused simply by the fact that family invited the assessor into their home⁵⁹ – given the evidence that for many they were not anticipating that there would then be a ‘request to inspect the children’s bedrooms’ and the invidious situation this creates. The fear that not cooperating could lead to the authority using this refusal to escalate its intrusive investigations and to use its significant statutory powers.

Article 14 ECHR.

2.36 Article 14 requires that States secure the rights of individuals under the Convention without discrimination on any ground – for example, disability.⁶⁰

⁵⁶ P Bahri, L Clements, AL Aiello and T Hutchinson *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (Cerebra 2020).

⁵⁷ Human Rights Act 1998 section 6.

⁵⁸ See for example *R (P and Q) v. Secretary of State for the Home Department* [2001] EWCA Civ 1151 where the Court of Appeal held that rigid guidelines were impermissible in the context of policies that sought to promote the welfare of a child.

⁵⁹ By analogy, see for example *Saint-Paul Luxembourg S.A. v. Luxembourg* (Application No. 26419/10) 18 April 2013 and *Sanoma Uitgevers B.V. v. The Netherlands* (Application No. 38224/03) 14 September 2010.

⁶⁰ See for example *Mathieson v. Secretary of State for Work and Pensions* [2015] UKSC 47; *Burnip v. Birmingham City Council* [2012] EWCA Civ 629; *Glor v. Switzerland* (2009) Application No. 13444/04

- 2.37 In *Thlimmenos v Greece* (2000),⁶¹ the Court held that the right ‘not to be discriminated against in the enjoyment of the rights guaranteed under the Convention is also violated when States without an objective and reasonable justification fail to treat differently persons whose situations are significantly different’.⁶²
- 2.38 The *Thlimmenos* principle was applied by the Court of Appeal in *Gorry v. Wiltshire Council and others*.⁶³ The case concerned the so called ‘bedroom tax’ that penalised families that were in receipt of housing benefit if their house had more bedrooms than deemed necessary by the regulations. These stipulated (among other things) that only one room was required for two children under 10 years of age – on the basis that it would be reasonable for them to sleep in the same room. However, the Gorry sisters, although under 10, had impairments which meant that it was inappropriate for them to share a bedroom. The Court of Appeal held that the regulations violated the family’s rights under the Convention, as the Government had failed to provide objective and reasonable justification as to why it had failed to treat them differently from families whose situations were significantly different.

The UN Convention on the Rights of the Child (UNCRC)

- 2.39 The UK ratified the UNCRC in 1991, Article 3.1 of which provides:

In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.

- 2.40 The Supreme Court⁶⁴ considers that Article 3.1 not only generates an interpretative principle,⁶⁵ but that it also creates a ‘rule of procedure’ – that:

Whenever a decision is to be made that will affect a specific child, an identified group of children or children in general, the decision-making process must include an evaluation of the possible impact (positive or negative) of the decision on the child or children concerned ... Furthermore, the justification of a decision must show that the right has been explicitly taken into account ...’.⁶⁶

- 2.41 Article 5 requires that States ‘respect the responsibilities, rights and duties of parents’ and Article 16 provides protection against the arbitrary or unlawful interferences or attacks with a child’s privacy, family, home, correspondence,

30th April; 2009; *Çam v. Turkey* Application No. 51500/08 February 24, 2016; and *Enver Şahin v Turkey* (2018) 30 January Application No. 23065/12.

⁶¹ *Thlimmenos v Greece* (2001) 31 EHRR 15; Application No. 34369/9731 6th April 2000.

⁶² *Ibid* at para 44 and see *Burnip v. Birmingham City Council* [2012] EWCA Civ 629, para 14.

⁶³ [2012] EWCA Civ 629.

⁶⁴ *R (SG) v Secretary of State for Work and Pensions* [2015] UKSC 16, [2015] 1 WLR 1449, at paras 105-106.

⁶⁵ That where a legal provision concerning a child’s best interests is open to more than one interpretation it should be interpreted so far as possible to confirm to the meaning ascribed to it by the UN Committee on the Rights of the Child, in its General Comment No 14 (2013) on Article 3.1.

⁶⁶ UN Committee on the Rights of the Child, in its General Comment No 14 (2013) on Article 3.1, para 6(c).

honour and reputation. Article 23 recognises that disabled children are entitled 'to special care' and have the general right to state assistance 'in a manner conducive to the child's achieving the fullest possible social integration and individual development'.

2.42 Guidance concerning the nature and extent of State obligations to disabled children under Article 23 was provided by the Committee on the Rights of the Child in 2006 as 'General Comment No. 9'. The General Comment requires (at para 13) that States:

... develop and effectively implement a comprehensive policy by means of a plan of action which not only aims at the full enjoyment of the rights enshrined in the Convention without discrimination but which also ensures that a child with disability and her or his parents and/or others caring for the child do receive the special care and assistance they are entitled to under the Convention.

and at para 41, that:

Children with disabilities are best cared for and nurtured within their own family environment provided that the family is adequately provided for in all aspects. Such support to families includes ... psychological support that is sensitive to the stress and difficulties imposed on families of children with disabilities; ... material support ... that is deemed necessary for the child with a disability to live a dignified, self-reliant lifestyle, and be fully included in the family and community. ...

2.43 As the Joint Committee on Human Rights has observed (in the context of 'parent carers needs assessments') 'Children's rights are not in conflict with parents' rights Indeed, the UN Convention on the Rights of the Child recognises that a child is not isolated from his or her family'.⁶⁷

The UN Convention on the Rights of Persons with Disabilities (UNCPRD)

2.44 The UK ratified the UNCPRD in 2009, Article 4 of which places the 'general obligation' on the UK Government to 'ensure and promote the full realization of all human rights and fundamental freedoms for all persons with disabilities without discrimination of any kind on the basis of disability' and to this end (among other things):

- a. To adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognized in the present Convention;
- b. To take all appropriate measures, including legislation, to modify or abolish existing laws, regulations, customs and practices that constitute discrimination against persons with disabilities;
- c. To take into account the protection and promotion of the human rights of persons with disabilities in all policies and programmes;
- d. To refrain from engaging in any act or practice that is inconsistent with the present Convention and to ensure that public authorities and institutions act in conformity with the present Convention;
- i. To promote the training of professionals and staff working with persons with disabilities in the rights recognized in this Convention so as to better provide the assistance and services guaranteed by those rights.

⁶⁷ Joint Committee on Human Rights *Legislative Scrutiny: Care Bill* chapter 5 para 113.

- 2.45 The Court of Appeal has confirmed that when seeking to determine the meaning of Article 14 of the ECHR (where domestic law is 'elusive or uncertain') the UNCRPD 'has the potential to illuminate our approach to both discrimination and justification'.⁶⁸
- 2.46 In a similar vein the Supreme Court has held⁶⁹ that the 'best interests' requirement in Article 3.1 UNCRC is indistinguishable from the 'best interests' principle in Article 7.2 UNCRPD: that in 'all actions concerning children with disabilities, the best interests of the child shall be a primary consideration'.

⁶⁸ Lord Justice Maurice Kay in *Burnip v. Birmingham City Council* [2012] EWCA Civ 629 at para 22.

⁶⁹ *Mathieson v. Secretary of State for Work and Pensions* [2015] UKSC 47 at para 40.

3. Research project methodology

3.01 The research team was led by Professor Luke Clements and Dr Ana Laura Aiello at the School of Law, Leeds University with the assistance of 48 student volunteers. Quantitative and qualitative methods were used to obtain the data underpinning this report.

Search for, and analysis of, assessment protocols

3.02 149⁷⁰ English children's services authorities websites were searched between 14th October and 12th December 2020 in order to locate their 'local protocols for assessment'.⁷¹ Where this proved possible, the relevant protocol was then analysed in order to answer standardised questions concerning its content. In total 143 such protocols were identified.

3.03 Although the LEaP⁷² programme has heard from families in both England and Wales expressing concern about local authority disabled children's assessment procedures, it was decided to limit the research study to English authorities. This decision was taken for a number of reasons, including the fact that the relevant English and Welsh law is distinct (albeit with significant similarities) and that there is no requirement for assessment protocols to be published in Wales (and the contents of these protocols formed a key element of the research programme).

Survey of parent carer-led support organisations

3.04 An online survey comprising eight questions sought the views of 'independent parent carer-led'⁷³ support organisations about how well assessments were being carried out in their geographic area. A copy of the survey is at Appendix 1 to this report.

3.05 The survey was placed online by Cerebra using 'SurveyMonkey' between the 21st July 2020 and the 31st August 2020. The LEaP research team emailed all their known independent parent carer-led group contacts and asked that they notify other independent parent carer-led groups of the survey – i.e. with a 'snowball' approach to attracting respondents. In total 92 responses were received.

3.06 Many of the survey responses referred to the difficulties in obtaining disabled children's assessments (as opposed to 'children in need' assessments). A

⁷⁰ The City of London, The Isles of Scilly and the new unitary authorities which result from the division of Northamptonshire were not included in the research sample.

⁷¹ The statutory guidance HM Government *Working Together to Safeguard Children* (HM Government 2018) Chapter 1 para 46 (in the iteration of this on-line guidance as at the 1st May 2021) requires that authorities develop these protocols: this duty is considered at para 2.20 above.

⁷² The Cerebra Legal Entitlements and Problem-solving research programme – see page 1 above.

⁷³ The aim was to contact local groups who were independent of their local authority in the sense of being a distinct organisation (rather than - for example - a local authority advisory group) and 'parent carer-led'. Being 'independent' did not however mean that the group did not receive any funding support from their local authority.

significant cause of these difficulties stemmed from their authority's official and unofficial assessment eligibility criteria. The (official) eligibility criteria of 126 of these authorities had been identified in the earlier (2020) report⁷⁴ and so this data has been used (where relevant) to analyse the survey responses.

Testimonies from parents and scoping web searches

- 3.07 Prior to, and during the data gathering phases detailed above, the LEaP programme received many emails from parents and carers of disabled children expressing their distress about the way their child's / family's assessments had been undertaken. Material from these contacts has been taken into account in the drafting of this report and where cited (albeit anonymised) - it is done so with the permission of the correspondent.
- 3.08 In addition to the use of this material, semi-structured web searches were undertaken by the research team of social media sites (for example '[Mumsnet](#)', '[Netmums](#)', '[Twitter](#)' and the '[Family Rights Group](#)') for references to discussions held by parents and carers of disabled children concerning their experiences of social care assessments.

⁷⁴ P Bahri, L Clements, A L Aiello and T Hutchinson *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (Cerebra 2020) para 3.03.

4. Research findings

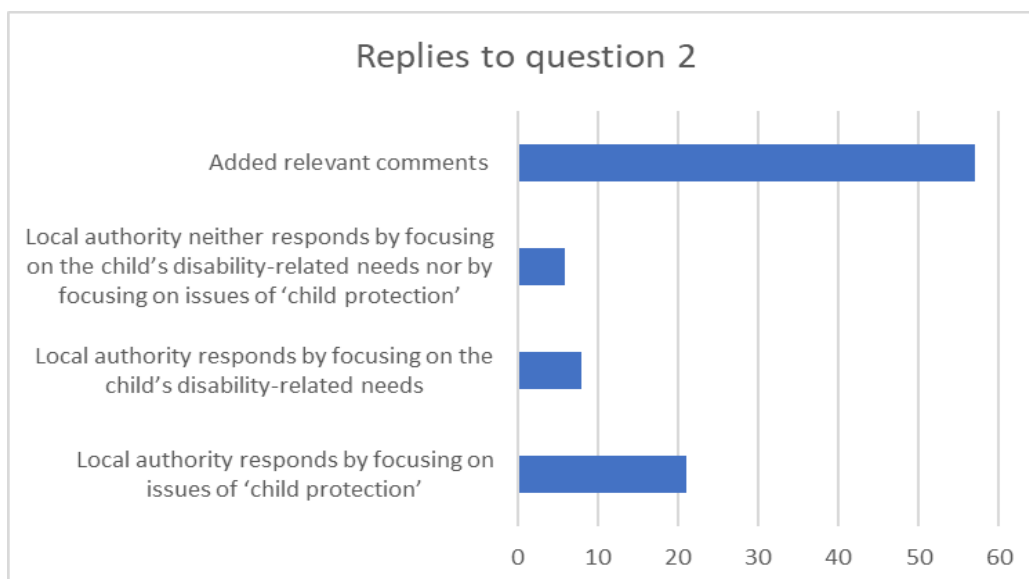
Parent carer-led support organisations survey results

4.01 As noted above (para 3.04) an online survey comprising eight questions sought the views of ‘parent carer-led’ support organisations about how well assessments were being carried out in their geographic area. Some of these questions sought quantitative data and some qualitative. The survey was placed online using ‘SurveyMonkey’ between the 21st July 2020 and the 31st August 2020 and in total 92 responses were received. A copy of the survey questionnaire is at Appendix 1 to this report.

Quantitative results

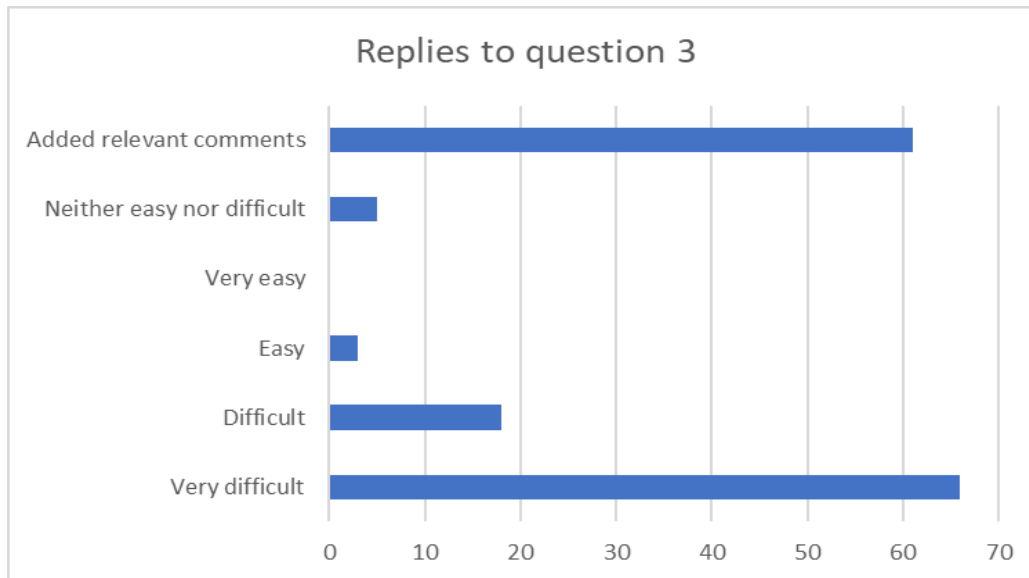
4.02 Question 1 asked respondents to name the social services authority with which their group had most dealings – and if there was more than one. They were asked to name them all and (if possible) to list first, the one with which they had most contact. 90 respondents replied to this question, naming in total 59 separate authorities. This means that the survey results covered almost 40 per cent of all English children’s services authorities.

4.03 Question 2 concerned parent carer-led support organisations perceptions as to how local authorities responded to requests for support to help meet the needs of their disabled child: whether the response focused on the child’s disability-related needs, on issues of ‘child protection’ (i.e. investigating potential abuse and / or neglect) or on other issues. 92 respondents replied to this question of which 21 considered that the response focused on issues of ‘child protection’; 8 on the child’s disability-related needs; 6 replied ‘neither’; and 57 added descriptive / open comments to this question.



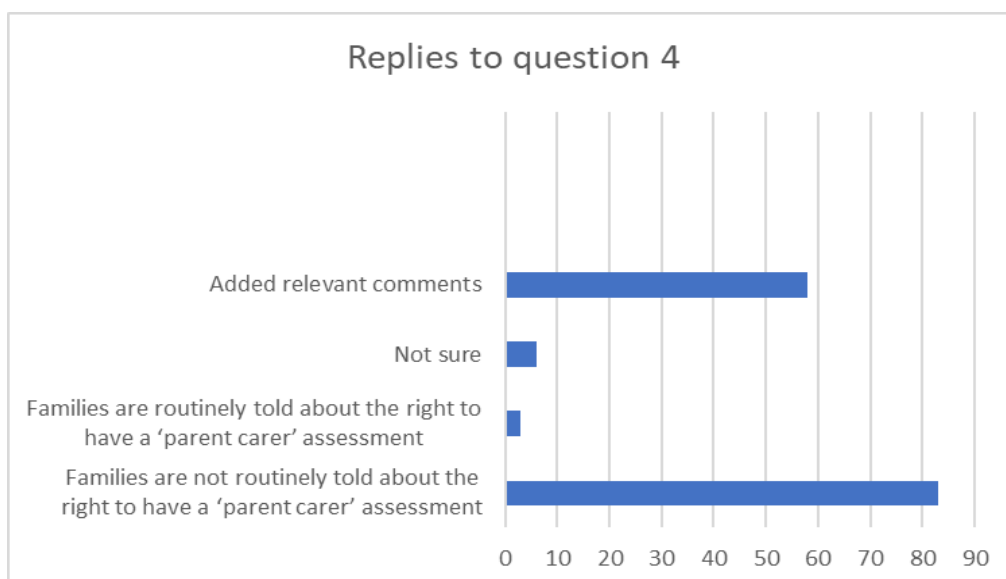
Graphic 2

4.04 Question 3 asked respondents how easy or difficult it was to get the authority to carry out an assessment of a child’s disability-related needs. 92 respondents replied to this question, of which 66 rated access to an assessment as ‘very difficult’; 18 as ‘difficult’; and only 3 rated as ‘easy’. None rated access to an assessment as ‘very easy’. 5 respondents answered ‘neither easy nor difficult’ and 61 respondents added relevant comments.



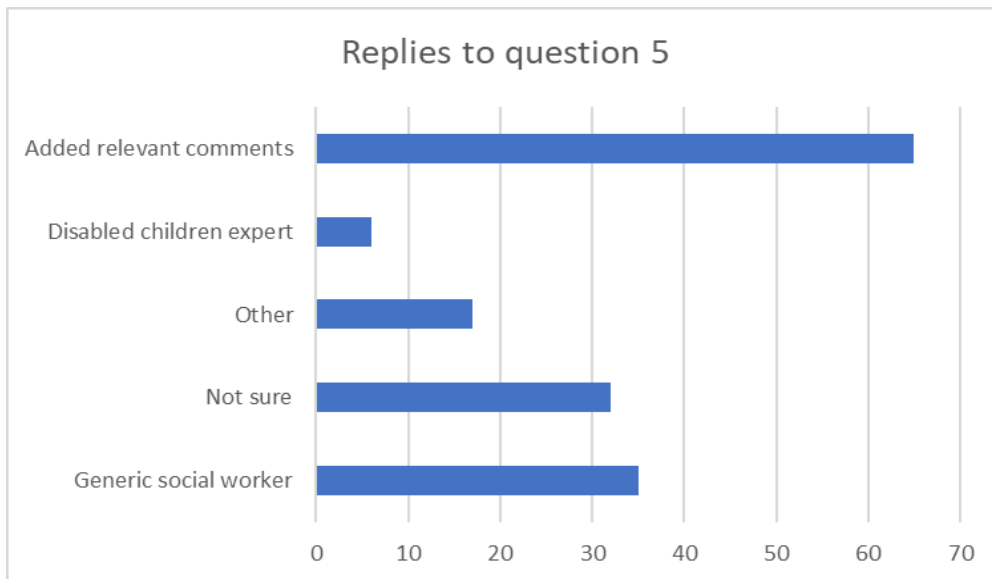
Graphic 3

4.05 Question 4 asked respondents if families were routinely told about the right to have a ‘parent carer’ assessment. 92 respondents replied to this question – of which 83 stated that families were not routinely told about the right; 3 that families were routinely told of this right; and 6 that they were ‘not sure’. 58 respondents added relevant comments.



Graphic 4

4.06 Question 5 asked respondents if the assessments of disabled children were usually undertaken by a social worker with specific training in the needs of disabled children and their families – or by a generic ‘child-in-need’ social worker or someone else. 90 respondents replied to this question of which 35 stated that the assessment was usually undertaken by a generic social worker; 32 answered that they were ‘not sure’; 17 stated that the assessment was usually undertaken by ‘other’ and 6 stated that the assessment was usually undertaken by a disabled children’s expert. 65 respondents added relevant comments.



Graphic 5

Qualitative results

4.07 The section that follows describes the comments / responses provided by respondents to questions 6 to 8 of the survey. Question 6 asked respondents to highlight those aspects of the assessment which they considered to be well done. Only 15 per cent of the respondents to this question described positive aspects of their assessments. Question 7 focused on the aspects of an assessment that respondents considered to be problematical. 86 per cent of the respondents to this question considered the assessment process that parents and their disabled children experienced to be unsatisfactory. Question 8 of the survey asked respondents for any other relevant comments they might want to add.

Difficulties in accessing appropriate disabled children’s needs assessments

4.08 A number of respondents referred to challenges they had encountered in obtaining assessments of their child’s disability related needs – on the grounds that their child did not fit the authority’s criteria for a ‘disabled children’s assessment’. A number of respondents referred to their authority’s policy of refusing disabled children’s assessments for children and young people with

autism. This problem was highlighted in the 2020 report⁷⁵ noted above (see para 1.03) that identified 41 English local authorities whose assessment policies explicitly discriminated against young people with autism. Respondents to the present survey named seven authorities that operated discriminatory policies of this kind. Only one of these authorities had been identified as having 'explicit' 'autism plus' policies in the 2020 report – a finding further analysed below (see para 5.05).

Barriers that restrict access to disabled children's needs assessments

- You cannot get a social services referral unless there are serious child protection needs. Parents can only get an assessment from the early help team but only if the family can prove its at breaking point. The early help team are not qualified and some have no SEN experience.
- Assessments are usually turned down straight away as the child 'not meeting criteria' ... I was personally told my autistic child wasn't disabled enough, and that they usually deal with children with more severe disabilities.
- They wouldn't bother until the assessment is ordered by tribunal.
- I was told assessment team needed to see her have a melt down [down] to make an assessment!
- Parents and children are constantly referred back to 'Early Help'.
- Usually gets passed down to Early Help services without any assessment being carried out.
- Most families get an Early Help Assessment.

Illustrative comments from parent carer-led support organisations 1

4.09 The survey suggested that it was not only disabled children with autism who experienced additional barriers when attempting to secure an appropriate needs assessment. Responses include statements that in some cases people from low socio-economic groups and / or disabled children with learning disabilities found it more difficult to obtain appropriate needs assessments compared to people in higher socio-economic groups and / or physically disabled children. In addition, some responses suggested that disabled children perceived as 'high-functioning' faced greater barriers to getting an appropriate needs assessment. Concern was also expressed about a lack of training of assessors when confronted by the needs of disabled children with 'hidden disabilities'.

Particular barriers of access for people in certain groups

- If a parent is in a low socio economic group they are more likely to focus on child protection.
- They say that (...) due to limited resources [they are] only dealing with children with physical disabilities (...).
- From [for] parents with autistic children...none. For those with obvious physical disabilities, maybe they might report differently. There is a severe lack of training and understanding regarding hidden disabilities.

⁷⁵ P Bahri, L Clements, AL Aiello and T Hutchinson *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (Cerebra 2020), available at <<https://cerebra.org.uk/research/unlawful-restrictions-on-the-rights-of-disabled-children-with-autism-to-social-care-needs-assessments/>> accessed 21 December 2020.

- Haven't heard of anyone with a positive 1st time experience, unless their children have actual physical disabilities.
- If a child has a significant physical disability - they will often receive a good assessment of need.
- Those who 'appear high functioning' get no help whatsoever.
- [council name] do not support children unless there is a safe guarding [safeguarding] need or the child has physical or visual needs.
- (...) those that haven't got the skills or the finances are the ones whose children are really missing out.
- The fact that families believe they have [to go] through legislation [to have access to] some right to support, but how the heck do they manage to get this support unless they have loads of money to hire a competent solicitor?

Illustrative comments from parent carer-led support organisations 2

Assessor failings

4.10 A number of respondents referred to problems relating to the staff assigned to undertake their disabled child's assessment: ranging from an assessor employing the wrong tone – to a lack of awareness (by staff) about children in need being legally entitled to an assessment. Issues raised by respondents included: staff carrying out the assessments not being 'understanding'; assessments conducted by student social workers; staff having pre-conceived assumptions about disabled children and their families; and a lack of proper training (particularly in the field of autism). References to positive experiences were rare. Staff who were part of a Disabled Children's Team were generally considered to be better trained and experienced about the needs of disabled children (and their families).

Assessor flaws

- The social workers doing assessments generally have no clue about the impact of autism and trying to access the children with disability team is like pulling hen's teeth.
- Eventually they did send a student social worker out who didn't have a clue about autism, never mind other disabilities.
- When cases get to a worker for assessment, the worker is a generalist and it is a matter of luck whether they have experience and competence in learning disabilities.
- Experience is split. No-one had their assessment done by a disabled child expert and 4 had a generic social worker. 3 had this completed by a family support worker and 1 completed the form on line [online] themselves.
- They don't have any experience and understand [understanding] about the child disability, just judge the child behaviour.
- If you have an autistic child and get to rock bottom you might get a generic social worker, who if you're lucky, may have read something on the internet about autism.
- All families with children with 'just autism' had been assessed by child protection social workers. Only those with a dual diagnosis of the [...] learning disability had been assessed by social worker from the children's complex disability team.
- [T]wice they sent SW [social work] students to do them.
- Sometimes can be initially assessed by Families First practitioner who is not disability specialist, sometimes by a worker from the specialist disability team.

- Social Workers with very little understanding of the nature of disability and or Autism make assumptions that the parents are to blame for the difficulties their family experiences due to their child's condition.
- Student social worker.
- In my own personal experience, I am a parent of an adult now with complex needs, they were actually quite good once you get to the stage of having the assessment. They had lots of experience in disabilities.
- Depends on whether the child is referred to the Children's Disability Team or the Assessment and Action team. If it is the disability team, the assessment will be conducted by a specialist SW [social worker] (I am not sure if they have any specific training in disability or are just burnt out from safeguarding work.) The Assessment and Action team don't have any specialism.
- You only get one done by a qualified disabled children's social worker if you come under the Disabled children and young people's team whose threshold is incredibly high.

Illustrative comments from parent carer-led support organisations 3

A focus on child protection and parent failings

- 4.11 The qualitative responses to the survey are dominated by profound misgivings about the underpinning approach of most assessments: that they are primarily concerned with safeguarding issues / parental failings rather than on the support needs of disabled children and their families. Respondents detailed their negative experiences of assessments – of feeling under scrutiny (as opposed to being supported).

Safeguarding and 'parent blaming' approach

- You cannot get a social services referral unless there are serious child protection needs.
- Parents were allocated child protection social workers whom had no experience of autism.
- Parents were offered (...) parenting courses.
- Parents were informed due to (...) not being safe guarding [safeguarding] concerns they could not access respite or support services for their child.
- The first thing they ask is is [if] the child in immediate danger. If you say no they close the call down. If you say yes they ask loads of questions about the child's safety, dismiss the child's challenges and say they will call you back which they don't. You call to find out the decision and they say we closed the case.
- There is a good deal of preoccupation with safeguarding reported by parents.
- Usually parents contact us desperate that people go to their homes but nothing happens and usually focus on the parent, as an unfit parent rather than focusing on the Autistic person disability needs.
- If the child did have an assessment from a child protection and a budget was given there was a lot of stigma as the child was seen as 'at risk from the parent.' Another parent was told 'you can only get a social worker if the parent is at risk to the child.'
- Discrimination – local authority routinely carries out a welfare check and does not provide the support and assessment which kids and families are entitled to.
- (...) most parents are told they need to go on a parenting course [course] and left feeling they are at fault and they are under scrutiny.

- the LA [local authority] will start with parenting classes which basically serves no purpose other than to keep the parents away from the LA [local authority] for a while.

Illustrative comments from parent carer-led support organisations 4

Issues of privacy

- 4.12 Survey responses included comments about situations where respondents considered that authorities had failed to respect their rights to privacy and cases where the authority had wilfully violated this right (for example when social workers inspected children’s bedrooms).

Intrusive practice

- Social Workers in [name of local authority] will always ask to see a child’s bedroom and when parents ask the question 'why?' as a number of them have, they are told it's part of the process and parents are made to feel like they have something to hide by daring to ask why. We even have instances of social workers looking in every bedroom in the home, parents bedrooms, siblings bedrooms etc not just the children who have needs.
- We asked them in to assess (PMLD child). It was awful, checking food cupboards, bedrooms etc. Lots of extremely intrusive questions totally irrelevant to the needs of child (...) I told them it was hard to sit and chat as my son requires 24 constant supervision and he likes to play in my bedroom. SS said we will chat in your bedroom, MY PRIVATE BEDROOM.
- Social workers asking to see bedrooms.

Illustrative comments from parent carer-led support organisations 5

Defective assessments

- 4.13 Various respondents referred to defective assessment processes: assessments with mistakes, inconsistencies and incorrect (and usually negative) information about the family – as well as the problem of delay.

Deficient assessments

- Parents also mention that most time the information shared by SS [social services] about family is highly negative and distorted, a twisted narrative!
- The assessment seems to be done quickly (...).
- Inaccurate reports were an issues [issue] and once reports were completed and corrected, the support identified as needed wasn’t always available.
- (...) poor reports (...).
- The local authority do not conduct assessment within time frame.

Illustrative comments from parent carer-led support organisations 6

Defective assessments and resultant harm

- 4.14 The survey responses included evidence of ‘devastating’ harm experienced by families as the result of a defective assessment process: harm manifested in the loss of family members; family breakdown; significant financial difficulties; the creation of fear (or panic); the loss of trust in social services; of frustration, exhaustion; and the repeated experience of being blamed (instead of supported) by children’s services.

4.15 A number of survey responses also referred to families' experiencing hostile action taken by authorities after the families had made complaints about flawed assessments. This issue has been analysed in a number of other contexts concerning the 'power imbalance'⁷⁶ that exists between individuals seeking support from statutory agencies and the statutory agencies themselves – leading to a widespread 'reluctance to complain': a hesitancy attributed to (among other things), a 'fear of the consequences' (i.e. fear of retaliatory action).⁷⁷ It is an issue highlighted in the 2021 report compiled by the Chief Social Workers for Adults and the Chief Social Worker for Children and Families⁷⁸ (considered at para 1.11 above), which referred to 'families who had been brought into the child protection process because of disagreements with practitioners' – in their opinion, a 'repeated concern that we hear from parents and carers outside of this study in the course of our ongoing communications with families over the years'.⁷⁹

Harm

- The panic the parent(s) endure becomes intolerable and unfortunately can result in the children being [being] taken away, without the parent being [being] able to fight it appropriately.
- Merely, parents in panic either unable to cope with Services or both the Services and the Autism condition.
- Many families are scared to approach social services.
- Parents have lost trust and so have I.
- The families we support routinely report an overwhelmingly difficult and distressing experience. Any positive outcomes are because of considerable parental effort - often at a significant emotional and financial cost.
- Just a devastating process on top of an already difficult life, with no sleep and no outside family help. Not something I would enter lightly in to ever again.
- Parents described themselves at breaking point and that the battle with the local authority was exhausting just to get an assessment, never mind services.
- Much fear of social services, being judged, having to explain everything.
- My advice to others would be to stay well clear. They have nothing to offer but distress, humiliation, intrusion [intrusion].
- In our case that ended with the suicide of our son, not 1 single professional guided us towards a diagnosis through 16 years of our son's life. Mild autism possibly. Not convinced it was that.
- Families become broken and children traumatised.
- Parents health and well being [well-being] are neglected and children's needs are ignored at great cost to their well being [well-being] and future.
- Of course how many families break down and become a one parent family, because of all the stress and resulting financial difficulties too?

⁷⁶ Joint Committee on Human Rights *The human rights of older people in healthcare* HL Paper 156-I HC 378-I (2007) para 234 et seq.

⁷⁷ K Simons *I'm Not Complaining, but ...* (Joseph Rowntree Foundation 1995).

⁷⁸ Chief Social Workers for Adults and the Chief Social Worker for Children and Families *A spectrum of opportunity: an exploratory study of social work practice with autistic young adults and their families* (Department of Health and Social Care 2021).

⁷⁹ See also L Clements *Clustered Injustice and the Level Green* (Legal Action Group) 2020 page 97 where reference is made to a number of examples of 'retaliatory action' of this kind, including a BBC investigation concerning 12 families who had asked their council for support for their disabled child and / or made a complaint about the failure to provide this support and in each case had then been accused of fabricating the extent of their child's impairment.

- Also a growing number [of parents] are finding that they are being investigated for fabricated and induced illness as a result of challenging the practice (at least 8 that I am aware of).

Illustrative comments from parent carer-led support organisations 7

The failure of the duty to provide parent carer needs assessments

- 4.16 The survey findings suggest a widespread failure by authorities to advise parents and carers of their right to have a parent-carer needs assessment.

Failure of providing parent carer needs assessments

- 70 per cent of families stated that they either never knew this existed or had to find the information themselves. Those that were told said "Yes, but also told it would not provide anything so effectively discouraged from completing one" and "was told it was requested for October 2019, it finally happened in June 2020 but i [I] still haven't seen the report".
- Most parents in [name of council] have never heard of a parent carer assessment until being told by another parent in stressful situations.
- We are told the opposite. Only can get an assessment if family is broken down.
- Most parents are unaware of their rights.
- Most social workers and early help workers don't even know what a Carers assessment is. When they do, it's a form given to the parent to complete on their own and then filed. It's a paper based [paper-based] exercise with rarely any support as an outcome.
- [name of council] says there is no such thing as a parent carer assessment.
- [T]he council often tell parents that they dont do them. A foi [Freedom of Information – FOI] request showed that [name of council] only completed 2 parent carer assessments in the last 5 years, one of which was my own which took over 2 yrs to complete.
- When we talk to parents at the support groups they are shocked that they are classed as carers. It has never been mentioned.
- Lots of promotion of a carers assessment.
- Absolutely shocking behaviour. Parents are refused any assessment even though it is a legal duty.
- We have been challenging the LA over PCNA's as it came to light that ... since 2014 we were unofficially told that [name of local authority] had conducted only 4 PCNA's and that nothing was actioned from any of them.

Illustrative comments from parent carer-led support organisations 8

Identification of local authority assessment protocols

- 4.17 Of the 149 applicable children's services authorities, the research team identified 143 (96 per cent) protocols for assessment.
- 4.18 114 (80 per cent) of assessment protocols identified, included a reference to 'child's bedroom has been seen'. This reference did not, however, appear in 29 of the protocols (20 per cent).
- 4.19 124 (87 per cent) of the assessment protocols identified, referred to the need for the assessor to have seen (or communicated with) the children alone. This reference has not been found in 19 of the protocols (13 per cent).

- 4.20 Only 5 (3 per cent) of the assessment protocols identified found included a reference to a carer's needs assessment.
- 4.21 Of the assessment protocols identified, 125 (87 per cent) appeared to be managed by a private organisation. A large number of these protocols were very similar – and in some material respects identical. In the context of this research, the following extract is illustrative – in that it appeared in a number of protocols in identical – or very similar terms:

... Regular review

...

The social worker's line manager must review the assessment plan regularly with the social worker and ensure that actions such as those below have been met:

- There has been direct communication with the child alone and their views and wishes have been recorded and taken into account when providing services;
- All the children in the household have been seen and their needs considered;
- The child's home address has been visited and the child's bedroom has been seen;
- The parents have been seen and their views and wishes have been recorded and taken into account;
- The analysis and evaluation has been completed;
- The assessment provides clear evidence for decisions on what types of services are needed to provide good outcomes for the child and family.

Parent carer social media discussions

- 4.22 As a separate exercise, (i.e. distinct from the main survey and systematic analysis of local authority assessment protocols) a brief exploratory search of social media was undertaken. Social media is seen as an important 'independent' space by parents of disabled children to communicate: to air their experiences and to seek support and advice concerning issues that have arisen. Students performed an initial search in online forums usually employed by parents and carers (such as Reddit, Twitter, Digital Spy, Instagram, Netmums and Family Rights Group) using key terms such as 'social worker' and 'children's bedroom'. The search identified a limited number of relevant discussions / posts from parents and carers of disabled children, which included references to: social workers asking to see their children's bedroom; parents and carers being told that their child did not qualify for a social care needs assessment; assessments that appeared to focus on parental failings rather than the additional support needs of the disabled child.

Comments made by parent carers in the social media

- I just presumed it was a standard thing they do? [Looking at the child's bedroom]
- I was told it was a S17, but would be escalated to a s47 if I didn't let them see the bedrooms.
- (...) its standard practice. [Looking at the child's bedroom]
- We also asked for a S17 assessment and was told my child was not disabled enough, (...).
- We ask for help then we get interrogated, then we fill in loads of forms for our child, only to be told that they do not meet the criteria.

- We've had the indignity of a child protection assessment when we've asked for a S17 assessment...only to be directed to the Local Offer. It has been traumatic.
- I really need help. We are in the middle of a child in need process, and we are having the children's disability team threatening to move the process on to child protection services. But we have had zero understanding or support.

Illustrative comments from parent carers in the social media 1

5. Analysis

Local authority assessment criteria

- 5.01 The CA 1989 and CSDPA 1970 place duties on children's services authorities to assess the care and support needs of disabled children, and the 1989 Act requires that they assess the needs of parent carers (see para 2.08 above). The 1989 Act provides that disabled children and their parents are entitled to materially different care and support arrangements than those of non-disabled children and their parents (see paras 2.04 and 2.12 above). Support under the 1970 Act, s2 is only available to disabled children.
- 5.02 These provisions reflect the Government's obligations to address the severe disadvantage that disabled children and their families experience, and the international commitments that the UK has accepted under the UNCRC and the UNCRPD (see paras 2.39 – 2.46 above) - to take specific measures to enable them to overcome the barriers to their full participation in all aspects of community living.
- 5.03 As mentioned above, children's services authorities have a duty to decide if a disabled child is eligible for support under the 1989 and 1970 Acts, and a duty to assess whether their parent has needs for support. The principal triggering criteria for assessments are that the child is a disabled child for the purposes of CA 1989 s17(11) and that the child may be in need of care and support.
- 5.04 Where Parliament has required a public body to discharge a statutory function it is not lawful for that body to fetter this duty by adding additional criteria that have to be satisfied before the duty is discharged.
- 5.05 The responses to the parent carer-led organisations survey indicate that many disabled children are, in practice, being refused assessments of their needs under the 1989 and 1970 Acts. The 2020 research⁸⁰ demonstrates that this refusal is rooted in defective local authority assessment criteria: policies that arguably place unlawful barriers to many disabled children and their parents accessing their statutory rights to the support services reserved for them under the 1989 and 1970 Acts. This is done by imposing a materially more severe definition of what constitutes a 'disabled child' than that provided in CA 1989 s17(11) (para 2.05).

Assessments are usually turned down straight away as the child 'not meeting criteria' ... I was personally told my autistic child wasn't disabled enough, and that they usually deal with children with more severe disabilities.

Parent carer-led organisation's survey response

- 5.06 The 2020 report (at para 1.03) gives examples of local authority assessment criteria of this kind, including the following:

⁸⁰ P Bahri, L Clements, AL Aiello and T Hutchinson *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (Cerebra 2020) page 15, para 3.07.

Local authority B

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.

Example of local authority assessment criteria 1

5.07 While it is necessary for local authorities to have guideline criteria that would in general 'trigger' a duty to provide care and support for a disabled child (and for this to be detailed in Central Government guidance – see para 2.15 above) – such 'eligibility' guidelines cannot be used to limit the right of disabled children and their parents to an 'assessment'. This would not only fetter the duties to assess, but it would also appear to be irrational. The level of a disabled child's needs can only be ascertained by a suitably skilled assessment and it is logically circular for a policy to stipulate that a disabled child's right to such an assessment only arises if they have needs above a certain level.⁸¹

5.08 During the current research project, a parent carer group respondent provided a copy of their authority's 'Eligibility Criteria for Disabled Children and Young People to access support' – which makes clear that 'support' includes 'the assessment itself'. The relevant part of the criteria is detailed in the box below:

⁸¹ By way of analogy, see for example *R v Bristol CC ex p Penfold* (1997–1998) 1 CCLR 315, 23 January 1998, QBD and the statutory guidance to the Care Act 2014 (para 6.13) that 'authorities must undertake an assessment for any adult with an appearance of need for care and support, regardless of whether or not the local authority thinks the individual has eligible needs.

Eligibility Criteria for Disabled Children and Young People to access support
... ..**Eligibility for Assessment**

A Lead Professional may be somebody who already knows/works with the child and family, a practitioner within the community or a Lead Professional from the Disabled children's team. A child/young person is eligible for the above if s/he:

- has a substantial and permanent disability, and
- appears to have needs arising from his/her disability that can only be met by accessing specialist support, or there is a need for additional funding to enable short breaks to take place, and
- has a home address within [name of council]
- The child should also meet one or more of the following criteria

Substantial and permanent disability for the purpose of eligibility is defined as being:

-

- A severe learning disability and/or autism with challenging behaviour
- A severe physical disability
- A severe sensory disability
- Complex and severe health needs
- Support for all basic self care functions when no longer age appropriate
- Constant supervision throughout the day and for prolonged periods at night when no longer age appropriate
- Communication needs which, without support severely effects personal safety
- They have behaviour as a result of the disability that is serious risk to self or others, including self harm

It is expected that the above disabilities are diagnosed by a Community Paediatrician or similar health professional.

Example of local authority assessment criteria 2

5.09 Local Government and Social Care Ombudsman reports also refer to policies and practices that restrict access to an assessment that could unlock support reserved for disabled children and their families under the 1989 and 1970 Acts. A 2021 report⁸² made reference to a policy of this kind. It specified four different levels – which determined support arrangements that could be provided for 'children in need' – namely:

Level 1 – Universal services. This provision is available to all children and families who have core needs such as parenting, health and education.

Level 2 – Additional support. For children and families who would benefit from or require extra help to improve parenting and / or behaviour or to meet specific health needs.

Level 3 – Intensive support. For vulnerable children and their families with multiple needs or who have a disability resulting in complex needs and where families need substantial support to care for their disabled child.

Level 4 – Specialist services. For children with significant impairment of function / learning or whose parents are unable to care for them; or, with profound and enduring disability and children are likely to suffer significant harm without the intervention of specialist services.

⁸² Report on complaint [no 20 002 897 against Essex CC](#), 17 February 2021.

- 5.10 This meant that parent carer needs assessments (PCNA) were only available to parents caring for disabled children who fell within the top level.
- 5.11 A parent was experiencing considerable difficulties caring for her son who had genetic and developmental conditions, learning difficulties, pathological demand avoidance and autism and requested that the authority undertake a PCNA. This was refused because the authority's Disabled Children's Team considered that her son did not 'meet the threshold' for such an assessment – i.e. Level 4 – that, in effect that the authority threshold policy took precedence over the statutory duties in the 1989 Act.
- 5.12 In a similar vein a 2018 LGO report⁸³ concerned a child with not insignificant mental health needs⁸⁴ and in relation to whom there was professional acceptance that respite care was 'needed to prevent a family breakdown'. This was refused because his impairment was not sufficiently severe to enable him to receive a service from the Council's child health and disability team.

Failure to provide parent carer needs assessments (PCNAs)

- 5.13 The duty to undertake PCNAs (and in so doing to have regard to the well-being obligations in the Care Act 2014) stems from an appreciation of the severe and multifaceted disadvantage that blights the lives of many disabled children and their families (considered at para 1.02 above).
- 5.14 The research underpinning this report finds that children's social care authorities are routinely failing to undertake PCNAs in situations where a statutory duty exists to undertake such an assessment. The statutory duty is triggered not only when the parent requests such an assessment, but also when it appears to the authority that the parent carer may have needs for support (para 2.12 above). As the 2021 report⁸⁵ cited above (para 5.09) demonstrates, the widespread existence of complex bands / levels of eligibility / thresholds employed by many local authorities has the effect of denying most parent carers their right to a PCNA.
- 5.15 Of the 143 local assessment protocols identified, only 5 (3 per cent) included a reference to assessing social workers being aware of this statutory duty (para 4.20 above).
- 5.16 The widespread failure of authorities to provide PCNAs is not merely a technical breach of their statutory duty – it is also (as this research reveals) causing significant harm to families. As the 2000 Practice Guidance noted (para 2.17) 'recognising the needs of parent carers is a core component in agreeing services which will promote the welfare of the disabled child'. A failure to assess parent carers would also – logic suggests - frustrate the strategic duty on children's services authorities to 'take reasonable steps to identify the extent to which there are parent carers within their area who have needs for support' (under s17ZD(14)).
- 5.17 In practice, however, many eligibility criteria / threshold documents had the

⁸³ Complaint [no 17 011 899](#) against [Poole Borough Council](#), 26 October 2018.

⁸⁴ Needs that meant that he was a 'disabled child' within the meaning of definition of the CA 1989 s17(11) – ie 'a mental disorder of any kind'.

⁸⁵ Report on complaint [no 20 002 897](#) against [Essex CC](#), 17 February 2021.

effect of denying parent carers the rights to PCNAs. The small subset who were in theory offered PCNAs, were those whose children were considered to be 'disabled' for the purposes of their local authority assessment criteria (i.e. policies that imposed a materially more restrictive definition of a 'disabled child' than that in section 17(11) of the 1989 Act).

- 5.18 Unfortunately, it appears that some of the PCNAs that were undertaken were themselves unlawful. The extent of this problem would need to be ascertained by separate research, but two issues were identified during this research study. The first concerns the practice of authorities refusing to undertake 'separate' PCNAs, asserting that the child's assessment included a consideration of the parent's needs. Although there is a power to combine assessments under section 17ZE of the 1989 Act, blanket policies of this kind constitute a fettering of an authority's discretion. The second (and connected) issue concerns the failure of such assessments to record whether (and if so, to what extent / with what consequences):⁸⁶ (a) it was 'appropriate for the parent carer to provide, or continue to provide, care for the disabled child' and; (b) the impact on the parent carer's 'well-being'. 'Well-being' in this context, includes (among other things) a consideration of the parent's mental health, their ability to have control over their daily life, their participation in work, education, training, the impact on their family life and personal relationships.⁸⁷ All factors highlighted by the research of being especially problematic for parent carers (see para 1.02 above).

Assessors lacking disability related expertise

- 5.19 Many responses to the survey of parent carer-led support organisations expressed concern about the generally poor quality of the social work assessments and the lack of relevant expertise of assessors.
- 5.20 Particular concern was directed at assessors lack of understanding about their child's impairments; the challenges that resulted from these impairments; and the forms of support that were most effective in making these challenges manageable. A recurring theme was that the assessments were formulaic – focusing on the completion of a rigid template and not on listening to and exploring the disabled child's and the family's lived experiences.
- 5.21 These misgivings are not new. The 2000 practice guidance noted that 'serious concerns [had] been raised about the quality of assessments of disabled children' over many years.⁸⁸ It referred to the danger of the process of

⁸⁶ Required by CA 1989 s 17ZD (9) and (10).

⁸⁷ CA 1989 s17ZD(11) states that for the purposes of CA 1989 s 17ZD(10) (the duty to have regard to the parent carer's well-being) 'well-being' has the same meaning as in Part 1 of the Care Act 2014.

⁸⁸ Department of Health *Assessing Children in Need and their Families: Practice Guidance* (The Stationery Office 2000) para 3.2, citing Audit Commission *Seen but not Heard: Co-ordinating Community Child Health and Social Services* (HMSO 1994); Department of Health *Services to Disabled Children and their Families: Report of the National Inspection* (Department of Health 1994); Department of Health *Disabled Children: Directions for their Future Care* (Department of Health 1998); Department of Health *Removing Barriers for Disabled Children: Inspection of Services to Disabled Children and their Families* (Department of Health 1998); Morris J 'Still Missing?' Vol 2: *Disabled Children and the Children Act*. (The Who Cares? Trust 1998); Kagan C, Lewis S and Heaton

assessment compounding the difficulties disabled children and their families encountered⁸⁹ and in so doing, it cited the following comment made by a parent:⁹⁰

I found assessment meetings a nightmare. I felt I was listening to people talk about somebody other than the child I lived with. After the first assessment at the child development centre I went home and cried for four days

5.22 The publication of the 2000 policy and practice guidance (see paras 2.17-2.18 above) constituted a powerful statement to local authorities and the social work profession of Government policy. They represented an important element of the Government's commitment to implement the UK's international obligations to address the needs of disabled children and their families. The guidance sought to articulate this issue in the language of equality and social justice - that radical action was necessary since:

discrimination of all kinds is an everyday reality in many children's lives, every effort must be made to ensure that agencies responses do not reflect or reinforce that experience and indeed, should counteract it ...⁹¹ [and] ensuring equality of opportunity does not mean that all children are treated the same. It does mean understanding and working sensitively and knowledgeably with diversity ...⁹²

5.23 However, as noted above (para 2.20) the 2000 policy and practice guidance have been repealed. All that remains in terms of statutory guidance is 'Working Together 2018': guidance dominated by concerns of neglect and abuse, and parental failings. It is a document that this research strongly suggests, has led many authorities to revive a conceptualisation of the 'problem' of disability as one that locates the problem within the individual family – or more particularly the parents'.⁹³

5.24 One consequence of this policy vacuum is, as the survey of parent carer-led support organisations strongly suggests, that many (almost certainly the majority) of disabled children are now treated in the same way as all other 'children in need'. In practice this means that they are being assessed by (sometimes multiple) professionals who do not have disability related expertise and are, not infrequently, insensitive to the challenges experienced by disabled children and their families. In effect subjected to a process that compounds,

P *Caring to Work: Accounts of Working Parents of Disabled Children* (Family Policy Studies Centre 1998); and Middleton L *Disabled Children: Challenging Social Exclusion* (Blackwell 1999).

⁸⁹ Ibid.

⁹⁰ Department of Health *Assessing Children in Need and their Families: Practice Guidance* (The Stationery Office 2000) para 3.16 the quote being taken from Murray P and Penman J *Let Our Children Be: A Collection of Stories* (Parents with Attitude 1996).

⁹¹ Policy Guidance (Department of Health et al, 2000, paragraph 1.42

⁹² Policy Guidance (Department of Health et al, 2000, paragraph 1.43. In the words of the Council for Disabled Children (CDC) 'Getting our system, services and practice right for every child does not mean treating every child the same – see CDC 'Social Care' at <https://councilfordisabledchildren.org.uk/our-work/social-care> accessed 1 May 2021.

⁹³ Para 3.9 of the 2000 Practice Guidance refers to the 'move' then taking place 'from an individual to a social model of disability. "The individual model and sees the causes as functional limitations or psychological losses assumed to arise from disability"' – citing Oliver M *Understanding Disability: From Theory to Practice* (MacMillan 1999), p.33.

rather than counteracts the discrimination that is an everyday reality in their lives.

5.25 The almost total lack of statutory guidance⁹⁴ concerning the importance of ensuring that disabled children are assessed by assessors with the training, skills, knowledge and competence in undertaking disabled children's assessments is in stark contrast to that relating to the assessment of disabled adults.

5.26 Regulations,⁹⁵ for example, require that assessors involved in the assessment and care planning of disabled adults, have 'the skills, knowledge and competence to carry out the assessment' and are appropriately trained. Expanding upon this requirement the Statutory Guidance to the Care Act 2014 states that (para 6.90):

Where an assessor does not have experience in a particular condition (such as autism, learning disabilities, mental health needs or other conditions), they must consult someone with relevant experience. This is so that the person being assessed is involved throughout the process and their needs, outcomes and the impact of needs on their wellbeing are all accurately identified.

5.27 The Statutory Guidance to the Care Act 2014 (at para 6.89) additionally summarises local authority obligations relating to the assessment of adults with autism,⁹⁶ namely to:

- make basic autism training available for all staff working in health and social care;
- develop or provide specialist training for those in roles that have a direct impact on access to services for adults with autism;
- include quality autism awareness training within the general equality and diversity training programmes across public services.

5.28 The research evidence underpinning this report demonstrates that the lack of disability specific guidance concerning the assessment of, and care planning for disabled children is causing significant harm to children and their families.

5.29 Given that an assessment is a service that authorities are legally obliged to provide for disabled people of any age, it is by no means obvious what the justification is, for a requirement that the service provided to adults be of a higher standard to that provided for children. In the absence of such justification, it is arguable that no reasonable Government knowing of this adverse impact could fail to take positive action to address this problem.

5.30 In legal terms, this failure can be expressed as a breach of the Government's public law obligations: obligations that (in addition to) ensure that English law and policy is consistent with its international commitments. These commitments include (as discussed at paras 2.39-2.43 above) those relating to

⁹⁴ Department of Health Care and Support for Deafblind Children and Adults Policy Guidance (2014) is the only guidance we have been able to identify that require such expertise.

⁹⁵ Care and Support (Assessment) Regulations 2014 reg 5.

⁹⁶ Obligations that derive from Department of Health *Fulfilling and rewarding lives: the strategy for adults with autism in England* (DoH 2010) and Department of Health *Think autism: fulfilling and rewarding lives, the strategy for adults with autism in England: an update* (DoH 2014).

Articles 3 and 23 UN Convention on the Rights of the Child (UNCRC) – not least the ‘special care’ due to disabled children and the general right to assistance ‘in a manner conducive to the child’s achieving the fullest possible social integration and individual development’. Article 23 requires the effective implementation of a ‘comprehensive policy by means of a plan of action’ that ensures that disabled children and their families receive the special care and assistance they are entitled to under the Convention.⁹⁷

- 5.31 The obligations that the Government has entered into, are to be interpreted by reference to the equivalent obligations under the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and its duties under the Human Rights Act 1998. In relation to the UNCRPD, this includes the general obligation (in Article 4) to take all appropriate measures, not only to abolish practices that constitute discrimination against persons with disabilities, and to ensure that public authorities and institutions act in conformity with the Convention – but also to promote the training of professionals and staff working with persons with disabilities in the rights protected by the Convention.

Treating disabled children as simply ‘children in need’

- 5.32 Analysis of the assessment protocols reveals that only six of the 143 local authorities identified, contained reference to the 2000 practice guidance and in fact, the vast majority of references to disabled children were phrased in the context of their risks of neglect or abuse. The survey of parent carer-led support organisations provides compelling evidence that significant harm is being caused by local authorities failing to ensure that disabled children (for whom no evidence of neglect and abuse exists) and their families are not treated in the same way as neglected and abused children (for whom such evidence exists).

[I was told that] although [child’s name] is a disabled child and therefore a ‘Child in Need’ eligible for Early Help services, [child’s name] did not meet the more stringent eligibility criteria of the Disabled Children’s Team, so therefore could not be assessed under the Chronically Sick and Disabled Person’s Act.

Parent carer-led organisation’s survey response

I felt bullied ... suddenly a stranger in our house demanding we answered these questions we had no choice it just was really really horrible ... and then she wanted to see [child’s] room ... and I [asked] why is that relevant to you coming to assess me [for a PCNA] ... and she just said ‘oh it’s just standard - just what we do’ and again I just felt that we can’t deny it because again you’ll think what am I hiding I just felt we were being treated like criminals ... it was almost like the police turning up at your door and say we’ve got a warrant to search your house.

Parent carer response

⁹⁷ Committee on the Rights of the Child in 2006 as ‘General Comment No. 9 para 13.

- 5.33 The failure to treat disabled children and families differently results in (among other things):
- many disabled children being denied their right to an assessment that might establish their entitlement to the statutory support services reserved for disabled children (see paras 4.08-4.09 above);
 - many parents of disabled children being denied their right to a PCNA (see para 4.16 above);
 - harm and trauma to many disabled children who are subjected to inappropriate assessments by assessors lacking the necessary expertise (see paras 4.14-4.15 above);
 - the intimidation, deep humiliation and offence of many families: souring what should be an important supporting and positive relationship.
- 5.34 Such a failure would appear to constitute unlawful discrimination contrary to Article 14 of the ECHR in combination with Article 8 (the right to respect for private and family life, home and correspondence). Unlawful discrimination results when (among other things), a person is ‘without an objective and reasonable justification’ treated in the same way as someone whose situation is significantly different⁹⁸ (see para 2.37 above). Treating disabled children and their families in the same way as those suspected of child neglect / abuse (in situations where there is no evidence of neglect / abuse) constitutes such an example. It is therefore necessary that legislation, policy and practice ensures that this does not happen. Sadly, the overwhelming evidence of the research study is that this is not occurring. The 2000 policy and practice guidance, which drew attention to this serious problem, have been repealed and the current guidance ‘Working Together 2018’ strongly encourages an approach that treats disabled children in the same way as children suspected of being neglected / abused.
- 5.35 This is a situation that has been described as using ‘the social work assessment as an opportunity to judge parenting capacity through a child protection lens rather than through a lens of social care need’⁹⁹ - and of upending the principles underpinning the 1989 Act, with children and families social workers becoming ‘child protection social workers in child protection teams’ practising ‘monitoring and surveillance of families, generating threat and fear’.¹⁰⁰

Disproportionate and discriminatory interferences with private and family life

- 5.36 A material reason for the research programme underpinning this report concerned feedback parent carers provided to the LEaP project concerning their experience of disproportionately intrusive social work assessments (see

⁹⁸ *Thlimmenos v Greece* (2001) 31 EHRR 15; Application No. 34369/9731 6th April 2000 at para 44 and see *Burnip v. Birmingham City Council* [2012] EWCA Civ 629, para 14.

⁹⁹ Chief Social Workers for Adults and the Chief Social Worker for Children and Families *A spectrum of opportunity: an exploratory study of social work practice with autistic young adults and their families* (Department of Health and Social Care 2021).

¹⁰⁰ Professor R Jones ‘Tackling funding, privatisation and poverty’ Community Care 8 January 2021.

para 1.04 above). Assessments that parents perceived as humiliating; assessments that started from a presumption that the problems being experienced were attributable to parental shortcomings. Parents who considered that local authority assessors were working to an inflexible script: one that required them to inspect the children's bedrooms, required them to speak to the child alone; an assessment process that Hood *et al* have described as 'a technocratic, adversarial mode of working'.¹⁰¹

- 5.37 The research findings reveal that 80 per cent of the assessment protocols identified (n = 114) included a requirement that the 'child's bedroom has been seen' and that 87 per cent of the protocols identified (n = 124) referred to the need for the assessor to have seen (or communicated with) the children alone. An example of an extract included in a typical assessment protocol of this kind can be found at para 4.21 above.
- 5.38 While it may be necessary for social workers to see children alone and to inspect their bedrooms in cases where there is evidence to suspect abuse or neglect, such a blanket requirement cannot be reasonable in cases where a family is simply seeking support for their disabled child or indeed requesting a PCNA. Even in cases where a child is a 'looked after child' the regulations¹⁰² specify that there may be situations where this is not appropriate – for example where a child of sufficient age and understanding refuses or if for some other reason the local authority representative considers it inappropriate to do so.
- 5.39 In contrast, however, 'Working Together 2018' simply states that '[w]here possible, children should be seen alone' (p.22) – without providing any guidance as to when this would be – and when it would not be – reasonable. Although (as noted above) over 80 per cent of the assessment protocols identified, specified that the child should be seen alone and/or have their bedroom inspected, none provided guidance as to when this would be / would not be reasonable.
- 5.40 Social workers are, the evidence suggests, routinely entering 'families' most intimate spaces':¹⁰³ going 'right into the heart of families' inner space – into their bedrooms, bathrooms and kitchens'¹⁰⁴. As discussed at para 2.34, such action constitutes a substantial interference with the fundamental right of disabled children and their families to 'respect for private and family life, and home'. Article 8 ECHR requires that States evidence the steps that they are taking to ensure that this 'respect' is 'practical and effective' – that the right is concrete, accessible and a reality for all citizens.¹⁰⁵ In this context, this must

¹⁰¹ R Hood, A Goldacre, S Gorin, P Bywaters, and C Webb *Identifying and understanding the link between system conditions and welfare inequalities in children's social care services* (Nuffield Foundation 2020) page 100 – 'while practice models often emphasise the importance of empathy, relationships and the search for solutions, the institutional context of [Children's Social Care] encourages a technocratic, adversarial mode of working'.

¹⁰² The Care Planning, Placement and Case Review (England) Regulations 2010 No. 959 reg 29 requires, for example that social work visits to see the looked after child 'must speak to [the child] in private'.

¹⁰³ H Ferguson 'Making home visits: Creativity and the embodied practices of home visiting in social work and child protection' *Qualitative Social Work* 2018, Vol. 17(1) 65–80 at 67.

¹⁰⁴ *Ibid* at 75.

¹⁰⁵ *Golder v. UK* (1975) *Artico v Italy* (1980).

include ensuring that there is explicit guidance and social work training – as to when an interference with this right is legitimate and proportionate and when it is not.

- 5.41 As noted above, (para 2.35) interferences of this nature are not excused simply by virtue of the fact that family invited the social worker into their home – or ‘agreed’ to the ‘request’ to inspect the children’s bedrooms / to allow their children to be interviewed alone, given the invidious situation this creates. Requests of this kind are an example of what the 2000 practice guidance (at para 2.17) refers to as ‘pretend choices’. They are in fact no choices at all, given the fear of many parents that the authority will use a refusal as grounds to escalate its intrusive investigations through the use of its significant statutory powers.¹⁰⁶
- 5.42 The requirement in ‘Working Together 2018’, that ‘children should be seen alone’ can also be seen as a further example of the document’s implicit discriminatory impact. Its disablist assumption that disabled children are the same as children who have been neglected or abused. Many disabled children have impairments that interfere with their ability to communicate or to comprehend what is said to them; many have sensory impairments and many experience social communication and social interaction difficulties. Interviewing such children alone may well cause them (and in consequence their parents) significant distress and be wholly counterproductive for all manner of reasons.
- 5.43 Clearly, it is going to be important for assessors to be able to see, communicate and where possible consult with a disabled child – but guidance that is fit for purpose must be particularly sensitive to how this is done. In this context, the 2000 practice guidance (paras 2.17-2.18 above) provides a graphic illustration of the problem – by citing the following comment made by a parent of a ‘13 year old boy with severe learning disabilities and autism’:

I have no problem with you consulting my child. In fact I would like to know how to do so myself. But sending him this questionnaire is just bizarre. I showed him the form and he tried to eat it.

Absence of truly ‘local’ protocols for assessment

- 5.44 As noted above (para 2.20), in 2013 a much briefer version of the ‘Working Together’ guidance was published which cancelled the 2000 Assessment policy and practice guidance: guidance that provided essential detail as to how the assessment process should be applied in ‘non-neglect / abuse cases’ - and importantly (in the context of this report) how it should be applied when considering the needs of disabled children and their families. In place of the 250 pages of cancelled guidance, the ‘Working Together’ guidance required that local authorities develop and publish ‘local protocols for assessment’. This requirement remains in the current (2018) iteration of the ‘Working Together’ guidance (paras 46 – 50):¹⁰⁷ requiring that these protocols should, for example

¹⁰⁶ By analogy, see for example *Saint-Paul Luxembourg S.A. v. Luxembourg* (Application No. 26419/10) 18 April 2013 and *Sanoma Uitgevers B.V. v. The Netherlands* (Application No. 38224/03) 14 September 2010.

¹⁰⁷ HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (HM Government 2018): the version of the on-line guidance as at 1 May 2021.

‘set out clear arrangements for how cases will be managed once a child is referred into local authority children’s social care’ and ‘reflect where assessments for some children will require particular care’.

- 5.45 If the intent behind this major policy change was to enable local authorities to develop responsive policies that reflected local circumstances, the research underpinning this report demonstrates that this has signally failed. As noted above (para 4.19), of the protocols identified (n = 125), 87 per cent appeared to have delegated the bulk of their drafting and management responsibilities for these protocols to the private sector. The vast majority of these protocols were found to be very similar – and in some material respects identical – giving the impression that many authorities have, in effect, purchased ‘off the shelf’ protocols.
- 5.46 What is conspicuous about the majority of these protocols is the absence of detailed guidance concerning the key issues highlighted in this report. The importance of assessing disabled children and their families differently to children suspected of being neglected or abused. The importance of ensuring that the assessments of all disabled children (who come within the definition in section 17(11) of the 1989 Act), specifically consider their entitlement to the support services reserved for them under the 1989 and 1970 Acts. The importance of not interfering unnecessarily with the Article 8 (ECHR) rights of disabled children and their families; the process by which a decision is made as to when it is legitimate and proportionate to seek to interview a child alone or to inspect a child’s bedroom; the importance of those involved in assessing the needs of disabled children having appropriate expertise and training; the legal duties on assessors to offer PCNAs and so on.

Inaccessible information

- 5.47 The obligation to ensure that information is accessible in order that disabled people can ‘live independently and participate fully in all aspects of life’ is a fundamental responsibility of the Government (Article 9 UNCRPD).
- 5.48 As with previous research, the current study has highlighted as problematic the issue of accessibility. Most obviously this has arisen in the relatively small number of assessment protocols that the research team were unable to locate (see para 4.17 above).
- 5.49 A much greater problem concerns the lack of detail concerning the process by which disabled children and their families can access their legal entitlements under the 1989 and 1970 Acts. The absence of explanations in assessment protocols, as to the process for assessing disabled children who are not being neglected or abused is compounded by separate and labyrinthine local policies describing local authority eligibility criteria and thresholds for assessments. These policies are invariably phrased in highly subjective terms – for example the need for conditions to be ‘severe’, ‘significant’, ‘profound’ etc. and not infrequently require that the child satisfy more than one such condition. The

2020 research study¹⁰⁸ was unable to identify 23 local authority children's services eligibility criteria policies (despite there being a legal duty to make these accessible)¹⁰⁹ and concluded that a further 33 policies were so defective as to be incapable of acting as functional criteria for determining eligibility. In addition, it found that out of those 93 eligibility criteria policies (with an intelligible criteria which could be found), a further 41 (44 per cent) appeared to unlawfully discriminate against disabled children with autism. The current research suggests that this latter figure is in practice greater. Findings from the parent carer-led organisations survey identified a further six local authorities operating implicit 'unwritten' policies of this last kind – meaning that, in total, 47 English local authorities were (at the time of the survey) operating either explicit (written) or implicit (unwritten) 'autism plus' criteria.¹¹⁰

5.50 Earlier reports have drawn attention to the failure of children's services authorities to meet their statutory duties to publish information – for example, on their 'Local Offer' websites – which the House of Commons Education Committee¹¹¹ has described as sometimes 'unusable and useless'. A 2016 report¹¹² concerning the duty to publish 'short breaks' details for disabled children found that in half the authorities surveyed they were difficult to locate (and especially so for parent carers), often out of date and frequently with broken hyperlinks.

5.51 In the context of the current research, one independent carer-led support group summarised the results of their internet search using 'disabled children + their authority name'. The search identified:

- Confusing and opaque routes to advice and assessment – an information directory is provided with a page for the DCYPS [Disabled Children and Young Person's Service]. When we used the listed email address to contact the service, we were instructed to instead contact 'the Family Information service' who would use a 'screening tool' before any referral could be possible, and for which we can find no information;
- Multiple versions of the same documents, often with no date on them and provided through links on the same webpage;
- These included eligibility criteria for a service from DCYPS, which make no mention of the screening process, but have changed from Autism being a 'substantial and permanent disability' for the purpose of eligibility, to requiring this to be a 'severe learning disability and/or autism with challenging behaviour';
- Information provided for families to access a support service and short breaks provision where the only referral telephone number is the safeguarding phone number; and
- "How to access support" documents that are several years out of date and which make reference to a support organisation which no longer exists.

¹⁰⁸ P Bahri, L Clements, AL Aiello and T Hutchinson *Unlawful restrictions on the rights of disabled children with autism to social care needs assessments* (Cerebra 2020).

¹⁰⁹ Children and Families Act 2014 s31.

¹¹⁰ I.e. half of the authorities for which it was possible to identify intelligible eligibility criteria.

¹¹¹ House of Commons Education Committee 'Special educational needs and disabilities' HC 20 (House of Commons 2019) p.5

¹¹² S Howley, B Thorne and L Clements *Local Authority Short Breaks Statements Accessibility and Accuracy* (Cerebra 2016).

Why have policies and practices of this kind developed?

- 5.52 This study identifies a range of state behaviour that appears to be unlawful. It is however outside the scope of the research to identify the reasons why these practices have developed, have been tolerated / encouraged and why they persist.
- 5.53 It is however clear from the above analysis, (see paras 2.19-2.21 above) that the various iterations of the 'Working Together' Statutory Guidance have sought to respond to a series of tragic deaths of children, deaths (and the subsequent reports of public inquiries) that have attracted very considerable publicity.¹¹³ Responses of this kind have been described by Professor Eileen Munro¹¹⁴ as creating an 'over-bureaucratised' system where social workers' ability to 'exercise professional judgment in deciding how best to help children and their families', has been stifled by a managerial culture whose primary concern was 'compliance': compliance with the auditing requirements of Ofsted and its perceived need for 'meticulous bureaucratically rational records'. In Munro's opinion, almost every inquiry into a killing of a child has recommended a ratcheting up of these mechanisms – the cumulative effect of which has been the present dysfunctional and heavily bureaucratised system.
- 5.54 This concern is echoed by the MacAlister review¹¹⁵ which referred to the substantial increase in section 47 investigations (see paras 2.10-2.11 above) and suggested that although this may be partially attributable 'to rationing of services', it also suggested 'a growing risk aversion in the system as diagnosed by the Munro review ten years ago' and that 'the underlying problems identified by Munro remain'.
- 5.55 The understandable political preoccupation with child neglect and abuse has not only overshadowed the pressing needs of disabled children and their families for support but it appears that these two quite distinct issues have also (at times) become inappropriately entangled. In 2013 – when it was proposed that parent carers should have a right to a separate need's assessment – this was opposed by the then Government, with its Education Minister stating:¹¹⁶

We are clear that any change to the Children Act 1989 to assess the needs of parent carers separately would change fundamentally the principles of the Act and risk the needs of the children becoming second to those of their parent. Recent serious case reviews for Daniel Pelka and Keanu Williams have shown starkly what can happen when the needs of parents are put ahead of those of the child.

¹¹³ See for example HM Government *Keeping Children Safe – the Government's response to the Victoria Climbié Inquiry Report and Joint Chief Inspectors Report: Safeguarding Children* CM 5861 (The Stationery Office 2003) to which the 2006 Working Together guidance was a response.

¹¹⁴ E Munro, *The Munro Review of Child Protection: final report. A child-centred system* Cm 8062 Department for Education, Stationery Office, 2011, and see also L Clements *Clustered Injustice and the level green* (Legal Action 2020) p84.

¹¹⁵ An independent review of children's social care (chaired by Josh MacAlister) *The Case for change* (2021) p.30 – see para 1.12 above.

¹¹⁶ See for example Joint Committee on Human Rights *Legislative Scrutiny: Care Bill* Eleventh Report, chapter 5 paras 106 – 114 and the House of Lords speeches of Baroness Lister of Burtersett (column 1194) and Lord Nash (column 1196) in *House of Lords Hansard Children and Families Bill Volume 751* (28 January 2014).

- 5.56 This argument was rejected by the Joint Committee on Human Rights¹¹⁷ and indeed the Minister later apologised for this comment.¹¹⁸ However the fact that it was made, may give an insight into the policy considerations of the Government at that time: a time when the pivotal 2013 'Working Together' guidance was published (see para 2.20 above).
- 5.57 There is certainly evidence to suggest a link between Ofsted inspections and the 'greater use of child protection interventions'.¹¹⁹ During the research programme evidence emerged that suggested that at least two councils preparations for an Ofsted inspection included checking that all assessment documents demonstrated that children had been seen alone and their bedrooms inspected (with one producing a 'crib sheet' to aid this process).
- 5.58 The downgrading / marginalisation of disabled children's assessments could well be seen as a natural consequence of this heightened child protection focus – such that the most recent data suggests that only 8.7 per cent of children's services assessments related to disabled or ill children.¹²⁰
- 5.59 The repeal in 2013 of the 2000 policy and practice guidance (see para 2.20 above) and the requirement that these be replaced by 'local' assessment protocols may well have been part of the 'Localism Agenda' that resulted in, among other things, the enactment of the Localism Act 2011. Although much of this is speculation and outside the scope of this research project – there is little doubt that these changes have significantly and negatively impacted on the well-being of disabled children and their families.

¹¹⁷ Joint Committee on Human Rights *Legislative Scrutiny: Care Bill* chapter 5 para 113.

¹¹⁸ Lord Nash (column 1196) in *House of Lords Hansard Children and Families Bill Volume 751 (28 January 2014)*.

¹¹⁹ R Hood, A Goldacre, S Gorin, P Bywaters, and C Webb *Identifying and understanding the link between system conditions and welfare inequalities in children's social care services* (Nuffield Foundation 2020) page 100.

¹²⁰ Department for Education *Characteristics of children in need: 2017 - 2018 England* (2018) Figure O (there were 35,209 assessments that year).

Cerebra and Leeds University Child in Need Assessment Survey 2020

Why are we carrying out this survey?

The purpose of a 'Child in Need' assessment is to gather enough information to decide what care and support needs to be provided for a disabled child and their family.

Cerebra receives a significant number of enquiries from families about 'child in need' assessments. The object of this survey is to obtain the views of parent carer support organisations about how well assessments are carried out in their geographic area highlighting things that are done well and things that could be improved / changed.

Some families have expressed concerns about the level of experience and / or knowledge that some practitioners have of the needs of disabled children. In addition, some families have expressed concerns about the fact that assessments have focused on child protection issues (to determine whether the child is suffering, or is likely to suffer, significant harm) rather than the child's (and the family's) disability related needs. A key objective of this research is to determine whether these concerns are isolated or representative of a more deep-seated and widespread problem.

The survey responses will be anonymised and then analysed by our Legal Entitlements and Problem-Solving (LEaP) Project Research Team under the supervision of Professor Luke Clements, Cerebra Professor of Social Justice at Leeds University.

We are aiming to publish the findings of this research in the Spring of 2021. Previous research reports of this kind produced by the LEaP Project can be accessed at https://essl.leeds.ac.uk/downloads/download/45/cerebra_pro_bono_research_programme.

If you know of any other 'parent-carer led' organisations which support disabled children and their families and who you think would be interested in completing the survey, please feel free to share this with them.

The survey has just eight questions.

The survey will close on **31 August 2020**.

-
1. Which is the social services authority your group has most dealings with? If there is more than one, please name them all and (if possible) list the one with which most contact it has, first.

Local authority name(s)

2. If you consider that the authority responds to parental requests of this kind by focusing on the child's disability related needs please answer 'Yes'. If you consider that the authority's response is primarily concerned with the issues of child protection (i.e. investigating potential abuse and/or neglect) please answer 'No'. If you consider that neither answer is correct – please answer 'Neither'.

In all cases, please provide any comments/additional information you think relevant in the box below:

Yes / No / Neither

Comments

3. Do you consider that, in general, getting the authority to carry out an assessment of a child's disability-related needs is:

Very easy / Easy / Neither easy nor difficult / Difficult / Very difficult

Please add any relevant comments]

Comments

4. Are families routinely told about the right to have a 'parent carer' assessment?

Yes / No / Not sure

Please add any relevant comments]

Comments

5. Is the assessment usually undertaken by a social worker with specific training in the needs of disabled children and their families or by a generic 'child-in-need' social worker or someone else?

Disabled children expert / Generic social worker / Other / Not sure

Please add any relevant comments:

Comments

6. What aspects of the assessment process do parents of disabled children generally report as being well done (i.e. in terms of focusing on the needs of the child and the family for support)?

Comments

7. What aspects of the assessment do parents of disabled children generally report as being problematical (i.e. in terms of focusing on the needs of the child and the family for support):

Comments

8. If you have any other relevant comments that you think will be of interest to us please could you put them in the comment box below:

Comments