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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.

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

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

Foreword from the CEO of Cerebra

There are moments in our work at Cerebra that stop us in our tracks. This report is one of them.

It is a painful truth that many disabled children and their families are being traumatised—not by illness, not by accident, but by the very public services that are meant to help them. This is not a fringe issue. It is not rare. It is not acceptable. It is happening every day, in every corner of our society, and it is breaking people.

We call it Systems Generated Trauma. And once you see it, you cannot unsee it.

This report lays bare the reality of what families face when they ask for help. It is a reality shaped by suspicion, blame, bureaucracy, and indifference. Families are forced to navigate systems that are fragmented, opaque, and often hostile. They are made to feel like liars, failures, or criminals. They are punished for their child's disability. They are left exhausted, isolated, and afraid.

We have spoken to parents who are terrified to ask for help again. Who have lost faith in the institutions that should be their lifeline. Who carry the scars of false accusations, intrusive investigations, and relentless battles for basic support.

This is not just a failure of policy. It is a failure of compassion.

At Cerebra, we believe that every child deserves to be seen, heard, and supported—and that every parent deserves to be treated with dignity and respect. We believe that asking for help should never cause harm.

This report is a call to action. It demands accountability. It demands change. It demands that public services recognise the trauma they are causing and work with families to rebuild trust and redesign systems that heal rather than hurt.

We know that change is possible. We know that solutions exist. But we must be brave enough to confront the truth, and bold enough to act.

To every family who shared their story: thank you. Your courage is the foundation of this work. We see you. We believe you. We stand with you.

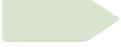
To policymakers, practitioners, and leaders: this is your moment. Read this report. Let it move you. Let it challenge you. And then—let it change you.

Because our children deserve better. And so do their families.

Jess Camburn-Rahmani

Chief Executive Officer, Cerebra

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Executive Summary

Executive Summary

This report explores the phenomenon of ‘Systems Generated Trauma’: the severe harm that disabled children and their families experience through their interactions with public services. The research identifies a persistent pattern of public policies and practices, particularly within health, social care, and education systems, that are complex, dysfunctional and actively harmful. While these harms are generally unintended, they lead to significant distress and negative consequences for already disadvantaged families. The study highlights the urgent need for a fundamental shift in institutional culture and a move beyond superficial policy adjustments to address these systemic issues.

The research underpinning the report included a survey of parent carers’ experiences, Freedom of Information requests and documentary review. The survey evidence (from over 1,200 parents) highlights that the majority of respondents experienced more significant distress from adverse institutional treatment than from other major life events. The harms include: deteriorating mental and physical health; financial strain; disrupted education for their children; profound loss of trust in public services; damaged family relationships; and thoughts of suicide.

The report considers a wide range of traumatising interactions with public services, including:

- parents who seek support to address their disabled child’s needs and who are then subjected to intrusive and humiliating investigations, where they are treated with suspicion (as if they are abusive or neglectful) and feel blamed for their child having such needs;
- parents of disabled children who are threatened with prosecution because their child is ‘school refusing’ and children with special education needs being disproportionately affected by school exclusions;
- carers of disabled family members who receive a modest ‘Carers Allowance’ being threatened with criminal prosecution after unwittingly breaching draconian earnings rules;
- a disturbing prevalence of unsubstantiated and traumatising allegations that parents are fabricating or inducing their child’s illness; allegations that remain on the family’s health and social care records even when they have been shown to be false.

Against this backdrop, the report examines the rise of ‘trauma-informed practice’ guidance in the UK: guidance that reminds practitioners that many people with whom they have contact, may have had traumatic life experiences. While welcoming the development of guidance on this issue, the report expresses grave concern that these documents, in general, fail to alert practitioners to the fact that institutional systems themselves can be the primary source of trauma.

These systemic failures are not isolated incidents but are widespread and embedded in official guidance and institutional practices. The research critiques the persistent failure of public bodies to take necessary action to mitigate known harms, even when presented with straightforward solutions. It cites examples where defective guidance and practices remain, despite being shown to cause significant trauma to families. It

characterises this inaction as a form of ‘indifference’: a profound inertia within these systems, which continue to compound the distress of families rather than provide the support that they desperately need.

The research paper argues that meaningful change requires a transformation in how public services operate, fostering genuine partnership, empathy, trust, and accountability. The report serves as a call to action for governments and public bodies to thoroughly review and reform their policies to prevent further harm, ensuring that their actions genuinely align with their stated commitment to serving the wellbeing of disabled children and their families.

Key Messages

- The overwhelming message emerging from the over 1,200 responses to the survey is that the system with which parents have to engage in order to obtain support for their disabled child’s needs is itself causing immense trauma. Trauma that in many instances is considered to be far in excess of the trauma families have experienced before coming into contact with the relevant institutions, for example traumas resulting from adverse childhood experiences, domestic violence, mental health difficulties and so on.
- Over 90 percent of the English public sector ‘Trauma Informed’ practice publications analysed in the research fail to acknowledge this very significant source of trauma. These publications describe the cause of ‘service user’ trauma as ‘other’: they locate its source outside the organisation - as generated by the individual’s past life experiences.
- There is a profound lack of accountability in terms of public bodies being held to account for the harm caused by their defective administrative systems.
- Although, in almost all cases, the trauma created by public sector systems was unintended, the failure of governments and other public bodies to take purposeful remedial action when the system defects are identified, renders untenable any assertion of blamelessness: in social harm theory, inaction of this kind is best described as ‘moral indifference’.

Key action points

There is a fundamental need for public bodies to take ownership of the trauma generated by their systems. To do this they must:

- Ensure that their ‘Trauma Informed’ publications fully acknowledge that the most damaging traumas many families experience, result from their dysfunctional systems.
- Undertake a review, working in co-production with parent carers and their support groups, (a ‘Systems Generated Trauma Impact Review’) of their existing (and any new) relevant policies and practices to minimise the adverse impact they have on disabled children and their families.
- Accept responsibility for the complex systems that they have developed and in consequence to provide meaningful support and advocacy to families who have to navigate them.

“

*Just a devastating
process on top of an
already difficult life*

”



Chapter one

Introduction

Chapter 1: Introduction

- 1.01. The Legal Entitlements & Problem-Solving (LEaP) project is an innovative problem-solving project that helps families of children with brain conditions cope with the legal barriers they face. We listen to families and help them get the knowledge they need to access health, social care and other support services. We identify the common legal problems that prevent families getting access to services and we develop innovative ways of solving those problems. We aim to reach as many families as we can by sharing our solutions as widely as possible.
- 1.02. Public service policies and practices that actively harm disabled children and their families have been a persistent finding of many of the LEaP project's research reports: harms resulting from dysfunctional siloed systems; systems that are impossibly complex to navigate; systems that institutionalise parent blame; systems that fail to factor in the multiple, synchronous challenges that families with disabled children encounter; and systems that traumatise. In this report harms of this nature are collectively referred to as 'Systems Generated Traumas'.
- 1.03. The harms caused by these systems are frequently serious or very serious but are generally unintended. In many cases our research has identified relatively straightforward system adjustments that could be taken to mitigate or entirely remove these unintended adverse impacts of the relevant policies. Sadly, all too often, those with the power to effect these ameliorating measures fail to take the necessary action, and we return to this issue in chapter 8.
- 1.04. An impetus for the research underpinning this report has been the publication by a number of English health and social care bodies of policy documents that advocate the adoption of 'Trauma Informed' practices. In themselves documents of this kind are to be welcomed as they convey an awareness that many of those with whom these organisations interact, have experienced life changing traumas. This research has sought therefore, to better understand the motivations for this policy innovation and the extent to which these documents acknowledge the Systems Generated Traumas that result from their own internal policies and practices.
- 1.05. A final element of the research programme involved an analysis of a survey of parent carers (in this report referred to as the 'Cerebra survey'). The survey asked that they describe the adverse impacts they had experienced as a result of their engagement with local authority, health, social care and education systems.

Trauma defined

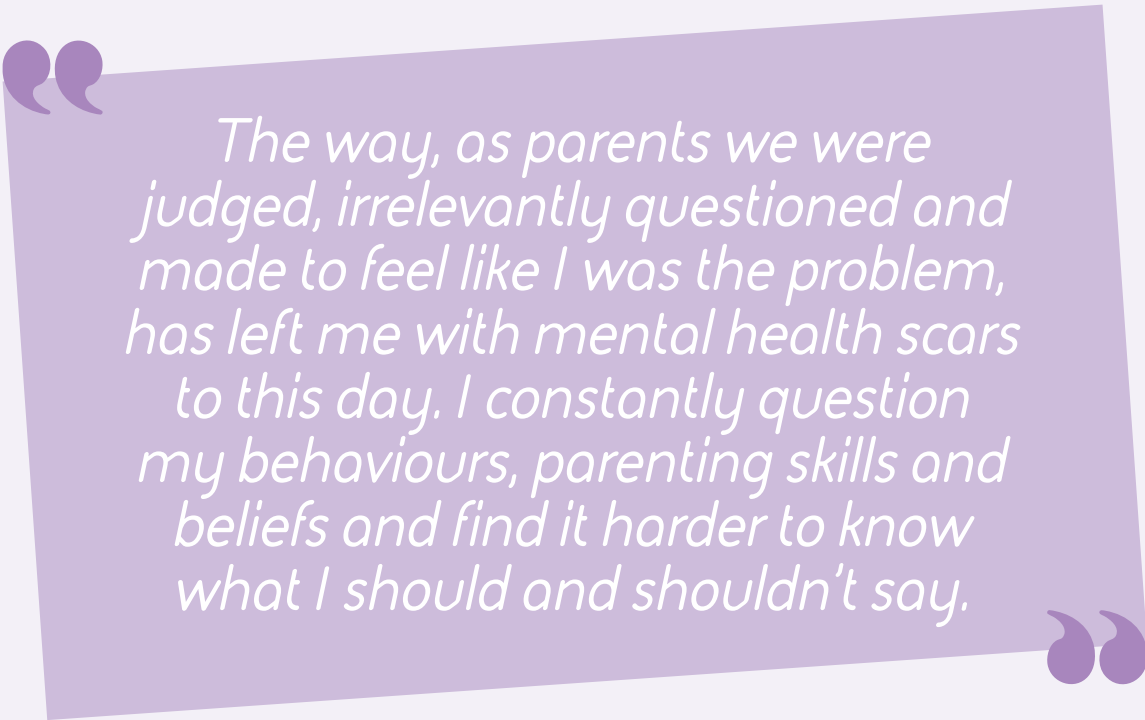
- 1.06. This report is concerned with individual experiences of 'trauma' - an expansive and evolving concept.¹ However, for the purposes this report, we adopt the

¹ A concept whose meaning has been 'relentlessly expanded ... colonizing new semantic territory and moving out of its original disciplinary home in general medicine into psychiatry, psychology, and, increasingly, the humanities' N Haslam & M McGrath 'The creeping concept of trauma' Social Research, (2020) 87, 509-531 at 510.

definition of trauma provided by the English Government in its 2022 guidance 'Working definition of trauma-informed practice',² namely:

Trauma results from an event, series of events, or set of circumstances that is experienced by an individual as harmful or life threatening. While unique to the individual, generally the experience of trauma can cause lasting adverse effects, limiting the ability to function and achieve mental, physical, social, emotional or spiritual wellbeing.

- 1.07. It is a definition derived in large measure from that adopted by the United States' Substance Abuse and Mental Health Services Administration (SAMHSA)³ (see para 3.09 below). It is a definition that closely parallels the definition in the equivalent guidance in Scotland⁴ and is similar to (but narrower than) the definition in the equivalent guidance in Wales.⁵ It is a definition that is subjective (i.e. as 'experienced by an individual') and one that takes no account of the source of the harm.



The way, as parents we were judged, irrelevantly questioned and made to feel like I was the problem, has left me with mental health scars to this day. I constantly question my behaviours, parenting skills and beliefs and find it harder to know what I should and shouldn't say.

² Office for Health Improvement & Disparities Guidance *Working definition of trauma-informed practice* (2022) at <https://www.gov.uk/government/publications/working-definition-of-trauma-informed-practice/working-definition-of-trauma-informed-practice>.

³ SAMSHA 'Concept of Trauma and Guidance for a Trauma-Informed Approach' (2014) p.7, at https://www.nctsn.org/sites/default/files/resources/resource-guide/samhsa_trauma.pdf.

⁴ Scottish Government 'Trauma-Informed Practice: A Toolkit for Scotland' 2021, p.8. where trauma is defined as resulting 'from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional or spiritual wellbeing' (see also para 3.11 below).

⁵ Ace Hub Wales '[Trauma-Informed Wales: A Societal Approach to Understanding, Preventing and Supporting the Impacts of Trauma and Adversity](https://traumaframeworkcymru.com/)' (2022) p.5 at <https://traumaframeworkcymru.com/> where trauma is defined as 'any experience that is unpleasant and causes, or has the potential to cause, someone distress and/or anxiety' (see also para 3.15 below).

Report structure

1.08. The succeeding sections of this report are structured as follows;

-  **Chapter 2:** reviews and re-analyses, from a ‘Systems Generated Trauma’ perspective, the findings of earlier research undertaken by the LEaP project as well as other research programmes that have described harms of this nature.
-  **Chapter 3:** considers the emergence of international interest in ‘trauma informed practice’ over the last 25 years and the publication of relevant documents/guidelines on this issue by the governments in Scotland, Wales and England.
-  **Chapter 4:** provides an overview of the extent to which domestic law can require public bodies to amend their practices and procedures where there is cogent evidence that they are having a disproportionately adverse impact on individuals.
-  **Chapter 5:** contains a brief summary of a range of theoretical approaches that scholars and social policy activists have adopted in order to conceptualise the severe harms that individuals experience as a result of dysfunctional institutional systems.
-  **Chapter 6:** outlines the methodology adopted in this research study.
-  **Chapter 7:** describes and categorises the empirical data (both quantitative and qualitative) obtained in the research study.
-  **Chapter 8:** critically analyses and contextualises the research findings in order to better understand: (1) the extent to which families with disabled children experience systems generated traumas (and the nature of these adverse experiences); (2) the extent to which local ‘trauma-informed practice’ documents acknowledge the systems generated traumas experienced by families with disabled children; and (3) what needs to be done to minimise the harms that result from such systems.
-  **The Appendices:** comprising, (1) the Cerebra survey questions; (2) the text of the Freedom of Information requests submitted to local authorities; and (3) selected extracts from responses to the Cerebra survey question 7.



Chapter two

*The impact of Systems
Generated Trauma on disabled
children and their families*

Chapter 2: The impact of Systems Generated Trauma on disabled children and their families

2.01. In this chapter we consider the systems generated traumas identified in previous LEaP project research reports.⁶ In addition, we reference other research papers and publications that have described severe harms of this nature. At chapter 8 we describe and analyse the responses provided by the responsible institutions when their attention has been drawn to the traumas generated by their systems.

Seeking social care support for a disabled child and their family

- 2.02. For many years, Cerebra has received reports from families describing their negative interactions with local authority children's services departments, often in terms of a 'fight' or 'battle' for support.
- 2.03. Parents already exhausted from their caring responsibilities describe making repeated requests for help; getting assessed by professionals who have no training or expertise in disability and who don't understand the additional demands of caring for a disabled child; failing to get their views heard at meetings or recorded in paperwork (which is not shared with them); not being informed of decisions or the reasons for those decisions; having to correct mistakes, challenge assumptions about their child's needs and decipher inscrutable eligibility criteria; having to stifle any display of emotion for fear of being labelled 'uncooperative' or 'difficult'; being expected to give up work to meet their child's needs; being referred to unsuitable services; having their case closed or 'stepped down' without notice; being left bewildered by circuitous complaints handling and an absence of advocacy support.
- 2.04. Families regularly report feelings of exhaustion, isolation and despair. Cerebra has supported parents from all backgrounds, who, without exception, have encountered significant difficulty in asking for help – including special needs teachers and social workers whose professional expertise provided little or no protection from the trauma generated by the system itself.
- 2.05. Not untypically, these reports 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 they are treated in a manner that suggests to them that they are considered to be neglectful and/or abusive parents.
- 2.06. Parents describe how social work visits may take place with little or no notice and at inconvenient times,⁷ with the parent then being told that each of their

⁶ Particular reference is made to the following publications emerging from Cerebra Research studies: L Clements & A L Aiello [*Institutionalising Parent-carer Blame. The experiences of families with disabled children in their interactions with English local authority children's services departments*](#) (Cerebra, 2021); L Clements & A L Aiello [*The prevalence and impact of allegations of Fabricated or Induced Illness*](#) (Cerebra, 2023); and L Clements, A L Aiello & D Tilley 'Managing the data: allegations that parents are fabricating or inducing their child's illness' in L Clements & A L Aiello (eds) *Understanding Parent Blame Institutional Failure and Complex Trauma* (Policy Press, 2025).

⁷ 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.

children had to be interviewed alone and their bedrooms inspected. Parents describe the power imbalance that exists in such situations; the fear that they are being ‘judged’; the fear that resistance to such ‘requests’ risks being treated as evidence of parental awkwardness – as of the parent having something to hide.

2.07. Some of the comments made by organisations representing parents of disabled children, describing these humiliating and intimidating interactions with children’s services, include:⁸



- *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.*
- *Much fear of social services, being judged, having to explain everything.*
- *The panic the parent(s) endure becomes intolerable*
- *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.*
- *Parents described themselves at breaking point and that the battle with the local authority was exhausting just to get an assessment, never mind services.*
- *My advice to others would be to stay well clear. They have nothing to offer but distress, humiliation, 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.*
- *Families become broken and children traumatised.*
- *How many families break down and become a one parent family, because of all the stress and resulting financial difficulties too?*



2.08. A 2020-2021 Cerebra research programme undertaken by the LEaP project sought to better understand the prevalence and reasons for such intrusive policies. The report on this research (entitled ‘Institutionalising Parent Carer Blame’⁹) demonstrated that harmful action of this kind is not unusual and,

⁸ Extracted from L Clements & A L Aiello *Institutionalising parent carer blame. The experiences of families with disabled children in their interactions with English local authority children’s services departments* (Cerebra 2021) para 4.15.

⁹ *ibid.*

indeed is well documented. It has been described by researchers, carer and disability organisations as well as in official reports.¹⁰ The research identified central government statutory guidance¹¹ as a key driver for this trauma generating phenomenon: guidance that had then been embedded by English local authorities into their assessment protocols and practices and in all probability reinforced by the auditing regime by which these authorities are judged.

Seeking medical care and support for a disabled child and their family

- 2.09. During the parent carer blame research programme (outlined above) Cerebra was contacted by parents of disabled children who had experienced an extreme form of parent blame, namely that they had been accused of fabricating or inducing their child's illness/their impairments (FII) – a behaviour formerly referred to as Munchausen's Syndrome by Proxy. The fact that significant numbers of parents had experienced accusations of this kind was in itself surprising, given that FII is generally considered to be a very rare condition.¹² Without exception, the parents described the trauma that they experienced when they learned that such an accusation had been made and many spoke of the severe impact that the accusations had had on their children – including the disabled child that was the subject of the FII allegation.
- 2.10. In 2022-2023 Cerebra research, undertaken by the LEaP project, sought to better understand the prevalence of allegations of this kind, and the reasons why so many families reported that they had been accused. The 2023 report (entitled 'The prevalence and impact of allegations of Fabricated or Induced Illness'¹³) suggested: that **most FII accusations (over 80 percent) either resulted in no follow up action or were subsequently abandoned**;¹⁴ that although most allegations were made by healthcare practitioners, significant numbers were made by social workers and by schools; that **half of all the FII allegations in the research sample had been made after a parent carer had complained about the actions of the relevant public body**; and that disabled parents were four times more likely to be accused of FII than non-disabled parents.

¹⁰ See for example, 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* (2021) Department of Health and Social Care; and J MacAlister 'The Case for change' (2021) at <https://webarchive.nationalarchives.gov.uk/ukgwa/20230308122442/https://childrensocialcare.independent-review.uk/case-for-change/>.

¹¹ Then being, HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (HM Government 2018).

¹² There appears to be no reliable data concerning the prevalence of FII but the limited research that has been undertaken concerning Munchausen Syndrome by Proxy (and connected conditions) suggests a prevalence rate of 0.4 per 100,000 children under 16 – see R J McClure, P M Davis, S R Meadow & J R Sibert 'Epidemiology of Munchausen syndrome by proxy, non-accidental poisoning, and non-accidental suffocation' in *Archives of disease in childhood*, (1996) 75(1), 57-61; and see also F Gullon-Scott and C Long, 'FII and Perplexing Presentations' *British Journal of Social Work* (2022) 52, 4040 – 4056 at 4043.

¹³ L Clements & A L Aiello *The prevalence and impact of allegations of Fabricated or Induced Illness (FII)* (Cerebra 2023).

¹⁴ Ibid paras 5.06-5.07: of the research sample, most FII allegations (84 percent) resulted in no follow up-action or were abandoned and in 95 percent of the cases, the child(ren) remained living with the parent.

2.11. The research study included a survey of parents that (among other questions) asked that they describe the impact the FII allegation had had upon them and their family. **There were 377 responses to this question, comprising ‘41 pages of harrowing evidence’.**¹⁵ Parents described the impact using words such as ‘trauma’, ‘trust’ (as in ‘loss of’), ‘fear’, ‘scared’, ‘devastating’ ‘destroyed’, ‘suicidal’, ‘isolation’ (in the sense of avoiding contact with health, social care and education services) and in terms of having to move homes and of lost employment. Comments included:¹⁶



- *I am completely traumatised so are the children. Just the thought of engaging with social care gives me a panic attack where I really feel like I am going to die.*
- *Daughter too traumatised to talk to professionals or to attend school.*
- *Huge trauma. Physical symptoms, nightmares, high heart rate, hair loss. Feeling of helplessness.*
- *We are not the same people. We are broken and traumatised. We cannot trust anyone any more.*
- *I had a break down. My eldest two children were traumatised as they thought that they were going to lose their brother to the care system. I am now scared to complain and it has affected my mental health. There was a point that I felt suicidal.*
- *Trauma Trauma Trauma. Total distrust of all professionals. Afraid to seek medical advice or treatment for any of the family. Living with the lasting impact of what this has done to our family.*
- *It’s caused lifelong trauma for all of us, especially my autistic son who as an adult is afraid to seek help he needs.*
- *My children and I are traumatised by the threat of having them taken away, I am traumatised having read MASH minutes and realising they were planning to arrest me and put my children into care. Recently my daughter has needed to go to A&E, and we were scared to access medical help.*
- *Trauma, fear, as a parent of a child who had a rare diagnosed condition that must attend hospital regularly it’s like going into battle every day.*



2.12. The research suggested that accusations of FII were geographically widespread impacting on families throughout England, Scotland and Wales. It identified guidance published by the Royal College of Paediatrics and Child

¹⁵ Ibid, Appendix 4 of which contains a 7-page summary of these responses.

¹⁶ Ibid para 5.03.

Health (RCPCH)¹⁷ as a key driver for this trauma generating phenomenon: guidance that was widely referenced by public bodies in the three nations and cited by the three National Governments. The relevant guidance had then been embedded in many local authority and health care safeguarding protocols which formed a core resource for the extensive safeguarding training delivered to healthcare, social care and education practitioners.

- 2.13. As with the earlier ‘parent blame’ research, the FII research programme demonstrated that harmful practices of this kind was not an isolated occurrence and was, indeed, well documented. The potential for the RCPCH guidance to cause disproportionate and adverse impacts had been predicted by other academic researchers,¹⁸ by carer and disability organisations¹⁹ as well as in formal guidance for social workers.²⁰

Unsubstantiated data records

- 2.14. The trauma experienced by families as a result of the way their medical and social care records had been processed, was a frequently mentioned and unforeseen response by parents to the above survey (para 2.11) – and in particular to the question concerning the adverse impact resulting from an unsubstantiated FII allegation.
- 2.15. Extensive electronic records are maintained and shared by the NHS and local authority Children’s Services: records that capture details of almost every interaction these bodies have with families. This information is uploaded onto electronic databases by practitioners and administrators both as free text and as codes (for example codes that denote a particular health condition or a particular safeguarding concern).²¹
- 2.16. For reasons that are obvious it is essential that these records are correct. However, responses to the survey and other contacts the LEaP team have had with parents suggests that this is frequently not the case.
- 2.17. Parents who had seen their NHS and/or Children’s Services records reported being traumatised when they realised that they contained unsubstantiated allegations of a safeguarding nature even in cases where the relevant public body had accepted that the allegations were without foundation. Other parents referred to healthcare consultations (for example at a surgery or A&E) and the

¹⁷ Royal College of Paediatrics and Child Health ‘*Perplexing Presentations (PP)/Fabricated or induced illness by carers: A practical guide for paediatricians*’ (2021) p.11, at <https://childprotection.rcpch.ac.uk/resources/perplexing-presentations-and-fii/>.

¹⁸ See for example, F Gullon-Scott and C Long ‘FII and Perplexing Presentations’ *British Journal of Social Work* (2022) 52, 4040 – 4056 at 4043.

¹⁹ See for example Autism Eye ‘Parents accused of fabricated illness’ (2014) at: <https://www.autismeye.com/parents-accused-of-fabricated-illness/> and Action for M.E. ‘Families facing false accusations’ June 2017 and see also BBC *Carers of children with ME ‘accused of fabrication’* 27 June 2017 at <https://www.bbc.com/news/uk-england-40407174>.

²⁰ C Long, J Eaton, S Russell, F Gullon-Scott, A Bilson, *Fabricated or Induced Illness and Perplexing Presentations. Abbreviated Practice Guide for Social Work Practitioners*, (2022) BASW (The professional association for social work and social workers).

²¹ See for example, L Clements, A L Aiello and D Tilley ‘Managing the data: allegations that parents are fabricating or inducing their child’s illness’ in L Clements & A L Aiello (eds) *Understanding Parent Blame: Institutional Failure and Complex Trauma* (Policy Press, 2025) p.112.

trauma they experienced of seeing a safeguarding ‘red flag’ alert appear on the clinician’s PC screen.²² Not infrequently this could happen when the family had no prior knowledge of such a concern, or where they had been assured that the safeguarding concern had been accepted as invalid. Given that by the age of five, 20 percent of children in England will have been the subject of a safeguarding referral²³ (and 25 percent in Scotland²⁴) this was, in Cerebra’s opinion, a cause for considerable concern.

2.18. This issue is made materially more disturbing by guidance issued by the Information Commissioner (ICO)²⁵ and adopted by the NHS²⁶ and Children’s Services.²⁷ The relevant extract from the guidance is summarised by NHS England, stating that if the data recorded ‘was correct at the time the entry was made but has since changed’ then it is ‘important that this is not amended’.²⁸ This strongly suggests that if an allegation of FII is made (innocently, negligently or indeed malevolently) and it is then accepted as being without foundation – the fact that an allegation was made (with all its pejorative connotations and possible PC ‘red flag pop up’ consequences) must remain on the families’ records.

2.19. Comments made by families on this issue, include:²⁹



- *I’m now scared to even speak to professionals, take my children to seek medical attention over fear & panic attacks & if I do, I’m instantly judged as safeguarding now still appears on my children’s records which instantly affects the treatment my children get.*
- *We live in fear constantly now, I’m too scared to go to a GP or anything else for me and my child. If he’s ill I try and deal with it at home now unless he’s not breathing then I wouldn’t have a choice to phone 999.*



²² Ibid p.113.

²³ A Bilson and K E C Martin ‘Referrals and Child Protection in England: One in Five Children Referred to Children’s Services and One in Nineteen Investigated before the Age of Five’ in British Journal of Social Work (2017) 47, 793–811.

²⁴ A Bilson and M Macleod ‘Social Work Interventions with Children under 5 in Scotland: Over a Quarter Referred and One in Seventeen Investigated with Wide Variations between Local Authorities’ in The British Journal of Social Work (2023) 53(4), 2217–2236.

²⁵ ICO (2024) ‘Your right to get your data corrected’ at <https://ico.org.uk/for-the-public/your-right-to-get-your-data-corrected/>.

²⁶ NHS England (2022) ‘Amending patient and service user records’ at <https://transform.england.nhs.uk/information-governance/guidance/amending-patient-and-service-user-records/>.

²⁷ ICO (2024) ‘What rights do children have?’ at <https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/childrens-information/children-and-the-uk-gdpr/what-rights-do-children-have/>.

²⁸ NHS England (2022) ‘Amending patient and service user records’ at <https://transform.england.nhs.uk/information-governance/guidance/amending-patient-and-service-user-records/>.

²⁹ Responses to question 9 of the FII survey analysed in L Clements & A L Aiello *The prevalence and impact of allegations of Fabricated or Induced Illness (FII)* (Cerebra 2023) para 5.02. The survey question asked respondents to describe the effect on them and their family, of the FII or Perplexing Presentation allegation.



- *I have tried to get this removed by complaining to [the] NHS Trust but they said they wouldn't as it was a data protection issue (which makes no sense!).*
- *You cannot get things removed from medical reports even if you can prove they are wrong and that is not right and worries me hugely.*
- *I don't feel able to seek support for this via my GP due to the safeguarding allegations and hate knowing that I am flagged up on a system in the same way that actual abusers are.*
- *This record is on my [child's] file for life, ... I have no control of this, I appealed and they refused to remove it from my child's file even though it was a false allegation of FII. Whenever I see a doctor etc they read about the allegation ... so I feel like they are judging me. I feel physically and mentally violated.*



Disabled children, their parents and the education system

- 2.20. At the time of writing (September 2025), the most recent data concerning school suspensions and permanent exclusions in England³⁰ reveals a 21 percent increase in suspensions and a 16 percent increase in permanent exclusions (from the previous year) – and that **children with special education needs are over 3 times more likely to be excluded than children with no identified SEN and over 3 times more likely to be the subject of permanent exclusions.**
- 2.21. Through Cerebra's close interactions with disabled children and their parents it is in no doubt as to the traumas many have experienced as a result of the way that they have been treated by the state education system.
- 2.22. In the context of the English system, the House of Commons Education Committee has identified the lack of resources as a key barrier to disabled children's inclusion within mainstream schools. The Committee (in 2023) accepted evidence that the resulting 'unmet need':³¹

translates to internalising—for instance, an increase in anxiety and mental health challenges, externalising behaviours that challenge and the beginning of problems with attendance. That led to poor and at times traumatic experiences in the school environment, increased pressure on home and family life and, ultimately, to further deterioration in attendance, up to the point of non-attendance and placement breakdown.

³⁰ Department for Education *Academic year 2023/24 Suspensions and permanent exclusions in England* 10 July 2025 at <https://explore-education-statistics.service.gov.uk/find-statistics/suspensions-and-permanent-exclusions-in-england/2023-24>.

³¹ House of Commons Education Committee *Persistent Absence and Support for Disadvantaged Pupils*, (2023) Seventh Report of Session 2022–23, HC 970, para 1.01 citing oral evidence given to the Committee on 16 May 2023 by Dr Daniel Stavrou, Policy Vice Chair, Special Educational Consortium at <https://committees.parliament.uk/oralevidence/13160/html/>.

2.23. The evidence suggests that the traumas experienced by disabled children and their parents are further exacerbated by: rigid and punitive pupil behavioural policies;³² the tolerance of bullying;³³ the terror of national targets;³⁴ and threats to prosecute parents³⁵ for their child's non-attendance even when absent for legitimate reasons.³⁶ It is a system that is not working for very many children who are not disabled,³⁷ but disabled children are – in effect – the system's 'canaries'. It is a system where staff are often overstretched and in consequence lack the cognitive space to cope well with criticism and parents who single mindedly advocate for their profoundly unhappy child – a child who may spend all day at school masking³⁸ and then have unmanageable meltdowns at home.³⁹

2.24. Mullally and Connolly in their research⁴⁰ use the term 'School Distress' to describe the difficulties that children have attending school due to extreme emotional distress and the:

devastating impact on the mental health of parents, with parents displaying significantly heightened daily anxiety and significantly lower mood during, but not before, their children's school attendance difficulties.

2.25. In this respect their research engaged with parents who reported (among much else) 'overwhelmingly negative treatment from professionals, including being disbelieved or blamed for their children's difficulties, threatened with fines and

³² Written evidence PA0130 February 2023 submitted by the Children and Young People's Mental Health Coalition to the House of Commons Education Committee (ibid) expressed concern about the rigid use of punitive approaches to behaviour in schools and how this can adversely impact on disabled children and make them less likely to attend school. As one parent observed 'School followed their behaviour policy despite telling me they thought my child was autistic, detentions and isolation escalated the issue in year 7 to persistent absence and now total non attendance.'

³³ The evidence suggests that the proportion of pupils who have been a victim of bullying is higher for pupils with SEND (37% compared with 20% for non-SEND pupils, and 40% for pupils that have an EHCP compared with 23% of those who don't) see for example, S Hingley, E Edwards et al *Parent, Pupil and Learner Panel recruitment wave Department for Education* (2022) at https://assets.publishing.service.gov.uk/media/624444c98fa8f527710aae94/Parent_Pupil_and_Learner_Panel_recruitment_wave_1.pdf; and see also L P Engels 'Parent blame in education: Working together to find solutions to school attendance difficulties' in L Clements & A L Aiello (eds) *Understanding Parent Blame Institutional Failure and Complex Trauma* (Policy Press, 2025) p.38.

³⁴ The 'targets-and-terror system of governance of annual performance (star) ratings' G Bevan and C Hood, 'What's measured is what matters: targets and gaming in the English public health care system', *Public Administration*, (2006) 84(3) 517–538 at 523.

³⁵ Section 444(1) Education Act 1996.

³⁶ 'Such as being more prone to illness or a higher than average number of medical appointments' House of Commons Education Committee *Persistent Absence and Support for Disadvantaged Pupils* (2023) Seventh Report of Session 2022– 23, HC 970, para 1.02.

³⁷ B Bryant & N Parish *Reform of the SEND system* (Isos partnership & the LGA, 2025) at <https://www.local.gov.uk/publications/reform-send-system-what-might-next-stage-look-and-how-can-we-build-consensus>.

³⁸ See for example, C Long, J Eaton, S Russell, F Gullon-Scott & A Bilson *Fabricated or Induced Illness and Perplexing Presentations. Abbreviated Practice Guide for Social Work Practitioners* (BASW 2022) at p.8; and L P Engels 'Parent blame in education: Working together to find solutions to school attendance difficulties' p.38 in L Clements & A L Aiello (eds) *Understanding Parent Blame Institutional Failure and Complex Trauma* (Policy Press, 2025).

³⁹ See generally L P Engels (ibid).

⁴⁰ S L Mullally and S E Connolly "I felt shamed and blamed": an exploration of the parental lived experience of school distress' in *Frontiers in Psychiatry* (2025) 24(16):1489316.

court action, and disempowered by the actions of professionals surrounding their child'. They conclude:

This study highlights a bleak, adversarial, and lonely picture for parents of CYP struggling to attend school. More specifically, the findings depict a system rife with parental blame; a system that appears to isolate parents through hostile, threatening, and punitive actions.

- 2.26. On the basis of the above analysis, it is unsurprising that many families with disabled children feel compelled to remove their children from the mainstream education system⁴¹ and into (in the opinion of the Children's Commissioner for England) 'forced' home education – with the numbers making this decision in England having doubled in five years.⁴²
- 2.27. Conflict is also experienced in relation to the system that dictates the route that families must take in order to obtain support for their child's special educational needs. It is a process that over 90 percent of parents to a 2024 survey⁴³ considered to be 'actively detrimental to their mental health'. It is a process engendering enormous anxiety in many families and one characterised by a 'fight at all costs' approach by many authorities – graphically illustrated by the data on outcomes. The 2025 Local Government and Social Care Ombudsman's (LGO) Annual Review⁴⁴ reported that fault had been found in 94 percent of the cases her office had considered concerning special educational needs provision. Equally stark is a 2023 research finding⁴⁵ that English local authorities lost 96 percent of SEND Tribunal hearings in 2021-22. Commenting on the research, Stephen Kingdom of the Disabled Children's Partnership observed:

It is deeply against the British sense of fair play to pit parents and carers of disabled children against highly-paid barristers paid for by local authorities from money that comes out of the public purse. We hear time and again from parents about the fight they have to go through to get the support their children need.

⁴¹ Children's Commissioner *Lost in transition? The destinations of children who leave the state education system* February 2024 at <https://www.childrenscommissioner.gov.uk/resource/lost-in-transition/> noted (at para 4.2.5) that a 'disproportionate number of children in our sample who went into home education had some form of special educational needs' and noted that in 2021/22 '30% of children who moved into home education had some form of identified SEN' – p.48 and Figure 19.

⁴² A Hattenstone *More families being 'forced' into home education* BBC 14 November 2024 at <https://www.bbc.co.uk/news/articles/c704x7e5515o> and see also Children's Commissioner *ibid* at p.41.

⁴³ Sharon Smith *Parent carers protest as 92.3% say engaging with their local SEN Team was "actively detrimental to their mental health"* in *Special Needs Jungle* 1 May 2024 at <https://www.specialneedsjungle.com/parent-carers-protest-engaging-local-send-team-detrimental-mental-health/>.

⁴⁴ LGO Annual Review of Local Government Complaints 2024-25 July 2025 at <https://www.lgo.org.uk/assets/attach/6814/LG-Review-2024-25-FINAL.pdf>.

⁴⁵ J Jemal and A Kenley *Wasting money, wasting potential: The cost of SEND tribunals Pro Bono Economics* (2023) at <https://pbe.co.uk/wp-content/uploads/2025/03/read-the-full-report-93a69e8a.pdf>.

2.28. In this context, relevant responses to the Cerebra survey (para 6.02) include:



- *My child self-harmed and wanted to die. 3 schools failed her, by age 8 she has [been] in burnout after being in 3 schools by 7.*
- *Ultimately, I stopped working and changed careers (became self-employed) so that I could support my son at home, since school wasn't interested and visibly delaying the process until he was out of there. To present, I get physically ill when looking at the school (next to my son's junior school). For years, I've made an effort to park away from it and enter through the back entrance when I can for my own mental health and wellbeing. The injustice of it all stays with me, and it's sickening. I try not to think about it too much, or it triggers me.*
- *The school and [name of council] have caused us to be in a significant level of stress since January 2022 when we first tried to get help. Trauma for my child (who has zero behavioural needs, but 'just' wants to learn). Child was depressed, crying often. Thankfully better now that she has left the school. The overall situation is a significant strain on our family life and relationships. At times I have been unable to sleep due to worries.*
- *Horrendous impact... there came a point that I momentarily believed it would be best if I ended my son and my life (thank god I didn't). We were lucky that we had a positive experience with CAHMS, a CETR and Mash at the [name of hospital]. My son was diagnosed with School based Trauma, he lost all of his education, he was unable to return to education for 4 years, he is tentatively making moves to start college next year. It's hard to vocalise just what a nightmare the whole experience was.*
- *Both my son and I were traumatised by the experience, and both meeting criteria for PTSD because of the abusive school behaviour system... My son used to go into fight/flight response whenever he was sanctioned. It took months for him to settle. I used to go into the fight/flight response with any call or email from the school. I would shake.*



Carers and the Department of Work and Pensions (DWP)

2.29. For many years concern has been expressed about the punitive impact DWP systems have on carers in relation to the payment of the Carers Allowance. In 2019, for example, a Westminster Parliamentary Committee⁴⁶ referred to problems with the system that resulted in carers suffering considerable distress when required to repay overpayments that they had no idea they were accruing. Despite a commitment by the Government to address these systems failures,⁴⁷ it is clear (as at August 2025) that no effective action has been taken.

2.30. In 2024, research undertaken by the Guardian Newspaper revealed how:

Tens of thousands of unpaid carers looking after disabled, frail or ill relatives are being forced to repay huge sums to the government and threatened with criminal prosecution after unwittingly breaching earnings rules by just a few pounds a week'.⁴⁸

2.31. The Guardian coverage⁴⁹ referred to carers saying:

- that it had led them *'to consider killing themselves'*;
- that they had become *'severely depressed, suicidal and self-harming'*;
- that on hearing from the DWP, *'I couldn't eat or sleep. I lost weight. I was on antidepressants. I was terrified I'd go to prison. I'm still traumatised, years later. It's a terrible system. It feels like a trap'*;
- One carer reported that she had been left *'traumatised'* by the DWP's demands to repay about £5,000 and *'I cannot begin to describe the avalanche of utter stress that those DWP overpayment letters triggered Carers allowance and universal credit overpayments are damaging, draining and destroying the fragile lives of ill and disabled patients and their carers'*.

2.32. In 2024 a National Audit Office report⁵⁰ revealed that more than 262,000 repayable overpayments totalling in excess of £325m were clawed back from carers. That the DWP had created internal targets to maximise the recovery of (often innocently acquired) overpayments rather than to ensure carers were prevented from inadvertently accruing them in the first place.

⁴⁶ House of Commons Work and Pensions Committee *Overpayments of Carer's Allowance* Thirtieth Report of Session 2017–19 Report HC 1772 (House of Commons, 24 July 2019).

⁴⁷ House of Commons Work and Pensions Committee *Overpayments of Carer's Allowance: Government Response to the Committee's Thirtieth Report of Session 2017–19 First Special Report of Session 2019* HC 102 (House of Commons, 5 November 2019).

⁴⁸ P Butler *Carers threatened with prosecution over minor breaches of UK benefit rules* 7 April 2024 at <https://www.theguardian.com/society/2024/apr/07/unpaid-carers-allowance-payment-prosecution-earnings-rules>.

⁴⁹ J Halliday and J Butler *Carers describe 'avalanche of utter stress' from DWP clawing back benefits* Guardian 19 April 2024 at <https://www.theguardian.com/society/2024/apr/19/avalanche-of-utter-stress-carers-health-suffering-as-dwp-claws-back-benefits>.

⁵⁰ National Audit Office *Carer's Allowance* Department for Work & Pensions Session 2024–25 11 December 2024 HC 377 at <https://www.nao.org.uk/wp-content/uploads/2024/12/carers-allowance-1.pdf> and see also P Butler and J Halliday *Hundreds of thousands hit by ruinous carer's allowance penalties, audit shows* Guardian 11 December 2024 at <https://www.theguardian.com/society/2024/dec/11/hundreds-of-thousands-hit-by-ruinous-carers-allowance-penalties-audit-shows>.

2.33. What emerges from the various reports and the Guardian investigation is that the system developed to pay some carers a modest⁵¹ weekly sum is dysfunctional and, in consequence, is causing distress and trauma to hundreds of thousands of the very people it was ostensibly designed to assist.

A constellation of systems that traumatise disabled children and their families

2.34. The brief review (above) has considered some of the systems generated traumas identified in previous LEaP research programmes as well as in other research papers and publications. Once this phenomenon is acknowledged – instances can be seen in all manner of contexts. In relation to disabled children and their families these include, for example, the traumas that result from:

- systems that blame and then abandon parents who adopt or foster disabled children:⁵² a system in relation to which a recent research report states that the *‘single, biggest issue adopters were unprepared for, and that impacted significantly on accessing support, was the sheer lack of understanding of trauma in statutory services’*.⁵³
- systems that make no provision (or profoundly inappropriate and deeply humiliating provision) for disabled children in need of paediatric continence services;⁵⁴ a system in relation to which a recent research report cited a parent’s comment: *‘The stress it creates really starts to affect your mental health and I still vividly remember bursting into tears with frustration the last time they tried to cut his supply’*.⁵⁵
- a complex legal system where legal representation is unaffordable for the many, where courts can be characterised as *‘unsafe and traumatic place for women and children’*,⁵⁶ where delay *‘devastates victims emotional and*

⁵¹ A sum described as ‘horrendous’ by Marion Fellows MP: *Oral evidence taken before the Work and Pensions Committee* on 6 March 2024, on Carer’s Allowance, HC 591 Hansard Commons volume 748 22 April 2024 at <https://hansard.parliament.uk/Commons/2024-04-22/debates/E43FCD87-1F1D-41F4-BE0D-948482756398/Carer%E2%80%99SAllowance>.

⁵² T Gordon ‘Adoption Breakdown in the UK is a Silent Crisis Demanding Urgent Reform’ in politics.co.uk 8 April 2025 at <https://www.politics.co.uk/mp-comment/2025/04/09/tom-gordon-adoption-breakdown-in-the-uk-is-a-silent-crisis-demanding-urgent-reform/>; Adoption UK ‘Record crisis levels for adopted people’ at <https://www.adoptionuk.org/News/record-crisis-levels-for-adopted-people>; Written evidence from Adoption UK (CSC 126), Education Committee, Children’s Social Care at <https://committees.parliament.uk/writtenevidence/132253/pdf/>; M Woolgar, C Pinto and R A. González ‘Adoptive parents’ satisfaction with child and adolescent mental services and their mental health concerns over time: A question of fit?’ *Developmental Child Welfare* 6(1), March 2024, pp 50-64; see also, for example BBC Scotland *Foster family awarded £346,000 over false sex claims* BBC 3 July 2024 at <https://www.bbc.co.uk/news/articles/c9e90zn7dnxo>; S Allan *Woman wins six-figure payout after adoption broke down* 9 September 2024 at <https://www.bbc.co.uk/news/articles/c623we048yzo>.

⁵³ The Potato Group *Far, Far Beyond the Adoption Order: Lessons from Lives Impacted by Trauma* (June 2025) at <https://www.thepotatogroup.org.uk/research> and see also J Murray *‘It broke my heart’: the adopters forced to return their child to care after struggling alone* Guardian 21 May 2025.

⁵⁴ L Clements & A L Aiello *Inaccessible, unacceptable and unaccountable: the provision of paediatric continence supplies in England, Wales and Scotland*. (Cerebra 2025).

⁵⁵ Ibid at p.41.

⁵⁶ Women’s Aid *Family courts remain an unsafe and traumatic place for women and children* (June 2022) at <https://www.womensaid.org.uk/family-courts-remain-an-unsafe-and-traumatic-place-for-women-and-children/> and see also J Birchall, *Two years, too long: Mapping action on the Harm Panel’s*

*physical wellbeing*⁵⁷ and where indefensible behaviour by local authorities and the police can escape public censure;⁵⁸

- attempts to navigate (at any one time) multiple, impenetrably complex, siloed social welfare systems.⁵⁹ By way of example, a 2025 report concerning patients and carers experience of dealing with the NHS ‘system’ referred to their feeling of being ‘*exhausted, burnt out, frustrated, angry and guilty, among other emotions*’ and how their ‘*physical and mental health may deteriorate because of the extra burden of navigating the health and care system*’. The report cited a parent’s experience:⁶⁰



• *[our child’s] behaviour was so difficult during these times. She was very physically demanding and awake for hours and hours. This was a time we needed most support and had the least ... Every parent ... finds it difficult to negotiate [the health and care system] ... you are exhausted because your child needs 24-hour care ... [we] are the ones that constantly have to be on top of everything ... [but could] reach the point of shall we even bother. Then the child is affected.”*



- knowing that in relation to most decisions made by public bodies, that are of vital importance to disabled children and their families – that these bodies are (as we discuss in chapter 4 above), in essence ‘unaccountable’.

findings Women’s Aid (2022) at <https://www.womensaid.org.uk/evidence-hub-two-years-too-long-mapping-action-on-the-harm-panels-findings/>.

⁵⁷ S Murray, S Welland & M Storry *Justice delayed: The impact of the Crown Court backlog on victims, victim services and the criminal justice system* March 2025 Victims’ Commissioner at <https://cloud-platform-e218f50a4812967ba1215eaecede923f.s3.amazonaws.com/uploads/sites/6/2025/03/OVC-Crown-Court-backlog-report-10.03.25.pdf> – based on a survey where half of the victims were disabled people. The report makes many references to the direct and indirect impact on children – as in a case where, as a result of the delay a mother attempted to take her own life and the mental anguish resulted in her children being taken into care (p.29).

⁵⁸ Louise Tickle *Family judge keeps press in the dark about “indefensible” case* in Culture Society, Identity and Belonging 5 November 2024 at <https://www.tortoisemedia.com/2024/11/05/family-judge-keeps-press-in-the-dark-about-indefensible-case>.

⁵⁹ Health Services Safety Investigations Body (HSSIB) *Workforce and patient safety: primary and community care co-ordination for people with long-term conditions* 10 April 2025 at <https://www.hssib.org.uk/patient-safety-investigations/workforce-and-patient-safety/fourth-investigation-report/>, Executive Summary; see also A Gregory *England’s ‘complex’ health and care system harming patients, report says* Guardian 10 April 2025 at 2025 at <https://www.theguardian.com/society/2025/apr/10/englands-complex-health-and-care-system-harming-patients-report-says>; and see generally, L Clements *Clustered injustice and the level green* (Legal Action Group 2020).

⁶⁰ HSSIB (ibid) at para 2.8.



Chapter three

*The emergence of 'Trauma
Informed Practice' guidelines*

Chapter 3: The emergence of 'Trauma Informed Practice' guidelines

- 3.01. The need for public sector bodies and their practitioners to be 'trauma informed' has become more widely recognised since the turn of the century. A notable early (2001) publication on this issue by Harris and Fallot,⁶¹ aimed to raise awareness of the extent to which many users of mental health services were survivors of sexual and physical abuse, domestic violence and victimisation. They stressed the importance of practitioners having an understanding of trauma, its aftereffects and the way these experiences shaped the lives of survivors, and their interactions with mental health services. The authors identified what they considered to be the essential elements 'for a system to begin to integrate an understanding about trauma into its core service programs'.
- 3.02. Although Harris and Fallot's focus was on third party generated traumas (i.e. traumatic experiences for which the institution bore no responsibility) it recognised the need for institutions to undertake 'a careful review of [their] policies and procedures to determine whether any are hurtful or even harmful to trauma survivors' and to avoid 'intrusive practices [that] are both damaging in the moment and painful reminders of past abuses'.⁶²
- 3.03. In 2012 the Australian Blue Knot Foundation released a collection of 'Practice Guidelines' for (among other things) Trauma-Informed Care and Service Delivery.⁶³ The collection included, what has proved to be, an influential publication 'The Last Frontier: Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery'⁶⁴ (hereafter the 'Last Frontier').
- 3.04. In common with the approach of Harris and Fallot, the Last Frontier is primarily concerned with third party generated traumas, namely 'child abuse in all its forms, neglect, the impacts of living with or witnessing family violence in childhood and of other adverse childhood events'.⁶⁵ It, however, acknowledges that institutions can unwittingly generate harm – for example by wrongly diagnosing and medicating patients⁶⁶ or by retraumatising those seeking assistance, noting that:

the re-traumatisation of already traumatised people by and within diverse services of the health sector is highly prevalent. Research establishes that service practices which lead to retraumatisation rather than recovery are not

⁶¹ M Harris & R Fallot *Using Trauma Theory to design Service Systems. New Directions for Mental Health Services*. (Jossey-Bass, 2001).

⁶² Ibid p.9

⁶³ Accessible at <https://blueknot.org.au/product/practice-guidelines-for-treatment-of-complex-trauma-and-trauma-informed-care-and-service-delivery-digital-download/>.

⁶⁴ C Kezelman and P Stavropoulos *The Last Frontier' – Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery* (2012) Adults Surviving Child Abuse (ASCA) at <https://blueknot.org.au/product/practice-guidelines-for-treatment-of-complex-trauma-and-trauma-informed-care-and-service-delivery-digital-download/>.

⁶⁵ Ibid p.xix.

⁶⁶ Ibid p.viii.

exceptional, but pervasive and deeply entrenched.⁶⁷ In fact research which supports this disturbing claim is growing.⁶⁸ Recognition of the reality that [t]rauma has often occurred in the service context itself⁶⁹ is a major impetus for introduction of 'trauma-informed' practice.⁷⁰

3.05. In the context of this research report, the Last Frontier appears to be one of the few trauma informed practice documents to acknowledge that:

- trauma is reproduced by and within mainstream social institutions and services (administrative, educational, legal, medical) including health services and settings;⁷¹ and
- complex trauma 'occurs not only in families in relation to children, but in the context of other social institutions'⁷² such as schools and that 'abuse and exploitation will occur in any institution in which it can occur'.⁷³

3.06. In 2014 'Concept of Trauma and Guidance for a Trauma-Informed Approach'⁷⁴ was published by the US Substance Abuse and Mental Health Services Administration (the 'SAMHSA guidance'). The guidance draws on the work of Harris and Fallot (among others), although it does not reference the 2012 Blue Knot Foundation Practice Guidelines – with which it has many parallels.

3.07. As with the Last Frontier guidance, the SAMHSA guidance seeks to develop a trauma-informed approach that is appropriate across an array of service systems and stakeholder groups in order to build a 'framework that helps systems "talk" to each other, to understand better the connections between trauma and behavioral health issues, and to guide systems to become trauma-informed.'⁷⁵

3.08. The guidance also gives emphasis to the importance of resisting the 're-traumatization of clients as well as staff' and, importantly, for the purposes of this research report, it then states: ⁷⁶

Organizations often inadvertently create stressful or toxic environments that interfere with the recovery of clients, the wellbeing of staff and the fulfillment

⁶⁷ Citing A Jennings *Models for Developing Trauma-Informed Behavioral Health Systems and Trauma-Specific Services*, Report produced by the National Association of State Mental Health Program Directors (NASMHPD) and the National Technical Assistance Center for State Mental Health Planning (NTAC) United States, 2004.

⁶⁸ Citing Sandra L. Bloom & Brian Farragher, *Destroying Sanctuary: The Crisis in Human Service Delivery Systems* (New York: Oxford University Press, (2011).

⁶⁹ Citing Ann Jennings, 'Models for Developing Trauma-Informed Behavioral Health Systems and Trauma-Specific Services', Report produced by the National Association of State Mental Health Program Directors (NASMHPD) and the National Technical Assistance Center for State Mental Health Planning (NTAC) United States, 2004 p.6.

⁷⁰ The Last Frontier p.86.

⁷¹ Ibid p.13

⁷² Ibid p.xxx.

⁷³ Ibid p.xii.

⁷⁴ SAMSHA 'Concept of Trauma and Guidance for a Trauma-Informed Approach' (2014) at https://www.nctsn.org/sites/default/files/resources/resource-guide/samhsa_trauma.pdf.

⁷⁵ Ibid p.3.

⁷⁶ Ibid p.10.

of the organizational mission.⁷⁷ Staff who work within a trauma-informed environment are taught to recognize how organizational practices may trigger painful memories and retraumatize clients with trauma histories.

- 3.09. The SAMHSA guidance (in common with the Last Frontier guidance) not only recognised that institutional practices could lead to retraumatism it also acknowledged that institutional systems can generate traumas in the first place, stating:⁷⁸

public institutions and service systems that are intended to provide services and supports to individuals are often themselves trauma-inducing. The use of coercive practices, such as seclusion and restraints, in the behavioral health system; the abrupt removal of a child from an abusing family in the child welfare system; the use of invasive procedures in the medical system; the harsh disciplinary practices in educational/school systems; or intimidating practices in the criminal justice system can be re-traumatizing for individuals who already enter these systems with significant histories of trauma. These program or system practices and policies often interfere with achieving the desired outcomes in these systems.

The development of domestic 'Trauma Informed' policies

- 3.10. The 2012 Blue Knot Practice Guidelines and the 2014 SAMHSA guidance provided the impetus for the development of Trauma Informed Policies by the Governments in Scotland, Wales and England as well as being influential in shaping of the content of these policies.⁷⁹

Scotland

- 3.11. In 2021 the Scottish Government published a Trauma-Informed Toolkit⁸⁰ to support its workforce 'with clear, tangible examples of where trauma informed practice has been successfully embedded across different sectors' so that this 'learning can be applied in a range of contexts' (p.5). In 2023 it published a follow up resource, 'Roadmap for Creating Trauma-Informed and Responsive Change,'⁸¹ 'to help identify and reflect on progress, strengths and opportunities for embedding a trauma-informed and responsive approach across policy and practice' (in the section that follows, these two documents are referred to as the 'Toolkit' and the 'Roadmap' respectively).

⁷⁷ Citing, Dekel, S., Ein-Dor, T., and Zahava, S. (2012). Posttraumatic growth and posttraumatic distress: A longitudinal study. *Psychological Trauma: Theory, Research, Practice, and Policy*, 4(1), 94-101.

⁷⁸ SAMSHA 'Concept of Trauma and Guidance for a Trauma-Informed Approach' (2014) at https://www.nctsn.org/sites/default/files/resources/resource-guide/samhsa_trauma.pdf p.2.

⁷⁹ By way of example, the Scottish Government's [Trauma-Informed Toolkit](#) (discussed below) includes 10 references to the SAMHSA guidelines and seven references the Blue Knot Practice Guidelines; the 'Trauma-Informed Wales' (2022) Framework includes five references to the SAMHSA guidelines and three references the Blue Knot Practice Guidelines; and the brief English guidance [Working definition of trauma-informed practice](#) (2022) cites the SAMHSA guidelines.

⁸⁰ Scottish Government 'Trauma-Informed Practice: A Toolkit for Scotland' 2021, p.8. at <https://www.gov.scot/publications/trauma-informed-practice-toolkit-scotland/documents/>.

⁸¹ NHS Education for Scotland [Roadmap for Creating Trauma-Informed and Responsive Change: Guidance for Organisations, Systems and Workforces in Scotland](#) (2023) at <https://www.nes.scot.nhs.uk/nes-current/roadmap-for-creating-trauma-informed-and-responsive-change/>.

- 3.12. The Toolkit contains several references to the importance of avoiding ‘retraumatisation’ – as in ‘to ‘prevent further harm or retraumatisation for those who have experienced psychological trauma or adversity at any stage in their lives’ (p.6); to ‘promote safety and trust and aim to prevent retraumatisation’ (p.8) and ‘a commitment to reducing retraumatisation, and promoting wellbeing and recovery’ (p.52).
- 3.13. These statements reinforce the idea of the source of trauma being ‘other’ (i.e. traumatic experiences for which the institution bears no responsibility) and that instances of retraumatisation are ‘unintentional’. They also conceptualise the active role of public service workforces as essentially reactive – to ‘assume that people have had traumatic experiences’ and where this appears to be the case, to make accommodations in the way that the individual’s services are ‘structured, organised and delivered’ (p.8)
- 3.14. Although the ‘othering’ of trauma pervades much of the Roadmap Guidance, it nevertheless contains oblique acknowledgements that organisational systems may themselves have the potential to be the primary source of trauma. Sadly, these tangential references are not then the subject of analysis and are made in the context of their potential to harm individuals who have already experienced trauma. The following extract is illustrative (Executive Summary (p.12):

All services and organisations operate within complex systems. The complexity of these systems can sometimes mean they work in ways that can be unintentionally re-traumatising, risk causing more harm For example, people with lived experience of trauma highlight that it can be re-traumatising having to tell our story to multiple workers in different organisations and that having to navigate complex, lengthy pathways to support can leave us feeling disempowered and a sense of loss of control. Trauma-informed and responsive systems ... may sometimes impact the smooth running of the system.

Wales

- 3.15. In 2022 the Welsh Government ‘supported’ the publication of a Framework document ‘Trauma-Informed Wales’ (2022).⁸² It aims ‘to set out an all-society Framework to support a coherent, consistent approach to developing and implementing trauma-informed practice across Wales, providing the best possible support to those who need it most’ (p.6).
- 3.16. It is a broader and briefer publication than the Scottish Government’s Toolkit but, in many respects, it mirrors its approach. It contains several references to the importance of avoiding ‘traumatising individuals again’ – as in the need to ‘resist traumatising people again and prevent and mitigate adverse consequences’ (p.15). Objectively (as with the Scottish Toolkit) it conceptualises the causes of trauma as ‘other’ (i.e. resulting from experiences for which the institution bears no responsibility).
- 3.17. As with the Scottish Roadmap, the Welsh Guidance alludes briefly to the idea that organisational systems may, themselves, have the potential to be the

⁸² Ace Hub Wales ‘[Trauma-Informed Wales: A Societal Approach to Understanding, Preventing and Supporting the Impacts of Trauma and Adversity](https://traumaframeworkcymru.com/)’ (2022) at <https://traumaframeworkcymru.com/>.

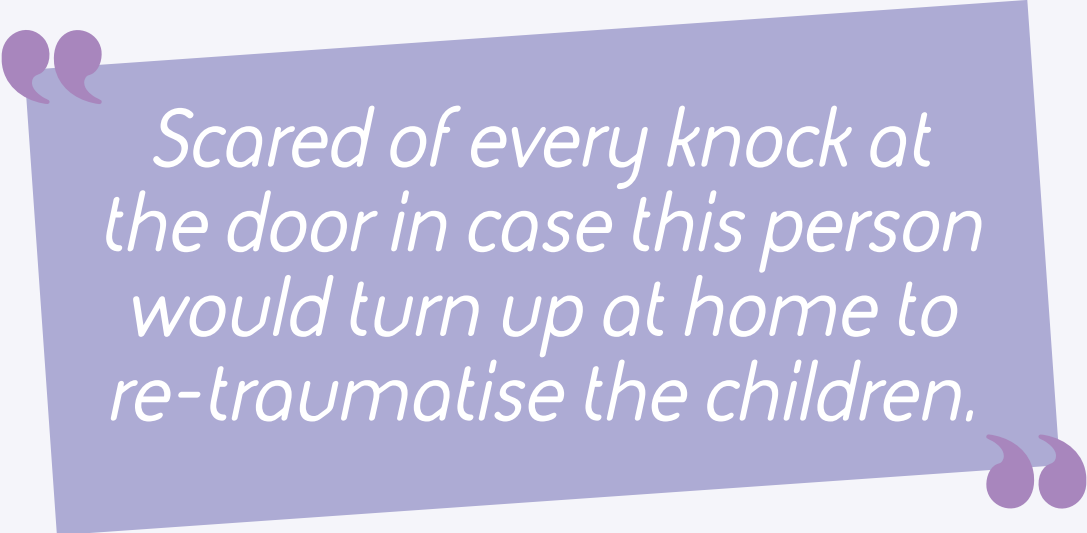
primary source of trauma, but then fails to develop or critically analyse this observation, simply stating (p.21):

All trauma-informed organisations operate within a system, or collection of systems, that are complex, complicated and have the potential to be trauma informed or cause more harm. Systems that are not trauma-informed risk traumatising individuals again through multiple contacts and requests to retell or relive their trauma, or siloed working that focuses on individual problems based on expertise, rather than taking a holistic and often whole family approach to understanding the needs of people who may need support.

England

- 3.18. In 2022 the Office for Health Improvement & Disparities in England published brief (925 words) online guidance, ‘Working definition of trauma-informed practice’⁸³ in order to provide ‘a working definition of trauma-informed practice for practitioners working in the health and care sector’.
- 3.19. As noted above, the guidance speaks of ‘trauma’ in neutral terms, in the sense that it does not specify (or discuss) the nature or source of the ‘event, series of events, or set of circumstances’ that results in the individual experiencing trauma. It is, therefore, silent on the question of the potential for public body ‘systems’ to generate trauma. In common with the Scottish and Welsh guidance⁸⁴ the guidance refers to the importance of preventing re-traumatisation:

the re-experiencing of thoughts, feelings or sensations experienced at the time of a traumatic event or circumstance in a person’s past. Re-traumatisation is generally triggered by reminders of previous trauma which may or may not be potentially traumatic in themselves.



Scared of every knock at the door in case this person would turn up at home to re-traumatise the children.

⁸³ Office for Health Improvement & Disparities Guidance *Working definition of trauma-informed practice* (2022) at <https://www.gov.uk/government/publications/working-definition-of-trauma-informed-practice/working-definition-of-trauma-informed-practice>.

⁸⁴ Which are listed in its section ‘Other professional resources and tools’.



Chapter four

The Legal and policy context

Chapter 4: The Legal and policy context

4.01. This chapter provides an overview of the extent to which public bodies can be required to amend their practices and procedures where there is cogent evidence that they are having a disproportionately adverse impact on individuals. It considers the laws that could in theory address injustices of this kind and their practical accessibility: their ability to be a tool for driving meaningful systems' change.

Claims for damages

4.02. Individuals who suffer harm (including psychiatric harm) as a result of the actions by a third party (including a public body) can make a legal claim for damages. Claims of this kind can, for example, assert that the impugned act was negligent or constituted a public nuisance or amounted to unlawful discrimination or breached one or more of their human rights.

4.03. Diffuse harms such as those caused by smoking or injuries on construction sites, or asbestos related diseases are all examples where the risk of 'damages' litigation has materially changed practices. However, if it is more difficult to identify the specific source of the harm, or if the cause is itself contested or where the harm results (for instance) from the unintended and cumulative impact of a complex system, litigation of this kind is significantly less effective in changing behaviours.

4.04. In this respect, the harm resulting from systems generated traumas could be compared to the harm resulting from the agricultural nitrate and phosphate pollution of waterways or to air pollution caused by vehicles. These harms could be characterised as diffuse and unintended by-products of a legitimate process. Compensation claims could be used to challenge what is happening, but this could well require a complex class action. If individually each farmer or motorist is not shown to be breaching specific regulations, then the fact that the cumulative impact of the pollution means that children die of asthma attacks or all life in a river 'dies' is not something that could easily be addressed by personal or property damages litigation.

4.05. That is not to say that a multiplicity of individual claims could not result in system changes, but in the field of social welfare practice, there are few successful examples.⁸⁵ In addition to the difficulties discussed above, common law claims (for example those based on tort law) contain an abundance of 'queer technical'⁸⁶ rules, not least the constrained judicial interpretation of the notion of foreseeability⁸⁷ of harm and the 'strikingly anti-intuitive'⁸⁸ scope of

⁸⁵ See for example, *Phelps v Hillingdon LBC* [1999] 1 WLR 500 where a damages claim succeeded in negligence on the basis of a failure to recognise and provide for dyslexia support and see also A Jackman and E Wright 'Education law rights: a shifting picture', Legal Action November 2022 at <https://www.lag.org.uk/article/213331/education-law-rights-a-shifting-picture>

⁸⁶ K N Llewellyn, *The Cheyenne Way*, (University of Oklahoma Press, 1941) p. 41.

⁸⁷ That decides that 'a blameless victim should receive no compensation from a blameworthy party who could have been expected to foresee such a loss' J Conaghan & W Mansell *The Wrongs of Tort* (Pluto Press 2nd ed 1999) p.51.

⁸⁸ Ibid p.45.

those to whom public bodies have a ‘duty of care’ (or more accurately ‘don’t have’ such a duty).

- 4.06. To understand the difficulties that the law has in addressing systems generated injustices, the Post Office scandal is a prime example. A public body; a wholly dysfunctional system; courts presiding over the wrongful convictions of over 700 postmasters over a 15 year period; the suspected suicide of 13 postmasters; and the persistence in 2025 of an ‘unnecessarily adversarial attitude’ to over 10,000 individuals seeking financial redress.⁸⁹

Public law ‘good governance’ obligations

- 4.07. The findings of the present research also raise questions concerning the extent to which public bodies are required to uphold legal principles of good governance – in essence: ‘what must they do in order to satisfy the requirements of human rights and non-discrimination law’?
- 4.08. Public law (also referred to as administrative law) is concerned with the duties, powers and obligations of public bodies.⁹⁰ Public law requires that such bodies behave ‘reasonably’; that their decisions are rational – which in turn requires that in reaching them, they take into account all relevant evidence and disregard irrelevant matters. In relation to ‘significant decisions’ that may affect many individuals (for example those that engage their fundamental human rights), public law generally requires that the public body consults key parties before making its decision and then gives evidence-based reasons for so deciding.
- 4.09. The Parliamentary and Health Services Ombudsman (PHSO) in England has developed a set of Principles of Good Administration⁹¹ which, in summary, comprise: (1) Getting it right (in essence, taking reasonable decisions, based on all relevant considerations); (2) being customer focused; (3) being open and accountable; (4) acting fairly and proportionately; (5) putting things right; and (6) seeking continuous improvement.
- 4.10. There is broad agreement at an international level as to what ‘good governance’ looks like. While acknowledging that ‘there is no internationally agreed definition of ‘good governance’, the United Nations Office of the High Commissioner for Human Rights (OHCHR) states that:

the true test of ‘good’ governance is the degree to which it delivers on the promise of human rights: civil, cultural, economic, political and social rights. The key question is: are the institutions of governance effectively guaranteeing the right to health, adequate housing, sufficient food, quality education, fair justice and personal security?⁹²

⁸⁹ W Williams Post Office Horizon IT Inquiry Report Volume 1 HC 1119 House of Commons 8 July 2025 at <https://www.postofficehorizoninquiry.org.uk/volume-1-post-office-horizon-it-inquirys-final-report>.

⁹⁰ For the purposes of section 6(3) Human Rights Act 1998 a public body includes a body that fulfil functions of a public nature – see for example, *R (Karmakar and another) -v- The Royal College of General Practitioners* [2024] EWHC 2211 (Admin).

⁹¹ PHSO ‘Principles of Good Administration’ (2009) at <https://www.ombudsman.org.uk/about-us/our-principles/principles-good-administration>.

⁹² OHCHR ‘OHCHR and good governance’ at <https://www.ohchr.org/en/good-governance/about-good-governance>.

Public law as a mechanism to challenge systems generated trauma

- 4.11. Public law is, in large measure, reactive and process focussed. Public law challenges that can result in enforceable judgments almost invariably involve the making of an application to the High Court (a ‘judicial review’). In such cases the legal action is concerned with the legality of the decision-making process rather than the correctness of the decision or action in question. Although a judicial review can be used to question the lawfulness of a public policy of the kind considered in this report, to succeed an applicant would need, in general, to establish that the policy was either irrational or that its adverse impact in terms of discrimination or human rights interference was incapable of being lawfully justified.
- 4.12. Establishing that a public body is legally liable for the harm caused by a defuse policy or practice is challenging, as in almost all cases the policy or practice will have a legitimate aim – for example the safeguarding of children; the efficient administration of the education system; or the protection of data.
- 4.13. Almost all social welfare systems will have unintended and adverse consequences and judges are reluctant to hold public bodies liable for such unintended harms even when they interfere with family life and/or are discriminatory. From their law school days lawyers are schooled in the constitutional principle of the separation of powers – that judges must give due deference to the legislature and those to whom the legislature have delegated administrative powers – for example the power to make policies and practices. From a purely pragmatic perspective, judges appreciate that if routinely they are prepared to overrule the decisions of public bodies and to substitute their own, then the courts would be, in short time, overwhelmed.
- 4.14. The principle of ‘deference’ explains, in part, the dearth of individual legal claims directed against systems created by public bodies – even in cases where material harm results – for example draconian interventions in family life,⁹³ or a child’s extreme emotional distress in education settings⁹⁴ or the trauma carers experience due to the dysfunctional system for paying Carers Allowance,⁹⁵ or the trauma resulting from a refusal to erase incorrect data records;⁹⁶ and so on.
- 4.15. There are other factors that deter claims of this nature. One, of course, concerns the very material issue of the power imbalance between public bodies and individuals. Public bodies have in-house lawyers and in general give the appearance of having unlimited resources when it comes to resisting claims by individuals seeking to amend their systems, whereas legal aid is restricted as are the number of lawyers available to take on cases of this kind. Another material factor concerns the lack of effective remedies – an issue considered further below. A final factor, of central relevance to this research, is that **almost any mechanism that can be used to challenge the actions of a public body involves a process that is likely to generate considerable trauma for an applicant.**

⁹³ See paras 2.02 – 2.05 above.

⁹⁴ See paras 2.20 – 2.28 above.

⁹⁵ See paras 2.29 – 2.33 above.

⁹⁶ See paras 2.14 – 2.19 above.

Claims concerning discriminatory policies

- 4.16. Legal challenges can be taken where a public policy or practice adversely discriminates against members of a protected category⁹⁷ or recognised 'status'.⁹⁸ In cases of this kind, the evidential burden on the applicant is less onerous than in general public law challenges. Examples of successful legal action of this kind includes challenges to policies concerning access to social security benefits⁹⁹ and policies relating to the charging rules for social care.¹⁰⁰
- 4.17. The factors identified in para 4.15 above also represent significant barriers for applicants taking cases of this nature, not least funding difficulties. Although in theory the Equalities and Human Rights Commission is able to initiate legal action itself to challenge discriminatory policies, in practice its limited resources means that it restricts legal interventions to matters that fall within its (objectively narrow) 'strategic priorities'.¹⁰¹

Remedies

- 4.18. The limited range of remedies significantly impairs the potential effectiveness of legal challenges in bringing about material changes to defective public policies – none of which are objectively 'seriously dissuasive'.
- 4.19. In judicial review proceedings, the courts seldom award damages and in general the only remedy considered appropriate by the court is the making of a declaration that the policy is unlawful, and then leaving it to the public body to decide how it should be revised.¹⁰² The case will then be closed and a fresh application will have to be taken if the public body fails to review the policy or if its review results in the adoption of an equally unreasonable policy.
- 4.20. Public law is not, as the courts have stressed, a 'procedure for those seeking an after the event remedy; in those circumstances a complaint to the relevant ombudsman is the appropriate route.'¹⁰³
- 4.21. In those cases which involved a specific claim for compensation (for example in tort, or claims under the Human Rights Act 1998 or the Equality Act 2010), the level of damages tends to be relatively modest, particularly in relation to

⁹⁷ Contrary to the provisions of the Equality Act 2010.

⁹⁸ Contrary to the provisions of the Human Rights Act 1998, Article 14.

⁹⁹ See for example [R \(Burnip and others\) v Birmingham City Council and others](#) [2012] EWCA Civ 629 which concerned the adverse and discriminatory impact of the so-called 'bedroom tax'.

¹⁰⁰ *SH v Norfolk County Council* [2020] EWHC 3426 (Admin).

¹⁰¹ See Equality and Human Rights Commission [Strategic plan 2025 to 2028](#) (March 2025)

¹⁰² As Collins J observed in *Gunter v South Western Staffordshire PCT* [2005] EWHC 1894 (Admin) 'Judicial review is an unsatisfactory means of dealing with cases ... where there are judgments to be made and factual issues may be in dispute. At best, it can identify failures to have regard to material considerations and a need for a reconsideration. Very rarely if ever will it result in mandatory orders to the body which has the responsibility to reach the relevant decision.'

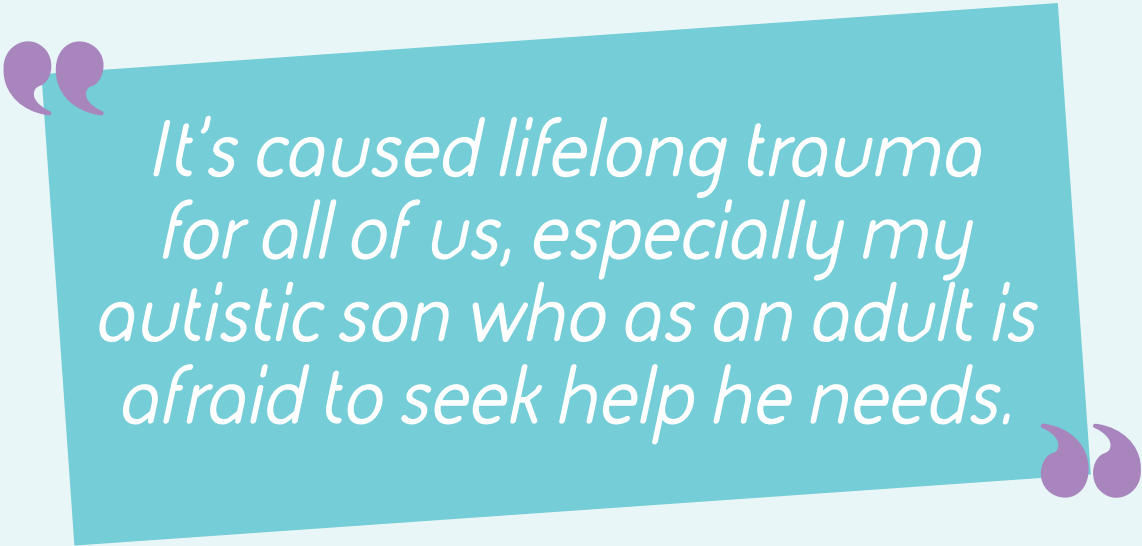
¹⁰³ Per Munby J (as he then was) in *R (Smeaton) v Secretary of State for Health* [2002] EWHC 886 (Admin).

discrimination and human rights claims¹⁰⁴ and in any event, low in comparison to awards in jurisdictions such as the USA.¹⁰⁵

- 4.22. Although cases challenging public law policies and practices can succeed before the ombudsman they do not result in a binding judgment and any recommended compensation is generally limited.¹⁰⁶

Concluding comments

- 4.23. Public law principles have their greatest impact in the hands of those crafting original policies – the hands on the potter’s wheel. Hands expert and sensitive to the nature of the task: to the demands of good governance, to the insidious nature of discrimination, to the fundamental importance of human rights protections and much more. Once cast, policies unlike porcelain can be refashioned. **They are living instruments and in need of constant attention – of being reviewed and updated, especially when they are seen to have unintended and adverse consequences.** As the above analysis demonstrates – it is essential that the executive and the legislature are diligent in attending to this task, as the judiciary is ill-equipped to fulfil this essential role.
- 4.24. Ultimately this function is the responsibility of governments, parliaments and public bodies. **At the very least, it is to be hoped that when developing their ‘trauma informed’ policies they will acknowledge, comprehend and reflect upon the extent to which their own policies and practices generate trauma – trauma that can upend the lives of disabled children and adults, parents, carers, families and countless others.**



It's caused lifelong trauma for all of us, especially my autistic son who as an adult is afraid to seek help he needs.

¹⁰⁴ See generally H Anthony and C Crilly Research report 99 Equality, human rights and access to civil law justice: a literature review Equality and Human Rights Commission (2015) at https://www.equalityhumanrights.com/sites/default/files/equality_human_rights_and_access_to_civil_law_justice_0.pdf

¹⁰⁵ See for example *Kowalski v. Johns Hopkins All Children's Hospital* 2018-CA-005321 (Twelfth Judicial Circuit Court of Florida) where an award of \$47.5 million was made for a particularly tragic case involving a false allegation of Munchausen's Syndrome by Proxy (now generally referred to as FII in the UK).

¹⁰⁶ See generally Local Government and Social Care Ombudsman Guidance on remedies (2025) at <https://www.lgo.org.uk/information-centre/staff-guidance/guidance-on-remedies>.



Chapter five

Brief note on theory

Chapter 5: A brief note on theory

- 5.01. A vital component of any flourishing civil society is the existence of benign, functioning institutions that help foster the resilience and capabilities of all individuals within the state's jurisdiction: schools, health and social care centres, institutions charged with the maintenance of social security, of justice and housing the homeless.
- 5.02. Vulnerability theory starts with a recognition that vulnerability is an essential characteristic of the human condition: that we live with an ever-present risk of harm and in consequence, a central responsibility of a responsive state and its institutions is to help build the resilience of its citizens – through the whole panoply of social welfare, environmental and security measures at its disposal.
- 5.03. Vulnerability scholars have sought to develop a 'taxonomy' of vulnerabilities¹⁰⁷ – for example inherent vulnerabilities (those that are intrinsic to the human condition) and situational vulnerabilities (those resulting from an individual's social, economic or environmental situation). Of particular relevance to this research, however, are what have come to be termed '**pathogenic vulnerabilities**'. **These are harms that can arise in many contexts, including when an institutional response 'intended to ameliorate vulnerability has the paradoxical effect of exacerbating existing vulnerabilities or generating new ones'**.¹⁰⁸
- 5.04. Research concerning the harm that results from pathogenic vulnerabilities – from the (generally) unintended consequences of social welfare system failures – falls (broadly) within the discipline that has come to be referred to as 'social harm theory'. Such an approach 'begins with a focus upon the social origins of harms, upon the structures that produce and reproduce such harms':¹⁰⁹ 'harmful social phenomena, encompassing ... physical, financial, psychological and cultural harms'¹¹⁰ and, for example, those resulting from flawed child protection policies and practices.¹¹¹ In the context of research concerning the harms experienced by families, it is an approach that questions the assumption that principal responsibility for these harms lie with 'mothers and fathers' – asking instead, 'what about the emotional damage wrought by unsympathetic styles of teaching, by bullying at school, by insensitive substitute care or by the penal

¹⁰⁷ C Mackenzie, W Rogers and S Dodds 'Introduction: What Is Vulnerability, and Why Does It Matter for Moral Theory?' in C. Mackenzie, W Rogers and S Dodds (eds), *Vulnerability: New Essays in Ethics and Feminist Philosophy* (Oxford University Press 2013), p. 9.

¹⁰⁸ *ibid.*

¹⁰⁹ Conclusion: 'Social Harm' and its limits? in P Hillyard, C Pantazis, S Tombs and D Gordon (eds) *Beyond Criminology: Taking Harm Seriously* (Pluto Press 2004) at p.271.

¹¹⁰ L Copson 'Beyond criminology: taking harm seriously' in F Gordon and D Newman (eds) *Leading works in law and social justice* (Routledge 2021) pp. 169-190 at 170.

¹¹¹ See for example, R Parker 'Children and the Concept of Harm' in P Hillyard, C Pantazis, S Tombs and D Gordon (eds) *Beyond Criminology: Taking Harm Seriously* (Pluto Press 2004) and L E Wroe 'When Helping Hurts: A Zemiological Analysis of a Child Protection Intervention' in *Social Sciences* (2022) 11, 263.

system?'.¹¹² Parker, for example questions the emphasis given to 'harms inflicted upon individual children by individuals' and how this:¹¹³

has the effect of relieving governments (and others) of the need to address the more politically contentious issue of the harms that arise from the structural arrangements of society. Furthermore, it is also possible to identify what might be termed policy harms. These are the harms that may be done to certain children as a result of initiatives that are either argued to be in their interest, but are not, or which simply fail to take them into account.

- 5.05. A social harm approach echoes many of Firmin's criticisms concerning the 'parental deficits' 'contextless assessment' approach authorities deploy in their safeguarding investigations. It is a process that judges parents as unable to control or to protect their child and assumes that this can be resolved by a parenting class to teach them to be a better parent. For Firmin, it is an approach that is unable to 'look beyond the front doors' of families and appreciate the contextual risks that confront young people – in the stairwells of their flats, the bus terminuses, the online spaces, the housing estates and parks, and the school toilets.¹¹⁴
- 5.06. Social harm theory enables greater consideration of the policy responses for reducing levels of harm which refocuses attention from the individual to the state: critically analysing situations where the state institutions avoid political risk by developing, maintaining and (arguably) being indifferent to insidious policies that cause widespread public harm.
- 5.07. In the context of this research report, the 'one-dimensional' political responses in England to high profile child deaths provides a germane illustration of this phenomenon. These responses have mandated defensive professional practice that arguably undermines children's 'best interests and paradoxically makes them less safe: an approach, that in Munro's opinion is 'risk averse' rather than 'risk sensible'.¹¹⁵ It is one that has resulted in a substantial increase in the numbers of families experiencing the trauma of being investigated by children's services, without any material evidence that it has resulted in a decrease in child maltreatment or child deaths.¹¹⁶
- 5.08. In seeking to portray the traumatic impact resulting from policies and practices of this nature, some social harm theorists have sought to depict it as 'violence'.¹¹⁷ It is a description first propounded by Galtung,¹¹⁸ (in the field of peace studies)

¹¹² R Parker (ibid) at p. 239.

¹¹³ Ibid at p. 240.

¹¹⁴ Firmin, C. (2017) Contextual Risk, Individualised Responses: An Assessment of Safeguarding Responses to Nine Cases of Peer-on-Peer Abuse, *Child Abuse Review*, 27(1), pp. 42–57.

¹¹⁵ E Munro *The Munro Review of Child Protection: Final Report* (Department for Education, Cm 8062, 2011) pp. 124, 134 and 135.

¹¹⁶ See L Clements & A L Aiello & D Tilley 'Recurring themes: parent blame and systems- generated trauma' in L Clements & A L Aiello (eds) *Understanding Parent Blame Institutional Failure and Complex Trauma* (Policy Press, 2025), p.9.

¹¹⁷ See for example, J Salmi 'Violence in Democratic Societies: Towards an Analytic Framework' in P Hillyard, C Pantazis, S Tombs and D Gordon (eds) *Beyond Criminology: Taking Harm Seriously* (Pluto Press 2004) p. 57.

¹¹⁸ J Galtung 'Violence, Peace, and Peace Research' *Journal of Peace Research* (1969) 6(3), pp. 167-191 at 168.

not as a metaphor but in its literal sense – as violence extending beyond individual acts of physical harm to encompass social structures and cultural norms that hinder human potential.

5.09. Galtung's argument that countless individuals are violated by these practices chimes with the original meaning of trauma,¹¹⁹ although, as Burstow argues, trauma 'is not a disorder but a reaction to a kind of wound. It is a reaction to profoundly injurious events and situations in the real world and, indeed, to a world in which people are routinely wounded'.¹²⁰

5.10. Structural violence, as depicted by Galtung, is distinct from personal violence, in that 'there may not be any person who directly harms another person in the structure. The violence is built into the structure and shows up as unequal power and consequently unequal life chances'.¹²¹

5.11. For Farmer et al the 'term 'structural violence' is one way of describing social arrangements that put individuals and populations in harm's way'¹²² and to this Moe-Lobeda argues, an additional element is 'the complicity or silent acquiescence of those who fail to take responsibility for it and challenge it'.¹²³ In place of complicity or silent acquiescence Farmer¹²⁴ speaks of collective 'anesthesia' and how:

Psychological, moral, or economic anesthesia dulls us most effectively to structural violence. We interpret disparities in health and income and good fortune as 'the way things are.' Structural violence is never anybody's fault. Inequalities of risk and outcome—and our toleration of them—are evidence of the effectiveness of such anesthesia.

5.12. A closely allied concept of 'slow violence' has emerged in environmental studies to describe the insidious but lethal impact of environmental pollution: a 'violence that occurs gradually and out of sight, a violence of delayed destruction that is dispersed across time and space, an attritional violence that is typically not viewed as violence at all'.¹²⁵

5.13. As with Galtung, slow violence proponents are unapologetic in their use of the word 'violence'. People's lives are violated, people suffer profound mental and physical breakdowns, but the perpetrator has long since left the scene: the

¹¹⁹ A 'wound or bodily injury' from the Greek. τραύμα

¹²⁰ Burstow, B. (2003). Toward a Radical Understanding of Trauma and Trauma Work. *Violence Against Women*, 9(11), 1293-1317 at 1302 and see also L Quiros & R Berger 'Responding to the Sociopolitical Complexity of Trauma: An Integration of Theory and Practice', *Journal of Loss and Trauma*, (2015) 20:2, 149-159 at 151.

¹²¹ J Galtung 'Violence, Peace, and Peace Research' *Journal of Peace Research* (1969) 6(3), pp. 167-191 at 171.

¹²² Farmer, P.E.; Nizeye, B.; Stulac, S. and Keshavjee, S. (October 2006) 'Structural Violence and Clinical Medicine', *PLoS Medicine* 3.10: e449 at <https://journals.plos.org/plosmedicine/article?id=10.1371/journal.pmed.0030449>.

¹²³ C D Moe-Lobeda *Resisting structural evil* (Fortress Press. 2013) p.72.

¹²⁴ P Farmer *To Repair the World: Paul Farmer Speaks to the Next Generation* (University of California Press, 2013).

¹²⁵ R Nixon *Slow Violence and the Environmentalism of the Poor* Harvard University Press (2011) cited in T Davies 'Slow violence and toxic geographies: 'Out of sight' to whom?' *Environment and Planning C: Politics and Space*, 40(2), 409-427 at 410.

polluter of the watercourse or the author of the deeply flawed policy. As Davies explains, '[s]low violence provokes us to expand our imaginations of what constitutes harm. It insists we take seriously forms of violence that have, over time, become unmoored from their original causes.'¹²⁶

Concluding comments

- 5.14. Benign public policies have the potential to transform the lives of families who live with disadvantage, but it is not enough for a policy to be well-meaning. Public policies are generally complex things and are, invariably, capable of producing unintended consequences. **What is so profoundly troubling about the Cerebra research evidence cited in this report, is not the unintended and adverse impacts that they have identified, but the failure of those public bodies¹²⁷ to act with expedition to rectify these defects** (an issue to which we return in chapter 8).
- 5.15. Social harm theorists have referred to this behaviour as moral 'indifference', arguing, for example, that **'indifference rather than intent may well be the greater cause of avoidable human suffering.'**¹²⁸ It is difficult to disagree with this, when one considers (for example) the number of children harmed by air pollution or as pedestrians by car collisions. For a public body to be cognisant of the data on risks of this kind and then to take no action, would defy the 'common sense hierarchy of morality'¹²⁹ (that reserves the greatest opprobrium for intentionality). Indifference would however appear to be too mild a word: objectively such inaction can only be rationalised as 'complicity'.

¹²⁶ T Davies 'Slow violence and toxic geographies: 'Out of sight' to whom?' *Environment and Planning C: Politics and Space*, 40(2), 409-427 at 410.

¹²⁷ Including 'hybrid' public bodies – ie independent institutions that exercise functions of a public nature – section 6(3) Human Rights Act 1998.

¹²⁸ Box, S (1983) *Power, Crime and Mystification* (London: Tavistock) p.21 cited in P Hillyard, C Pantazis. S Tombs and D Gordon (eds) *Beyond Criminology: Taking Harm Seriously* (Pluto Press 2004) at 68.

¹²⁹ Reiman, J (1979) *The Rich Get Richer, the Poor Get Prison. Ideology, Class and Criminal Justice* (Winchester: Wiley) cited in P Hillyard, C Pantazis. S Tombs and D Gordon (eds) *Beyond Criminology: Taking Harm Seriously* (Pluto Press 2004) at 68.



We are not the same people. We are broken and traumatised. We cannot trust anyone any more.





Chapter six

Research methodology

Chapter 6: Research methodology

6.01. The research programme involved four distinct dimensions: (1) analysis of anonymised survey data provided by Cerebra; (2) the making of Freedom of Information (FoI) requests and the subsequent analysis of the data provided; (3) searches of local authorities' websites; and (4) documentary analysis of local authorities' 'trauma-informed practice' documents.

The Cerebra Survey

- 6.02. An online survey (using an application called 'Microsoft Forms') was posted by Cerebra on the 25 July 2024 and closed on the 13 September 2024. The survey questions are detailed at Appendix 1 to this report.
- 6.03. The anonymised survey data was then shared with the Leeds University LEaP research team (including 50 pro bono student researchers). The sample (comprising 1,235 responses¹³⁰) was then subjected to detailed analysis. The number of responses to each survey question varied (as not all respondents answered all the questions) and in the chapter 7 analysis that follows, the actual figures are specified.
- 6.04. The survey comprised 10 questions. The analysis in this report focuses on the responses to Questions 7, 8, 9 and 10.
- 6.05. As we note above (paras 1.02 – 1.03) 'Systems Generated Trauma' has been a consistent theme emerging from many of the LEaP research programmes: of families with disabled children describing the severe distress they experienced when they sought assistance from a public body. Their distress is the result of having to deal with dysfunctional siloed systems; systems that they found impossibly complex to navigate; systems whose default response was 'parent blame'; systems that failed to factor in the multiple, synchronous challenges that families with disabled children encounter;¹³¹ and all too often, systems that failed to provide the assistance that the family desperately needed.
- 6.06. Questions 7 and 8 of the survey endeavoured therefore to ascertain what it was that the public body did (or didn't do) that caused the harm experienced by the respondent and the severity of that harm.
- 6.07. Question 7 asked respondents to describe comments and actions that they found 'upsetting', and question 8 asked respondents to rate the severity of the 'unnecessary upset'. The words 'upset' and 'upsetting' were chosen in order to provide a low threshold for the severity of the actions or words reported by respondents.
- 6.08. Question 9 asked the respondent to describe the impact that the public body's actions had on their family and question 10 asked the respondent to describe what changes they considered necessary to ensure that that other families with disabled children were not subject to the same experience.

¹³⁰ A total of 1,237 responses were received but the first two were discounted as they originated from the research team – being 'questionnaire testing' responses.

¹³¹ See generally, L Clements *Clustered injustice and the level green* (Legal Action Group 2020).

6.09. The responses to these questions are categorised and quantified in chapter 7 and subjected to a critical analysis in chapter 8.

Fol requests to English local authorities

- 6.10. Fol requests were sent to a sample of 50 English local authorities requesting information in order to better understand the extent to which the authority had developed a 'trauma-informed' policy, strategy, guidance or equivalent document(s) that described how the authority and its employees should best interact with individuals who have experienced psychological trauma; and if so, whether (and how) such families were consulted and when the consultation took place.
- 6.11. Prior to the commencement of the research study, we undertook exploratory web searches (between February and May 2024) to identify whether there were likely to be sufficient numbers of local authority 'trauma-informed' policy documents to justify this aspect of the research. The study suggested that 24 such documents had been developed, all of which had been produced by English local authorities.
- 6.12. A decision was then made to confine this aspect of the research to English Councils.
- 6.13. In order to ensure that the documents we had identified constituted the current iteration of those authorities' policies, a decision was made to include the 24 authorities in the list of authorities receiving the Fol requests. In the hope of finding further such policies, the number of authorities receiving Fol requests was then increased by 26 (making a total of 50). These councils were chosen on the basis of their population sizes. The assumption being that larger authorities might be expected to be more likely to have the resources to develop such policies.
- 6.14. The Fol requests were sent between October 2024 and February 2025 (via the local authorities' portals and/or via emails to the addresses specified for such requests) and the responses analysed between December 2024 and March 2025. Appendix 2 to this report includes the text of the Fol request.
- 6.15. Of the 46 authorities that responded to the request 21 provided a document (and in some cases, several documents) which they considered to be their trauma-informed policy.

Searches of English local authorities' websites and documentary analysis of local authorities 'trauma-informed practice' documents

- 6.16. To complement the information obtained as a result of the Fol requests, the research team searched the web sites of the 50 English local authorities to see if they had developed trauma-informed practice documents. This additional 'belt and braces' element of the research was undertaken due to the research team's past experience of the variable quality of local authority responses to Fol requests and also to ascertain if any of the provisionally identified documents had been amended.

- 6.17. Relevant new documents were found on the web sites for 18 of these 50 authorities. However, 8 of these shared the same document with one or more other authorities – such that the research team was left with 10 new ‘distinctive’ trauma-informed practice documents. These (together with the 21 documents obtained through the Fol process (para 6.15 above) were then subjected to a documentary analysis.



*Whenever I see a doctor
etc they read about the
allegation... so I feel like
they are judging me.
I feel physically and
mentally violated.*





Chapter seven

Data results and analysis

Chapter 7: Data results and analysis

- 7.01. As noted above, in addition to re-analysing (from a ‘Systems Generated Trauma’ perspective) the findings of earlier research undertaken by the LEaP project and other research programmes, the research underpinning this report sought to obtain new empirical data. This involved gaining information from the parents of disabled children as to their experiences of their interactions with public bodies in relation to their child’s disability related needs. Additionally, the research secured information in the form of guidance documents produced by English local authorities which were designed to inform their workforce on the nature of ‘trauma informed practice’.
- 7.02. This chapter describes the data in quantitative and qualitative terms. The following chapter (chapter 8) critically analyses and contextualises this data in order to better understand: (1) the extent to which families with disabled children experience systems generated traumas (and the nature of these adverse experiences); and (2) the extent to which local authority ‘trauma-informed practice’ documents acknowledge the systems generated traumas experienced by families with disabled children.

Freedom of Information (Fol) requests concerning ‘trauma-informed practice’ policy documents

Adoption of ‘trauma-informed’ strategies (or equivalent) by English local authorities

- 7.03. As detailed in para 6.10 above, Fol requests were sent to 50 English local authorities, seeking (among other things) information as to whether they had developed ‘trauma-informed’ policies, and if so requesting copies.
- 7.04. Of the 46 authorities that responded to the request 21 provided a document (and in some cases, several documents) which they considered to be their trauma-informed policy.
- 7.05. As detailed in para 6.17 above, in addition to the Fol requests, the research team searched the websites of the 50 authorities to check the accuracy of Fol responses. The searches yielded an additional 10 policies. Accordingly, 31 policies are considered in the following analysis
- 7.06. Most of these documents (16 – out of 31) were focused on childcare. Of the remaining documents, 13 concerned both adult and childcare, one concerned adult care and one concerned the council’s homeless population.
- 7.07. It was clear from the phrasing of many of the policies that many had, not unnaturally, drawn on the English Government’s Guidance document ‘Working definition of trauma-informed practice’ (para 3.18 above). Three of the policies also made explicit reference to the SAMHSA guidance (para 3.09 above). Although both the English Government and the SAMHSA guidance refer to the importance of authorities avoiding practices that have the potential to retraumatise, only the SAMHSA addresses the need for authorities to avoid service systems that are ‘themselves trauma-inducing’ (para 3.09 above).

The dangers or re-traumatisation

7.08. Of the 31 policies analysed, 13 made specific mention of the dangers of local practices resulting in the re-traumatisation (or 'retraumatisation') of those with whom the authority interacted - examples include:

- [the guidance is intended to] '[c]ontribute to the development of adversity and trauma-informed multi-agency policies and systems designed to reduce the likelihood of systemic re-traumatisation'.
- The organisation prioritises minimising unnecessary stress and the risk of re-traumatisation for all individuals.
- The way services operate may unintentionally cause distress and re-traumatisation to people or staff.
- Resist re-traumatisation: Organisational practices may compound trauma unintentionally, trauma-informed organisations avoid this.
- Intentionally resisting re-traumatisation by mitigating the risk of additional harm, while promoting an understanding of psychological safety.

Inadvertent and unintentional

7.09. Of the 31 policies analysed five used words such as 'inadvertent' and/or 'unintentional' - as in:

- The way services operate may unintentionally cause distress and re-traumatisation to people.
- A trauma-informed organisation ... incorporates core principles of safety, trust, collaboration, choice, and empowerment and delivers services in a manner that avoids inadvertently repeating unhealthy interpersonal dynamics in the practitioner/family relationship
- and the inadvertent but widespread re-traumatisation of children and adults within existing services and systems.
- Organisations often inadvertently create stressful or toxic environments that interfere with the recovery of clients.

7.10. At paras 8.33-8.35 we consider further, the phrasing of these specific sections.

Recognition of local systems themselves generating trauma

7.11. The analysis of the trauma informed policies sought to identify the extent to which they acknowledged that institutional practices could themselves be a primary cause of the trauma experienced by families. Of the 31 policies studied only two acknowledged that this was a possibility.

7.12. The first policy contains a brief, tangential acknowledgement of the phenomenon of systems generated trauma, stating:

The purpose of this document is to provide educational settings in [XXX] Local Authority with guidance on trauma informed approaches to behaviour. The guidance encourages more reflection on traditional behaviour management

approaches, which place a significant emphasis on rewards and punishments linked to behaviour and to empower schools to consider a more relational approach, which is inclusive for all, and can benefit the whole school community. It is intended to encourage schools to develop their behaviour policies in line with trauma informed principles, and to ensure that their trauma informed policy translates into whole school practice.

- 7.13. The second policy is materially more direct in its recognition of the phenomenon of systems generated trauma. The relevant section states:

We are all part of a system, or a collection of systems. These systems have the potential to become trauma-informed but also hold the potential to cause harm.

Historically most services and systems haven't been set up to consider the intersections of trauma with social, political and cultural contexts and how they impact the way individuals and communities engage with services, if they're able to access services at all.

In this way, systems can compound structural inequalities and past experiences of trauma and adversity. [quoting ACE Hub Wales: Trauma and ACE (TrACE) Informed Organisations Toolkit (2022)]

In health and social care systems in particular, organisations and services often exist and function within 'silos', focusing on specific symptoms or presenting problems without thinking of someone as a whole person, with interlinking and interwoven experiences and needs.

By working in silos and not recognising the widespread impact of trauma and adversity when it comes to designing and delivering services, there is a real risk that someone won't feel understood and that their experiences won't be responded to effectively or appropriately, and this is where further harm and re-traumatisation can occur.

There is a growing recognition of the need for partnership working, which is an opportunity to minimise harm and to build a trauma-informed approach into these spaces.

Systems are sometimes described in ways that place them as external or separate to us and they are dehumanised as a result. This creates a challenge for people working within systems as they can feel they have no ability to change or influence systems in a positive way.

But systems are made up of people and we all have a unique and important part to play, and contribution to make, in promoting and embedding a trauma-informed approach. (p. 25)

- 7.14. At paras 8.36-8.42 we consider further the phrasing of these specific sections.

Cerebra Survey analysis

- 7.15. As detailed in para 6.07 above the Cerebra survey of parent carers sought 'to assess the extent to which families have had "unnecessarily upsetting"¹³² experiences in their interactions with the organisations responsible for

¹³² For an explanation as to the use of the words 'upsetting' and 'upset' see para 6.07 above.

supporting disabled children and their families – and to assess the nature and extent of these adverse experiences’. The survey questions are detailed at Appendix 1 to this report.

Comments and/or actions performed by organisations

7.16. Respondents were asked (Q.7) to describe the experience that they considered to be unnecessarily upsetting, in terms of what happened and any key comments that were made either verbally or in writing, as well as the key actions taken (or not taken). There were 1,214 responses to this question and these are categorised in Table 1 below.

Adverse factor	Responses identifying this factor [number]	Words/phrases included where the context was appropriate [i.e. used where the context fitted the concept]
Lack of support (for the parent), poor support, removal of support	334 [27%]	‘lack of support’, ‘not offering’, ‘no support’, ‘refusal’, ‘rejected’, ‘refused help’, ‘refused access’, ‘refused access’, ‘refused assessment’, ‘denied help’, ‘denial of help’, ‘denial of support’, ‘denied support’, ‘failure’, ‘not adhered to’, ‘poor’, ‘remove’
Safeguarding allegations (including accusing parents of Fabricated or Induced Illness (FII), child protection and removal of children)	279 [22%]	‘accusations’, ‘accused’, ‘fabricated illness’, ‘FII’ ‘Munchhausen’, ‘child protection’, ‘remove’
Parent blame	249 [20%]	blame’, ‘parent blaming’, ‘blaming parents’, ‘fit to parent’, ‘judgment’, ‘judged parents’, ‘parenting skills’, ‘parenting course’, ‘parenting strategies’, ‘poor parenting’
Delay in the provision of support	145	‘delay’, ‘long’, ‘never ending’, ‘waiting list’, ‘took years’
Failure to listen (to parents)	124	‘not being listened to’, ‘ignored’, ‘denial’, ‘refusing to believe’, ‘refusal to believe’, ‘refusal to acknowledge’, ‘refusal to accept’, ‘refusal to recognise’, ‘my input was questioned and rejected’, ‘failure to listen’, ‘minimising’, ‘questioning’
Threats to parents	107	‘threat’
Gaslighting	86	‘gaslighting’, ‘gaslighted’, ‘gaslit’

Adverse factor	Responses identifying this factor [number]	Words/phrases included where the context was appropriate [i.e. used where the context fitted the concept]
Abuse to parents and/or children (including verbal abuse by the practitioner, physical abuse to children living in supported accommodation and bullying to parents by the practitioner)	53	'abuse', 'abusive', 'bullying'
Discrimination against parents	21	'discrimination'

Table 1 Question 7 responses

7.17. The survey responses were analysed to see if it was possible to identify which branch of the welfare system was the primary cause of the adverse experience described. Although in many cases this was relatively straight forward, this was not the case for a significant number, either because it was clear that several institutions bore responsibility or because the response was equivocal – referring to, for example, problems encountered with an EHCP. The figures cited below are therefore subject to these caveats and to be regarded as 'indicative'.

- The educational system (e.g. the use of the words 'school', 'teacher', or 'EHCP') was the most cited (1,104 responses).
- The social care system (e.g. the use of the words 'local authority', 'council', 'social services', 'social worker') was the second most cited (428 responses).
- The health system (e.g. the use of the words 'CAMHS', 'CAHMS', 'NHS', 'GP' and 'paediatrician') was the third most cited (268 responses).

Extent of the impact on families of the institution's actions

7.18. Question 8 of the survey endeavoured to gauge the level of harm that the respondent experienced as a result of the adverse institutional behaviour. As we note above (para 6.06) the question was phrased in neutral and subjective terms – asking the respondent to compare the impact of the 'unnecessary upset' (caused by the institution's behaviour) with other adverse life experiences that he or she had experienced: i.e. whether the adverse impact from the institutional behaviour was (compared to these other experiences) 'insignificant' or at the 'same level as' or was 'more significant'.

7.19. Out of a total of 1,214 replies for this question:

- 1,122 respondents replied that the impact of the unnecessary upset was more significant as compared to how they felt before their upsetting experience. [92 percent]

- 63 respondents replied that the impact of the unnecessary upset was insignificant as compared to how they felt before their upsetting experience.
- 31 replied that the impact of the unnecessary upset was at the same level as compared to how they felt before their upsetting experience.

Impact on families of the adverse institutional behaviour

7.20. Question 9 of the survey asked respondents to describe the harm that they/ their family experienced as a result of the adverse institutional behaviour, including whether this had had a lasting impact on them/their family.

7.21. 1,214 respondents replied to this question. We have grouped these responses into broad categories/themes in the table below (Table 2). For each grouping we then provide (for illustrative purposes) the text of a few of the relevant responses.

Impact category/ number of responses	Illustrative responses
Mental Health ~ parent 698	The aggressive confrontation with the headteacher who said “who would believe you over me” sent me into depression and PTSD while I had to care for my very ill child. His siblings felt like they were under siege and we lost important years of family time and happiness.
	It made me feel very alone. And that my child would be better off without me in this world.
	I thought about ending my life to escape it. I now understand why people do... but if I did that who would help my child? Nobody. So you carry on fighting.
Mental Health ~ children 347	We felt the only way to protect child’s mental health was to home educate. Child continues to suffer panic attacks and social anxiety to this day, is completely mistrustful and wary of unfamiliar adults. Impact on his brother who witnessed his distress and also experienced school avoidance as a result.
	My husband and I have both been diagnosed with depression, we have both had therapists. Sometimes it’s all too much. Our son feels awful and guilty and he shouldn’t feel like that. It really affects how he sees himself despite us trying to hide it all from him. – 66
	My son took an overdose age 13 due to the negative impact it’s all and on his life.

Trust (loss of) 296	Don't trust ... the SEND system (despite myself working for local authority).
	I will likely need to rely on services for support, but I would rather die than ask now.
	My son to this day has a deep distrust of social services. My husband and I, also, have had a valuable lesson on the need to maintain a deep distrust of anyone from social services.
Physical health – adult and child 286	I now have fibromyalgia, PTSD and had a major operation to remove cancer. I have no life outside of these duties to my very poorly disabled daughter.
	That support is still largely not being provided resulting in further deterioration in physical and mental health for all family members
	I don't feel like I've been a good mother at times as I've had so much to deal with, my own physical health had determined as I suffer from chronic pain and this has got significantly worse due to the stress.
Employment impact 283	I've had to give up my career because of the lack of support available to my kids.
	Had to quit my career, family lost income, 2 children without adequate education, full time carer for 3 disabled children with no support.
	If her illness was physical and I hadn't got help I would be charged with neglect. I have lost my job, bills are stacking up, I can't leave the house, I can't even speak on the phone if she is awake. I have given up everything.
Children's schooling 255	My daughter lost her education.
	My child is 400 miles away at school because no local school can meet needs.
	Both my children are now home educated and will never return to the school system. Everything I do is now in writing or recorded.
Relationships (impact on) 191	As a mum, I have never felt more emotional worn down and broken. I feel that that is their plan. It has also had an effect on my marriage and my relationship with my other two children.
	Lack of help and support has culminated in child going into foster care after 10 years with special guardian and now even more fractured wider family relationship.
	My marriage and other relationships were damaged as I was so consumed with navigating through the process of fighting our LA to allow my daughter to have the correct school named on her EHCP. My younger son feels left out as we just couldn't do the usual stuff we used to do.

Blamed/ punished 172	They have defamed my character making me out to be an inadequate parent due to my own disabilities.
	Our family broke down and our child ended up back in care. Sibling suffered significant trauma. He is also adopted and has autism. Since our daughter left 4 years ago, he has rarely left the house as he says he now feels safe for the first time in his life. Me, well the systems generated trauma has been worse for me than being chased around the house with a carving knife by my daughter or being assaulted and abused daily for years. I understood that this was her disability and loved her despite living in fear. The abuse by systems has broken me. I cry each day and have regular suicide ideation. I live in chronic pain and am a mess. We have been blamed, gaslighted, ignored and made to feel irrelevant. Who would ever realise how adopting a child and the subsequent treatment by agencies would ruin my life. My husband is depressed. Neither of us see a future that is filled with nothing but the same. Our daughter is an adult now, and still has high and complex needs and still does not have the support so it is down to us still.
	The way, as parents we were judged, irrelevantly questioned and made to feel like I was the problem, has left me with mental health scars to this day. I constantly question my behaviours, parenting skills and beliefs and find it harder to know what I should and shouldn't say.
Safeguarding procedures 163	We already were hidden homeless due to a traumatic pregnancy then forced to move after safeguarding accusations.
	We are both suffering emotionally and physically with ailments we did not have before. We do not trust anyone, we have lost our confidence. Our son is now suffering mental health issues, has been traumatised emotionally and was made physically ill from the anxiety leading to hospital admissions after each child protection investigation, the first of which were used as ammunition for the second child protection.
	PTSD and profound affect [effect] on children and ourselves that escalated to my daughter's breakdown and mh hospital. The ss blamed and lied and did everything they could to discredit us to protect the harm they have caused.
Ongoing impacts 156	I remain traumatised- it has affected my personality, wellbeing and happiness, relationships with family, mistrust of new people, my career.
	I am now only able to deal with one 'battle' at a time and need time to recover each time.
	Scared of every knock at the door in case this person would turn up at home to re-traumatise the children.

Loss (happiness) 107	His siblings felt like they were under siege and we lost important years of family time and happiness. He is still a shell of his former happy, lively, loud self and barely leaves his room and only speaks when spoken to. They broke my child.
	I haven't been able to enjoy my children growing up.
	I have no energy left to do fun things with my children.
Children's relationship 106	My child is a shadow of his former self. He has no qualifications, no friends and requires therapy for school-based trauma.
	Every single member of our family is now on anxiety medication. Mine and my husband's marriage is close to breaking down. My sons relationship with his sister has been shattered and both our children have lost years of their childhood.
	Loss of friendships when boys were placed outside their peer groups instead of suitable settings.
Trust (children's loss of) 77	In our daughter, poor mental health and trust issues with school.
	My daughter no longer trusts any adults from organisations to do with health, has not seen a gp for 3 years, will not let support workers into the house, Has been traumatised by the whole experience.
	My children have less trust in any system. My daughter doesn't really want to talk to professionals- if that's what you want to call them.
Autism specific impacts 68	My son was diagnosed as autistic at the age of 4. He didn't get support from SALT or CIT or MAST until ages 10 (in his 3rd mainstream primary school).
	General stress which isn't helpful when I have several autistic kids who require educating (not all Attend school), a husband with cancer and I have elderly family members who I now seem to have to help. I now find checking my Email stressful in case I receive an email from the LA. Since going through the ehcp process, dealing with an awful school with a vindictive head teacher who didn't believe my child was disabled!! and an appeal, my emails trigger a panic response in me.
	We lost my only child - she was disabled and autistic - [name of county council] are still trying to argue she was making it up and we exaggerated her needs - no apology or accountability has been received from either council.

Court procedures 34	... what has destroyed me is that the local authority, when provided with verifiable evidence that demonstrates unequivocally that what the social worker has written in her section 7 court ordered reports is grossly inaccurate and misleading, but the local authority has still not rectified the inaccurate information in almost three years. It is their dogged refusal to rectify the reports that has caused the most damage to my child and I.
	Increased flashbacks, suicidal thoughts from me and kids, self harm me and kids, increased medication, regret of leaving domestic abuse , lack of trust with anyone now , separation anxiety, out of school for 2 years in total so far, I have Functional neurological disorder caused by trauma and stress so now disabled , family torn apart - older kids not allowed in refuge , loss of job , chronic fatigue , fibromyalgia, eating disorder, Alopecia , kids panic attacks myself panic attacks , fear of reaching out for support , financial difficulties, isolation due to family court not allowed to speak about the case to anyone and the court cases judges and cafcas[s] caused increased ptsd massively in myself and kids.
	I believe I have PTSD. I have flashbacks from the court of protection.

Table 2 Question 9 responses



We have been blamed, gaslighted, ignored and made to feel irrelevant. Who would ever realise how adopting a child and the subsequent treatment by agencies would ruin my life.



Changes families think need to be made by organisations

- 7.22. Respondents were asked (Q.10) to describe the changes that needed to be made, so that other families with disabled children did not have the same upsetting experiences.
- 7.23. There were a total of 1,235 replies to this question, which we have grouped into the broad categories/themes detailed in the table below (Table 3). For each grouping we then provide (for illustrative purposes) the text of a few of the relevant responses.

Impact category/ number of responses	Illustrative responses
Communication 673	LA staff make the process adversarial and are frequently nasty and condescending towards parents, especially if you have (educated) yourself and are aware of SEND law.
	Professionals need to be allowed to listen to parents! Whilst they have medical degrees, we are the experts in our children.
	Parents need to be taken seriously. We know our children better than anyone yet we are talked down to, gaslighted, generally treated very poorly.
Training 398	Children's services need to be trained in about SEN, and include it in their assessments. They also need to be trained in domestic abuse and recognising post separation abuse. The family court judges need training in SEN and domestic abuse as well.
	There needs to be more understanding and training for school staff and to move away from blame culture and enforcing punishments. I felt like school staff decided that my PDA child was simply defiant and they were determined to break his will.
	Proper trauma training must be put into place for educators, social workers, healthcare staff.
Accountability 361	I've had complaints upheld and yet there is no change.
	There is no actual accountability, tribunals just apply the law and LA's lose 98% of the time but they are never fined for their illegal practices.
	There are currently zero consequences when parents win at Cour[t] and prove that their child has been discriminated against. Where is the incentive for the decision makers to improve if the only outcome is that they have to apologise?

Assessment/ diagnostic processes 215	Stop saying it's parenting when it's a 4 year wait for diagnosis.
	Given that our child is disabled we should have gone straight to a child in need assessment with a suitably experienced social worker rather than having an assessment at the level of early help.
	Social services and health use S17 assessments unlawfully... then put parents on S47 and CP for asking for support from service's... there should be a separate social care system and child protection for additional needs.
Allocation of funding 201	There needs to be sufficient suitable and local provision for students with SEN so that Local Councils have suitable provision to offer. Local councils need the funding to do this.
	More stability for adults... take away the annual dread that funding might be withdrawn.
	Legal Aid needs to receive a huge injection of investments and we should have solicitors not paralegals managing cases and the funding should include representation too.
Whole system changes 127	The whole system is demoralising and horrific. I won't get back into it again.
	The whole education system needs to be reevaluated.
	The whole system is adversarial with children treated as numbers.
FII specific changes 99	Any unfounded allegations of FII or anything similar, with no evidence to support it should be stripped from medical files in their entirety and families should receive apologies.
	The current FII & PP guidance is not doing what is guided to do, and that is identify children subjected to harmful abuse... instead it's actually placing families in a traumatic process which involves them being at the center of unnecessary investigation (which often involves families who have children with additional needs, or parents who have an already confirmed diagnosis, which makes them unique compared to other regular parents). It needs a better guidance or policy for this.
	Social care needs to see that FII is an easy cover up for hospitals when they make mistakes and over-medicalise... and they need to have a fair and objective view...

Table 3 Question 10 responses

There are currently zero consequences when parents win at Cour(t) and prove that their child has been discriminated against. Where is the incentive for the decision makers to improve if the only outcome is that they have to apologise?



Chapter eight

Discussion and analysis

Chapter 8: Discussion and analysis

- 8.01. Many disabled children and their families have, by virtue of their child's impairment, a materially greater need for social welfare support than families who do not live with disability. This need requires engagement with the professional and administrative systems that the state has put in place in order to facilitate access to appropriate support.
- 8.02. For the purposes of this report, it is accepted that these systems were designed to promote the wellbeing of disabled children and their families albeit that they were also informed by considerations of administrative efficiency, budgetary control and the avoidance of 'political risk'.¹³³ These are generally complex, siloed systems that have evolved over lengthy periods. Families with disabled children must endeavour to understand the different rules for each discrete system; must appreciate that professional and administrative joint working between these silos cannot be assumed; must repeat the same information on countless occasions to a myriad of practitioners; must read a multitude of documents where the information on their child/family is often incorrectly recorded; and must learn to weather the additional unintended harms that result.
- 8.03. It is little wonder, therefore, that so many families describe as traumatic,¹³⁴ their attempt to find a way through these complex sharp-edged systems in order to secure the support that they and their disabled child needs. These are experiences of the kind detailed in chapter 2, that result from their interactions with local authority children's services; education services; multiple disciplines within the NHS and the Department of Work and Pensions. As we note above (para 7.16), the 1,214 responses to the Cerebra survey question concerning the public authority actions that caused distress can be categorised under headings that include: lack of support; allegations of FII; blame; delay; not being listened to; threats; gaslighting; abuse; bullying and discrimination.

The inadequacy of support

- 8.04. A backdrop to the lives of many families with disabled children is the severe inadequacy of the support available to meet their essential disability related needs. This issue was the most cited by the Cerebra survey respondents,¹³⁵ comments including:



• *Removed support and then we battled for years to have it reinstated*



¹³³ See in this respect, paras 5.06-5.07 above.

¹³⁴ As we note at para 1.06 above, for the purposes of this research we have adopted the English Government's working definition of 'trauma', namely that which 'results from an event, series of events, or set of circumstances that is experienced by an individual as harmful or life threatening'. Office for Health Improvement & Disparities Guidance *Working definition of trauma-informed practice* (2022) at <https://www.gov.uk/government/publications/working-definition-of-trauma-informed-practice/working-definition-of-trauma-informed-practice>.

¹³⁵ See para 7.16 above.



- *They did not care about supporting my daughter - their sole aim was to avoid spending money.*
- *I had literally pleaded on my knees to the consultant to help her and teach me how to help her, I got “no” as an answer and he left.*
- *They kept quoting cases such as Baby P and Victoria Climbié and made me feel like a criminal. I just wanted some help!*
- *We asked for help and were told she ‘was not disabled enough’.*



8.05. Research by Baker et al¹³⁶ also identified a lack of services and support as the most cited adverse event and abuse experience ‘factor’ (cited by over 80 percent of respondents), including the parental comment:



- *An overwhelming sense of powerlessness. At any moment I can lose everything and everyone I love, no matter how hard I work or try. Impotent rage at a system that works against common sense and basic support needs. Feel like a beggar. At worst times felt like systems wanted us dead as it would be cheaper. Considered driving me and my son off a cliff because of how strong this feeling was over two years with no way out.*



8.06. The above comment concerning the precarity of care and support arrangements – the dread of support being withdrawn at a periodical review – was also highlighted by a number of respondents in the current and other research studies. Mullally and Connolly¹³⁷ for example identified families ‘living in fear’ as a major stress factor: of extreme concern about the loss of support, the fear of ‘punitive actions’ by local authorities – with the frequent mention by parents of the phrase ‘not yet’. A point echoed by a respondent to the Cerebra survey, who commented:



- *You have to redo your child’s EHCP every year and then it gets sent to the council for review. From submission to approval took 8 months! All this time I am stressed about his place at special school being withdrawn. I then go through this every year. Even on a good year the wait is about 6 months. It is unacceptable.*



¹³⁶ P Baker, V Cooper, W Tsang, I Garnett & N Blackman ‘A survey of complex trauma in families who have children and adults who have a learning disability and/or autism’ *Advances in Mental Health and Intellectual Disabilities*, (2021) 15(5), 222–239 at 226 and see also M Baginsky ‘Parents’ views on improving relationships with their social workers’ *Journal of Social Work*, (2022) 23(1), 3–18, which identified as a cause of ‘most dissatisfaction’ by parents the fact ‘that while they had been drawn into a statutory intervention, they had not been provided with sufficient support to address their problems’.

¹³⁷ S L Mullally and S E Connolly “‘I felt shamed and blamed’: an exploration of the parental lived experience of school distress” in *Frontiers in Psychiatry* 2025 24(16): 1489316.

The consequences of systems generated trauma

8.07. As noted above (para 7.20) the Cerebra survey (question 9) asked respondents to describe the harms that they/their family experienced as a result of the adverse institutional behaviour. We have sought to categorise the 1,214 responses to this question under headings that include: mental health of parents and children; loss of trust (in institutions and practitioners); impaired physical health of parents and children; impact on employment; impact on children's schooling; impact on personal relationships; being blamed/punished; and being subjected to 'safeguarding' procedures.¹³⁸

Mental health of parents and children

8.08. The most common harm described by respondents to the Cerebra survey question 9 can be categorised as adverse impacts on their mental health and that of their disabled child (see para 7.21 and Table 2 above). Responses included:



- *I suffered with my mental health as a result and became exhausted and had to take 6 months out of work.*
- *I thought about ending my life to escape it. I now understand why people do... but if I did that who would help my child? Nobody. So you carry on fighting.*
- *After the hearing I drove home and spontaneously vomited in the shower from stress... It is endless. It put me in therapy.*
- *I took an overdose believing from the social workers views that my children would be better off without me there.*
- *When my child was unable to attend at all the headteacher phoned me and shouted "you need to get your child to school. You will be prosecuted ". My child was later diagnosed by CAMHS as having PTSD as a direct result of how he was treated at this school.*



8.09. Mullally and Connolly¹³⁹ make a similar finding in their research concerning 'School Distress' (see para 2.24 above), noting the 'devastating impact on the mental health of parents, with parents displaying significantly heightened daily anxiety and significantly lower mood' as well as 'developing a new mental health condition since their child's difficulties began'.

8.10. These are specific impacts, over and above the physical and mental health exhaustion some parents experience, simply by attempting to navigate the

¹³⁸ See Table 2 para 7.21 above.

¹³⁹ S L Mullally and S E Connolly "I felt shamed and blamed": an exploration of the parental lived experience of school distress' *Frontiers in Psychiatry* 2025 (24)16: 1489316 at p.16.

health and care system:¹⁴⁰ the mental distress that some experience in dealing with the social welfare agencies, such as the DWP which the House of Commons Work and Pensions Committee observed could be so difficult and distressing, as to contribute to ‘claimants deciding to take their own life’.¹⁴¹

Relationships of trust

- 8.11. ‘Trust is a fragile commodity, slow and laborious to develop, but quickly and easily destroyed’.¹⁴² Public trust in institutions and their workforces is generally considered to be of paramount significance in societies that do not rely on coercion and totalitarian control.
- 8.12. Trust is an elusive concept – subjective, ethereal, fragile and yet of fundamental importance not only in personal relationships but also for the effective functioning of social welfare institutions. Individuals must believe that such institutions are focussed on advancing their best interests: are responsive, reliable, open, fair, accountable and have integrity.¹⁴³ The evidence of the Cerebra survey suggests that these qualities can be encapsulated in the broad idea of ‘institutional empathy’ – bodies whose practitioners listen, support and respect – in the sense of conveying some sense of understanding how incredibly difficult it can be for families with a disabled child to lead ‘ordinary lives’.¹⁴⁴
- 8.13. It is alarming therefore that the loss of trust in social welfare institutions and their practitioners was so commonly referred to by respondents. 30 percent cited their loss of trust and or that of their child(ren) (Table 2 para 7.21 above), and in addition 29 percent made reference to the lack of accountability (Table 3 para 7.23 above). A number of parent respondents also referred to their non-disabled children being traumatised by witnessing the systems generated traumas that they (ie the parent) and their disabled sibling had experienced.¹⁴⁵
- 8.14. Of the over 700 survey comments that referred to a loss of trust and/or a lack of accountability, the following provide a brief illustration:

¹⁴⁰ Report by the Health Services Safety Investigations Body (HSSIB) ‘Workforce and patient safety: primary and community care co-ordination for people with long-term conditions’ 10 April 2025 at <https://www.hssib.org.uk/patient-safety-investigations/workforce-and-patient-safety/fourth-investigation-report/>.

¹⁴¹ House of Commons Work and Pensions Committee *Safeguarding Vulnerable Claimants* First Report of Session 2024–25 HC 402, p.9 at <https://committees.parliament.uk/publications/47840/documents/250688/default/>.

¹⁴² S Bibb & J Kourdi *Trust Matters* (Palgrave Macmillan 2004) p.30.

¹⁴³ Organisation for Economic Co-operation and Development (OECD) ‘Trust in government’ at <https://www.oecd.org/en/topics/trust-in-government.html>.

¹⁴⁴ J Read & L Clements ‘Disabled Children and the Law’ (2001 Jessica Kingsley) ‘That it should not be regarded as an exotic idea for disabled children and those close to them to aspire to a quality of life comparable to that enjoyed by others who do not live with disability’.

¹⁴⁵ See, in this respect, K Drayak ‘A sibling perspective on fabricated or induced illness’ in L Clements & A L Aiello (eds) *Understanding Parent Blame Institutional Failure and Complex Trauma* (Policy Press, 2025).



- *will never trust teachers, senco, LA again;*
- *[son] does not trust adults, he doesn't feel safe [education];*
- *I was terrified, felt suicidal, angry and will NEVER trust social services ever;*
- *I didn't sleep for 6 months and I've completely lost trust in our local authority;*
- *my daughter no longer trusts any adults from organisations to do with health;*
- *I don't trust the education team and the SEND system (despite myself working for the local authority);*
- *devastating and virtually impossible to have any trust in public services;*
- *mistrust of health professionals who have been proven to lie and cover up those lies;*
- *I will never ever be able to trust another social worker;*
- *my children refuse to engage with professionals now, following these experiences. They are deeply mistrusting;*
- *our daughter saw how the education establishment /staff treated her brother and made her distrusting of school staff;*
- *we are hostile towards and mistrusting of all services and their so called professionals. I can't talk about our experiences without breaking down. My child and I are lucky to still be alive as we reached our lowest moods and I would happily have killed myself;*
- *we cannot trust a single doctor we meet. We will never ask for support from social services again.*



8.15. The survey responses suggest that in many cases the loss of trust will be life long and potentially intergenerational. This reality is a major problem, not just for disabled children and their families, but for the institutions and their practitioners and for wider society. If significant portions of the public lose trust in vital institutions, such as health, education and social care services – this must inevitably undermine the most fundamental asset any country has – namely, the wellbeing of its citizens.

8.16. Research reinforces the view that trust cannot be assumed in social welfare settings – for example in the relationships between practitioners and families with disabled children. It is 'conditional and has to be earned'¹⁴⁶ and as Calnan

¹⁴⁶ M Calnan & R Rowe 'Trust relations in a changing health service' *Journal of Health Services Research & Policy*. 200813(3) pp.97-103.

and Row have observed, in these contexts, much depends on the quality of the parent - practitioner interaction – not least on the competence and empathy that is displayed rather than being based on:

professional status and seniority, instead it appears to be conditional and may be earned through a variety of strategies that demonstrate honesty, reliability, competence, accessibility and an indication that colleagues share similar values and have a common agenda.¹⁴⁷

- 8.17. In settings of unequal power, for example personal relations between social welfare professionals and families, research suggests¹⁴⁸ that trustworthiness can be more difficult to establish and require effective accountability mechanisms as well as for ‘the more powerful to treat the less powerful with respect and fairness’. However as Cook et al observe, these relationships are fragile and ‘trust is more easily broken and probably less easy to repair in these relatively one-dimensional relationships’¹⁴⁹
- 8.18. Where the ‘parties find themselves in an ongoing relationships’ trust can be enhanced by ‘the extent to which each party depends on the good will of the other to make things run smoothly’. Arguably this equality of interest is not present in many of the contexts considered in this research. Schools and social care departments can simply exclude the disabled child or deny them adequate support and clinicians can stifle criticism by uploading notes that directly or indirectly suggest the possibility of there being FII.

Parental expertise and relationships of trust

- 8.19. Research concerning disabled children who have (or are suspected of having) a rare condition is also informative in relation to the conditions necessary for the development of trust (and the consequences where it is lost).
- 8.20. The Genetic Alliance has identified about 5,000 named rare conditions that affect children and notes that in addition each year about 6,000 children in the UK are born with genetic conditions so rare that they do not, as yet, have a name.¹⁵⁰
- 8.21. Research by Jones et al¹⁵¹ referred to patients ‘feeling unsafe or fearful if they were in a healthcare setting with healthcare professionals who lacked knowledge of their condition’. Budycha et al¹⁵² noted that due to (among other things) ‘poor knowledge of rare diseases ... physicians may not act as

¹⁴⁷ Ibid.

¹⁴⁸ S K Cook, R Hardin & M Levi Cooperation Without Trust? (Russell Sage Foundation 2005) p.4.

¹⁴⁹ Ibid.

¹⁵⁰ A rare condition is a condition that affects fewer than 1 in 2,000 people – see NHS England *Rare Condition Registration Statistics updated to 2022* (2025) at <https://digital.nhs.uk/data-and-information/publications/statistical/rare-condition-registration-statistics/updated-to-2022/what-is-a-rare-condition>; and The Genetic Alliance UK ‘Facts and figures’ at <https://geneticalliance.org.uk/campaigns-and-research/facts-and-figures/>.

¹⁵¹ J Jones, M Cruddas & A Simpson et al ‘Factors affecting overall care experience for people living with rare conditions in the UK: exploratory analysis of a quantitative patient experience survey’ *Orphanet Journal of Rare Diseases* 19, 77 (2024). p13.

¹⁵² K Budycha, T M Helmsa & C Schultz ‘How do patients with rare diseases experience the medical encounter? Exploring role behavior and its impact on patient–physician interaction’ *Health Policy* 105 (2–3) May 2012, pp 154–164 at 155–159.

competent technical experts who provide relevant information to the patients'. One consequence of this being that patients are 'forced to become experts on their own disease state'. In their opinion this can challenge the traditional 'paternalistic model, with the physician having the dominant role'. They suggest that in such cases 'both parties must revise their role identities and mutual expectations' but that 'professional role identity is highly resilient and resistant to change'.

- 8.22. A failure to make such adjustments can lead to distrust: indeed the RCPCH (see para 2.12 above) now lists as an indicator of possible FII, parents who insist 'on continued investigations ... when results of examination and investigations have already not explained the reported symptoms or signs' as well as parents who 'inappropriately' seek multiple medical opinions or who seek 'new treatments (sometimes based on internet searches)'.
- 8.23. Budycha et al's research suggested that, when confronted by a patient (or parent) who may have acquired considerable expertise concerning the nature of their condition 'a minority of physicians rejected the patient's assertive behaviour, demonstrating an almost arrogant attitude toward the patient'.

The relative severity of the adverse experience

- 8.24. As we note at para 7.18 above, respondents to the Cerebra survey were asked to give an indication as to the level of harm that they had experienced as a result of the adverse institutional behaviour. They were asked to do this in relative terms: to gauge whether the adverse impact was (compared to their other adverse life experiences) 'insignificant' or at the 'same level as' or was 'more significant'.
- 8.25. **Over 90 percent of the 1,214 replies for this question gauged the impact of the institution's behaviour as more significant than their other adverse life experiences.**
- 8.26. A not dissimilar finding emerges from research by Mullally and Connolly¹⁵³ (see para 2.24 above). They asked parents to rate their adverse experiences compared to other adverse life events involving a considerable long-term contextual threat. As their paper records:
- The result of this comparison was striking, with parents currently supporting children with School Distress rating this life experience as the second most threatening life event, superseded only by experience of a 'Death of a 1st Degree Relative, including spouse or child', and more threatening than events such as 'Death of a close family friend', 'Serious Illness or Injury to Self', and 'Serious Illness or Injury to Close Relative'.
- 8.27. In terms of the actual severity of the impact that 'dysfunctional, disjointed systems'¹⁵⁴ have on families who have children and adults with a learning

¹⁵³ S L Mullally and S E Connolly "'I felt shamed and blamed": an exploration of the parental lived experience of school distress' in *Frontiers in Psychiatry* 2025 24(16): 1489316 at p.20.

¹⁵⁴ P Baker, V Cooper, W Tsang, I Garnett & N Blackman 'A survey of complex trauma in families who have children and adults who have a learning disability and/or autism' in *Advances in Mental Health and Intellectual Disabilities*, (2021) 15(5), 222–239 at 229.

disability and/or autism, Baker et al's research¹⁵⁵ concluded that it was 'commensurate with complex post-traumatic stress disorder' (CPTSD).

Institutional and practitioner insight into Systems Generated Traumas

- 8.28. **The empirical research data obtained in this study provides compelling evidence that the systems that disabled children and their families have to navigate in order to access essential social welfare supports, are experienced as traumatising.** This evidence of systems generated trauma echoes the findings of the earlier research summarised in chapter 2 above.
- 8.29. Given the importance of this evidence and of the corresponding need for public bodies to be aware of the trauma their policies are generating, the publication by a number of English health and social care bodies of policy documents advocating the adoption of 'Trauma Informed' practices was a development that prompted this research study.
- 8.30. In themselves 'Trauma Informed' policy documents of this kind are (as noted above) to be welcomed, as they convey an awareness that many of those with whom these organisations interact, have experienced life changing traumas. This research has sought therefore, to better understand the motivations for this policy innovation and the extent to which these documents acknowledge that the internal policies and practices of authorities are, themselves, a source of trauma for families.
- 8.31. As we note in chapter 3, although the development of policy documents of this kind by the Welsh and Scottish Governments owes much to the research of Harris and Fallot (among others), England's online guide¹⁵⁶ draws heavily on guidance issued in 2014 by the US Substance Abuse and Mental Health Services Administration (the 'SAMHSA guidance').¹⁵⁷ The SAMHSA guidance conceptualises trauma as predominantly 'other' – namely, trauma experienced by refugees fleeing their homelands; by military veterans in war zones; by victims of natural disasters; by adults and children who have been victims of physical or sexual abuse or abuse by trusted caregivers and/or domestic violence.¹⁵⁸ However, the guidance also contains a brief reference to the potential for institutional systems to themselves generate trauma, noting that:¹⁵⁹

In addition, the public institutions and service systems that are intended to provide services and supports to individuals are often themselves trauma-inducing. The use of coercive practices, such as seclusion and restraints, in the behavioral health system; the abrupt removal of a child from an abusing family in the child welfare system; the use of invasive procedures in the medical system; the harsh disciplinary practices in educational/school systems; ...

¹⁵⁵ Ibid.

¹⁵⁶ Office for Health Improvement & Disparities Guidance *Working definition of trauma-informed practice* (2022) at <https://www.gov.uk/government/publications/working-definition-of-trauma-informed-practice/working-definition-of-trauma-informed-practice>.

¹⁵⁷ SAMSHA 'Concept of Trauma and Guidance for a Trauma-Informed Approach' (2014) at https://www.nctsn.org/sites/default/files/resources/resource-guide/samhsa_trauma.pdf.

¹⁵⁸ Ibid p.8.

¹⁵⁹ One paragraph in page 2 out of 17 pages of text.

8.32. Although this reference is, in essence, cautionary (i.e. stressing the importance of policies and practices avoiding the re-traumatisation of people already traumatised) it displays a degree of awareness that could have (and arguably 'should have') roused policy makers and practitioners to explore and unpick the implications of this insight.

The 'othering' of trauma

8.33. As we note at para 7.08 above, of the 31 policies analysed, 13 made specific mention of the dangers of local practices resulting in the re-traumatisation of those with whom the authority interacted.

8.34. These references, valuable and welcome as they are, have (again) the potential to engender a conceptualisation of trauma as being 'other' i.e. of past 'external' adverse experiences for which the authority bears no responsibility – as in:

- [our policy] seeks to avoid re-traumatisation which is the re-experiencing of thoughts, feelings or sensations experienced at the time of a traumatic event or circumstance in a person's past.
- The organisation prioritises minimising unnecessary stress and the risk of re-traumatisation for all individuals.

8.35. This portrayal of institutional blamelessness is arguably reinforced by the use of words such as 'inadvertent' and 'unintentional' – which appeared in five of the 31 policies analysed. A typical example being a reference to the 'way services operate may unintentionally cause distress and re-traumatisation to people' (para 7.09 above). One such policy contained the observation that '[o]rganisations often inadvertently create stressful or toxic environments that interfere with the recovery of clients'. We discuss below the extent to which public bodies are able to absolve themselves of responsibility for 'unintended' but materially harmful systems that they operate. In the context of the last cited policy extract, a further relevant question concerns the extent a public body can 'inadvertently' create a toxic environment and having done this, is the 'inadvertence' of relevance?

Recognition that local systems can be the original source of trauma

8.36. As we note at para 7.11 above, our analysis of the 31 trauma informed policies sought to identify the extent to which they acknowledged that their own institutional practices could, themselves, be a primary cause of trauma experienced by families. With two exceptions, these documents contained no such acknowledgement. This is, in effect, the most compelling evidence concerning the absence of insight by authorities of the not insignificant role that their internal systems and practices have in traumatising the very families that they were created to help.

8.37. We provide above (paras 7.12-7.13) the text of the two local authority documents that acknowledge that their own systems are capable of generating trauma.

8.38. The purpose of the first such policy is narrow in focus – namely to provide educational settings with guidance on trauma informed approaches to

behaviour management. Two sentences within this 21-page document,¹⁶⁰ contain a tangential acknowledgement that internal policies may themselves be a primary cause of traumatic experiences, namely:

The guidance encourages more reflection on traditional behaviour management approaches, which place a significant emphasis on rewards and punishments linked to behaviour and to empower schools to consider a more relational approach, which is inclusive for all, and can benefit the whole school community.

It is intended to encourage schools to develop their behaviour policies in line with trauma informed principles, and to ensure that their trauma informed policy translates into whole school practice.

8.39. The second policy contains a materially more significant and direct acknowledgement of the phenomenon of systems generated trauma. The purpose of the guidance is to develop a system (across several authorities) that ‘recognises the potential impact of trauma and adversity and that can respond in compassionate and timely ways that support recovery and prevent further harm.’ Although the relevant section comprises only one page in a 51-page document,¹⁶¹ it is an important, insightful and refreshingly different document compared to the other policies considered in this research programme.

8.40. Importantly the document identifies internal ‘systems’ as a key driver of harm, stating ‘systems have the potential to become trauma-informed but also hold the potential to cause harm’. It then identifies how systems can fail to take into account:

the intersections of trauma with social, political and cultural contexts and how they impact the way individuals and communities engage with services, if they’re able to access services at all.

8.41. Welcome too, is the document’s identification of the harms caused by the siloed nature of institutional functioning – of ‘working in silos and not recognising the widespread impact of trauma and adversity when it comes to designing and delivering services’ adding:

Systems are sometimes described in ways that place them as external or separate to us and they are dehumanised as a result. This creates a challenge for people working within systems as they can feel they have no ability to change or influence systems in a positive way.

But systems are made up of people and we all have a unique and important part to play, and contribution to make, in promoting and embedding a trauma-informed approach.

8.42. As a first step towards a recognition of the traumatising impact that social welfare systems are having on disabled children and their families (among others) the above extract serves as a very welcome template.

¹⁶⁰ 21 pages, excluding the appendix.

¹⁶¹ 51 pages excluding references and template forms.

Why do institutions and practitioners act this way?

- 8.43. Baker et al, in their analysis of the prevalence and impact of systems generated trauma, express the view that the negative experiences of families ‘could and should be avoided in the first place, particularly as the causes are almost invariably predictable and preventable’. They then pose a particularly telling question, namely: ‘If families can identify these risk factors, then arguably health, education and social care services should also be able to do this?’¹⁶²
- 8.44. Why then do such institutions have such difficulty identifying and/or acknowledging this problem?
- 8.45. Baker et al suggest that one possible explanation is the difficulty in extricating institutions from their default approach of ‘locating the ‘problem’ within the family member’.¹⁶³ Research by Mullally and Connolly (see para 2.24 above) lends support to this view. They document the ‘devastating impact on the mental health of parents’ that resulted from their child’s difficulties in attending school due to their extreme emotional distress. They note that the professionals involved in the research expressed frustration with the lack of help for the families, and yet, despite ‘understanding how threatening the experience was for the parents, they were often quick to blame parents for their children’s difficulties’.
- 8.46. **The responses to the Cerebra survey (see para 7.16/Table 1) provide further validation of the difficulty practitioners have in conceptualising these difficulties as system failings, as opposed to parental failings. Of the 1,214 responses over 40% of respondents made reference to their experience of parent blame/family safeguarding accusations.**

Ignorance, indifference and impaired insight

- 8.47. Without seeking to minimise the role played by organisational ‘parent blame’ default positions¹⁶⁴ this cannot be a complete answer to Baker et al’s question (para 8.43). It does not explain, for example, why public bodies persist with hopeless and self-evidently ‘family harming’ policies. For example:
- Why, knowing how stressful the adversarial Special Education Needs Tribunal process is for families (see para 2.23 above), do English local authorities contest so many tribunal applications, when the evidence suggests that they fail in 96 percent of cases?¹⁶⁵
 - Why, knowing how incredibly stressful it is for families to experience an intrusive child protection investigation, do local authorities persist with

¹⁶² P Baker, V Cooper, W Tsang, I Garnett & N Blackman ‘A survey of complex trauma in families who have children and adults who have a learning disability and/or autism’ in *Advances in Mental Health and Intellectual Disabilities*, (2021) 15(5), 222–239 at 230.

¹⁶³ Ibid.

¹⁶⁴ L Clements & A L Aiello *Institutionalising parent carer blame. The experiences of families with disabled children in their interactions with English local authority children’s services departments* (Cerebra 2021).

¹⁶⁵ J Jemal and A Kenley *Wasting money, wasting potential: The cost of SEND tribunals* Pro Bono Economics (2023) at <https://pbe.co.uk/wp-content/uploads/2025/03/read-the-full-report-93a69e8a.pdf> and see para 2.27 above.

policies that involve 20 percent of children in England under the age of five in safeguarding enquiries¹⁶⁶ (and 25 percent in Scotland¹⁶⁷);

- Why, knowing how stressful and administratively time consuming it is for families to pursue ombudsman complaints concerning the failures of children's services, do authorities in England contest so many, when they are found to be at fault in 80 percent of cases (and at fault in 96 percent concerning their failure to abide by statutory procedures)?¹⁶⁸

8.48. It is simply implausible to suggest that the impact on families of the practices listed above is 'inadvertent' or 'unintended'.

8.49. The individual research findings concerning the impact of the trauma generating policies and practices described in chapter 2 above have been shared with the governments and public bodies, together with advice as to the necessary remedial action that needs to be taken. In none of these cases has there been a response conveying any sense of grave concern or an urgency to address the trauma generating defects within the systems. Our experience of seeking relatively straightforward change of this kind has been well described by Payne (in a similar context) to that of 'prodding a behemoth'.¹⁶⁹ Three brief examples of this lack of action and apparent lack of concern are illustrative:

- At paras 2.02 – 2.08 we refer to 2021 research,¹⁷⁰ that identified a material defect in 2018 guidance issued in England that was resulting in many disabled children and their families being subjected to a wholly inappropriate and traumatising assessment process. The research (shared with the English Government) detailed relatively straight forward remedial action that would rectify the problem – namely a revision to the 2018 guidance. In 2023, the 2018 guidance was reissued without the necessary changes and at the time of writing (September 2025) there appears to be no prospect of any action being taken to address the harms caused by this counterproductive policy.
- At paras 2.09 – 2.13 above we refer to research that identified material defects in 2021 guidance issued by the Royal College of Paediatrics and Child Health (RCPCH). The research suggested that in consequence, it was probable that large numbers of parents (particularly disabled parents) were being falsely accused of injuring their disabled child. The RCPCH is a 'public

¹⁶⁶ A Bilson and K E C Martin 'Referrals and Child Protection in England: One in Five Children Referred to Children's Services and One in Nineteen Investigated before the Age of Five' in *British Journal of Social Work* (2017) 47, 793–811.

¹⁶⁷ A Bilson and M Macleod 'Social Work Interventions with Children under 5 in Scotland: Over a Quarter Referred and One in Seventeen Investigated with Wide Variations between Local Authorities' in *The British Journal of Social Work* (2023) 53(4), 2217–2236.

¹⁶⁸ LGO Press Release Are children's voices being heard? Two Ombudsman reports highlight issues councils face dealing with statutory process 24 July 2025 at <https://www.lgo.org.uk/information-centre/news/2025/jul/are-children-s-voices-being-heard-two-ombudsman-reports-highlight-issues-councils-face-dealing-with-statutory-process>.

¹⁶⁹ A Payne 'That Woman!' in L. Clements & A. L. Aiello (eds) *Understanding Parent Blame Institutional Failure and Complex Trauma* (Policy Press, 2025), p. 50.

¹⁷⁰ L Clements & A L Aiello *Institutionalising parent carer blame. The experiences of families with disabled children in their interactions with English local authority children's services departments* (Cerebra 2021).

body'¹⁷¹ for the purposes of the Human Rights Act 1998, and its guidance is endorsed by the NHS in England, Scotland and Wales. Despite concerted action by many NGOs, families and researchers to have the guidance (and NHS support for it) withdrawn pending its revision – the guidance remains in force and unrevised.

- At paras 2.29– 2.33 above we refer to long standing concerns about the system by which payments of the Carer's Allowance are made. Despite a call for reform of this system in 2019 by a Westminster Parliamentary Committee¹⁷² together with a straightforward suggestion as to how the defect could be remedied¹⁷³ it remains the case that no effective action has been taken.¹⁷⁴

8.50. It is entirely reasonable to believe that the defective systems considered in this research were developed with good intentions and that the adverse impacts were unintended. However, the failure in each case to take purposeful remedial action when the defects were identified, renders untenable any assertion of blamelessness. As we note above (para 5.15), social harm theorists have referred to behaviour of this kind as moral 'indifference', and that 'indifference rather than intent may well be the greater cause of avoidable human suffering'.¹⁷⁵

8.51. Cerebra commissions and publishes its LEaP research reports with the aim of bringing about meaningful change to systems that are (albeit unintentionally) severely harming disabled children and their families. It was for the self-same reason that the House of Commons Work and Pensions Committee in 2019 undertook its investigation and published its report concerning the harm being caused to carers by the system that resulted in overpayments of Carer's Allowance.¹⁷⁶ The question that demands to be answered, is therefore "why do governments find it so difficult to make even the smallest 'corrective' changes of the kind we have identified as needed in this research?" Why, at the very least, can they not acknowledge systems' errors of this kind and commit to their rectification? Why, with all the resources at their disposal are they incapable of grasping the levers of power and correcting errors of this kind?

¹⁷¹ For the purposes of section 6(3) Human Rights Act 1998 a public body includes a body that fulfil functions of a public nature – see for example, *R (Karmakar and another) -v- The Royal College of General Practitioners* [2024] EWHC 2211 (Admin).

¹⁷² House of Commons Work and Pensions Committee *Overpayments of Carer's Allowance* Thirtieth Report of Session 2017–19 Report HC 1772 (House of Commons 24 July 2019)

¹⁷³ Ibid paras 50 – 52.

¹⁷⁴ See for example, J Halliday 'Carer's allowance: woman who won case against DWP calls for end to 'sickening harassment' BBC 16 June 2025 at <https://www.theguardian.com/society/2025/jun/16/carers-allowance-woman-who-won-case-against-dwp-calls-for-end-to-sickening-harassment>.

¹⁷⁵ S Box (1983) *Power, Crime and Mystification* (London: Tavistock) p.21 cited in P Hillyard, C Pantazis' S Tombs and D Gordon (eds) *Beyond Criminology: Taking Harm Seriously* (Pluto Press 2004) at 68.

¹⁷⁶ House of Commons Work and Pensions Committee *Overpayments of Carer's Allowance* Thirtieth Report of Session 2017–19 Report HC 1772 (House of Commons 24 July 2019)

What needs to be done

8.52. Baker et al,¹⁷⁷ in their survey of complex trauma conclude with the following observation:

Any working model of family experiences of trauma must include the understanding of how services may contribute to family trauma in the context of an already stressful life experience for families. It must also include an understanding of the interactions and negative feedback processes that can take place involving personal family vulnerabilities.

8.53. At Table 3 (para 7.23) above, we categorise the 1,235 responses to the Cerebra survey, where families with disabled children detail the changes that they believed necessary in order to create a benign system of support rather than one that generates trauma. The responses, in part, echo the comments made above (para 8.12), concerning the need for ‘institutional empathy’. Of the vital need for practitioners to listen to parents and to disabled children, and to endeavour to understand their perspectives and their needs. However, it is clear that families believe that this alone is insufficient: that allied to these essential changes there is a vital need for wholesale change – not least, in terms of the system being properly funded and proactive. In essence, where support is provided to sustain family life and independent living rather than to react to family breakdown and for there to be meaningful accountability – in terms of there being accessible and seriously dissuasive remedies to challenge institutional misbehaviour.

Improved Communication and Listening

8.54. Over 50 percent of the responses stressed the need for improved communication – in particular for practitioners to listen to them and to respect their expertise as parents of disabled children. **The importance of families being heard/being listened to, is a reoccurring theme of research studies of this kind¹⁷⁸ – and the survey responses are evidence that this is not happening on a routine basis.** A 2023 publication¹⁷⁹ produced by parent carers to inform the principles that should guide the process by which disabled children’s needs are assessed is of relevance in this context. It commenced with the following ‘overarching’ principle:

The importance of beginning with the assumption that parents are best-placed to judge the wellbeing of their disabled child: that as a result of their daily

¹⁷⁷ P Baker, V Cooper, W Tsang, I Garnett & N Blackman ‘A survey of complex trauma in families who have children and adults who have a learning disability and/or autism’ in *Advances in Mental Health and Intellectual Disabilities*, (2021) 15(5), 222–239.

¹⁷⁸ See for example, K Drayak ‘A siblings perspective on fabricated or induced illness’ in L. Clements & A. L. Aiello (eds) *Understanding Parent Blame Institutional Failure and Complex Trauma* (Policy Press, 2025) pp.123-141; and M Gallagher, M Smith, M Hardy & H Wilkinson ‘Children and Families’ Involvement in Social Work Decision Making’ *Children & Society* (2012) 26(1) pp 74-85: a literature review concerning children’s and parents’ involvement in social work decision making, that identified as ‘[c]entral to this are the establishment of relationships of trust and respect, clear communication and information and appropriate support to participate’.

¹⁷⁹ L Clements and A L Aiello (facilitators) *Draft Guidance: Assessing the Needs of Disabled Children and their Families* (2023 Leeds University) p.2. at <https://essl.leeds.ac.uk/download/downloads/id/937/draft-guidance-assessing-the-needs-of-disabled-children-and-their-families.pdf>.

experience and special bond they have a ‘sense of knowing’ of their child’s condition and needs.

Appreciating that many parents of disabled children feel that their expertise regarding their children’s wellbeing is not always recognised or taken seriously.

Training for Professionals

8.55. Almost a third of the responses called for the practitioners with whom families interact, to be ‘better trained’. Respondents called for, for example: ‘Children’s services ... to be trained about SEN, and include it in their assessments’ as well as being ‘trained in domestic abuse and recognising post separation abuse’ (adding that ‘family court judges’ needed training of a similar nature). Another response referred to the need for:

more understanding and training for school staff and to move away from blame culture and enforcing punishments. I felt like school staff decided that my PDA child was simply defiant and they were determined to break his will.

8.56. The evidence suggests that many parents of disabled children understand the limited ability of practitioners to secure support services that are sufficient to meet their family’s needs. However, the fact that families continue to highlight the need for training suggests strongly that they perceive the lack of understanding of the nature of impairment and the consequences of disability to be a problem of similar proportions to that of grossly inadequate budgets. In this context, research suggests that from a parent’s perspective, having the appropriate ‘skills’ includes relationship skills – in ‘appreciating the parent’s position’.¹⁸⁰

Enhanced Accountability and Redress

8.57. Almost a third of the responses to the question concerning the changes that needed to be made, referenced the issue of ‘accountability’ (in the sense of ‘an absence of accountability’). Not untypical comments include ‘I’ve had complaints upheld and yet there is no change’ and calls for ‘better forms of accountability – in terms of swift, accessible procedures leading to adequate and timeless redress and of bad individual and institutional behaviours being held to account’.

8.58. As we note in chapter 4, the legal mechanisms for holding to account health and social care bodies for their decisions concerning the provision of support services are objectively ineffective. Such mechanisms, as there are, are (on cost grounds) inaccessible to large swathes of the population and/or are incapable of imposing seriously dissuasive penalties on misbehaving public bodies. Indeed, 2019 research¹⁸¹ concluded that it was, from a costs perspective, not in local authorities’ interests to maintain an effective social care complaints process.

8.59. It is beyond the scope of this research study to describe in detail what an ‘effective accountability’ regime would look like. It is however an issue of

¹⁸⁰ See for example D Platt ‘Care or Control? The effects of investigations and initial assessments on the social worker–parent relationship’ in *Journal of Social Work Practice*, (2008) 22(3), 301–315.

¹⁸¹ L Clements & A L Aiello *Unacceptable delay: Complaints procedures for disabled children and their families* (Cerebra 2019) para 6.23.

considerable importance, as is the scheduling of its introduction. Arguably, children's services authorities lack the necessary financial resources to provide adequate support to meet the needs of disabled children and without radical 'whole system changes' the introduction of accessible and enforceable remedies would not, in itself, address this issue. Indeed, it could exacerbate care inequalities by diverting scarce resources to those families with the skills and networks that enable them to make best use of such remedies.

Whole System Changes addressing the root causes of blame

- 8.60. Response of this kind included comments on the adversarial nature of the current system: its 'siege mentality', its 'institutional defensiveness' and the need for – in essence – more understanding and less parent blaming culture. A positive example of change provided by one respondent concerned the implementation of the 'Martha's Rule':¹⁸² a specific systems change that has, brought about meaningful improvements in childcare safety.¹⁸³ The Rule addresses the power imbalance between families and clinicians – requiring that they not only listen to parents' concerns but also that they take specific action to address these concerns.
- 8.61. In the context of local authority approaches to assessing the needs of disabled children and their families, a valuable insight as what aspects of a 'whole systems change' might look like, can be gleaned from the foundational 'Trauma Informed Practice' documents. As noted above (paras 3.01 – 3.02) in 2001 Harris and Fallot¹⁸⁴ identified the importance of institutions undertaking 'a careful review of [their] policies and procedures' to avoid damaging 'intrusive practices'.¹⁸⁵ This need was echoed by the 2012 Last Frontier guidance¹⁸⁶ and in the 2014 SAMHSA guidance¹⁸⁷ – not least in its acknowledgment that 'public institutions and service systems that are intended to provide services and supports to individuals are often themselves trauma-inducing'.
- 8.62. It follows that one of the most straight forward and symbolic 'first step' actions that public bodies can take, is to adopt Harris and Fallot's appeal and produce

¹⁸² Martha's Rule gives patients and their families in England the legal right to a second opinion from senior clinician in the same hospital (but not within the immediate care team) if they are deteriorating rapidly and feel their concerns are being dismissed – see NHS England Martha's Rule (2024) at <https://www.england.nhs.uk/patient-safety/marthas-rule/>.

¹⁸³ House of Commons Health and Social Care Committee Oral evidence: The Work of NHS England, HC 563 Wednesday 26 March 2025 Q.102 at <https://committees.parliament.uk/event/23764>; and see also D Campbell *Martha's rule having 'transformative effect', NHS England data shows* Guardian 17 December 2024 at <https://www.theguardian.com/society/2024/dec/17/marthas-rule-having-transformative-effect-nhs-england-data-shows>.

¹⁸⁴ Harris, M., & Fallot, R. (2001). *Using Trauma Theory to design Service Systems*. New Directions for Mental Health Services. San Francisco: Jossey-Bass.

¹⁸⁵ Ibid p.9

¹⁸⁶ C Kezelman and P Stavropoulos *The Last Frontier' – Practice Guidelines for Treatment of Complex Trauma and Trauma Informed Care and Service Delivery* (2012) Adults Surviving Child Abuse (ASCA) at <https://blueknot.org.au/product/practice-guidelines-for-treatment-of-complex-trauma-and-trauma-informed-care-and-service-delivery-digital-download/> - For example in its references to 'the reality that [t]rauma has often occurred in the service context itself' and that 'abuse and exploitation will occur in any institution in which it can occur' – see paras 3.03 – 3.05 above).

¹⁸⁷ SAMSHA 'Concept of Trauma and Guidance for a Trauma-Informed Approach' (2014) at https://www.nctsn.org/sites/default/files/resources/resource-guide/samhsa_trauma.pdf p.2 – see para 3.09.

‘Trauma Informed’ policy guidance that unequivocally acknowledge the traumas that their internal systems are visiting upon disabled children and their families.

- 8.63. Such an acknowledgment would, of necessity, require a concomitant commitment to wholesale systems change. This in turn requires a strategic plan jointly developed with families, containing goals, milestones and an ambitious timetable. Its overarching aim will be to review, amend and if needs be ‘root out’ existing policies and practices that harm. Central to such an initiative will be the provision of keyworkers whose role is to guide families painlessly through these systems: keyworkers with the authority to work across boundaries (the system silos) and the power to make resource decisions.¹⁸⁸
- 8.64. Change of this kind will not, of course, be a panacea. It will not, for example, address the chronic under-resourcing or the lack of ‘accountability’ that characterises this sector. But that is not a reason for public bodies to take decisive action of the kind detailed above. Many such bodies have identified the importance of becoming ‘trauma informed’ and this research has hopefully been of value in clarifying what being ‘trauma informed’ entails.

Conclusion

- 8.65. Almost all the systems critically analysed in this report were developed for understandable and humane reasons – to safeguard children, to identify abusive parents, to support unpaid carers, to ensure children from all backgrounds attend school.
- 8.66. Inevitably all systems with such a broad reach will have imperfections – feedback loops and unintended consequences. This report has identified an abundance of such failings. What is so troubling is the inaction of the public bodies, when these imperfections have been identified and solutions proposed: **the profound inertia – even when it is accepted that these unintended consequences are having traumatic consequences for hundreds and indeed hundreds of thousands of individuals.**
- 8.67. The evidence overwhelmingly demonstrates that interactions with social welfare and education systems are a significant source of trauma for disabled children and their families in England: that despite the rhetoric of promoting ‘trauma-informed’ practice, there is a critical failure to acknowledge and address the systemic nature of this harm. Addressing systems-generated trauma requires not just superficial policy adjustments but a fundamental shift in institutional culture, accountability, and the training of professionals to foster trust, listen to lived experience and to work in partnership with families. Without such changes, public services risk continuing to compound the distress of already disadvantaged families, rather than providing the support that they desperately need.

¹⁸⁸ See generally, L Clements *Clustered injustice and the level green* (Legal Action Group 2020) chapter 7.



Chapter nine

Appendices

Chapter 9: Appendices

Appendix I : The Cerebra Survey questions

1. When requesting social care or healthcare or educational support for your disabled child have you had an experience which you believe has had an unnecessarily upsetting impact on you?

Yes/No. [Please circle your answer]

If Yes, please answer all of the following questions.

If No, please go to question 10.
2. When did the experience occur?
3. How old was your disabled child when the experience occurred?
4. How long did the impact of the experience last?
5. Which service(s) do you consider responsible for this experience? [social care services/education services/health services/other (in which case please specify)]
6. What was the name(s) of the organisation(s) responsible? (Please skip this question if you'd prefer not to say)
7. Please describe briefly what happened: including any key comments that were made either verbally or in writing, as well as the key actions taken (or not taken) which you found upsetting.
8. Please circle the statement below which best matches your experience.
 - a. The impact of the unnecessary upset was insignificant as compared to how I felt before my experience.
 - b. The impact of the unnecessary upset was at the same level as compared to how I felt before my experience.
 - c. The impact of the unnecessary upset was more significant as compared to how I felt before my experience.
9. Please briefly describe the impact the actions of the organisation(s) have had on you and your family.
10. If you have concerns about the system (organisations/public bodies/services), please briefly describe what changes you think need to be made so that other families with disabled children aren't subject to the same experience.

Appendix 2: Copy of the Formal Freedom of Information Request sent to English local authorities

Formal Freedom of Information Request: Trauma Informed Policies.

Dear [Name of English Local Authority]

I request that you provide the following information in compliance with your duties under the Freedom of Information Act 2000.

The purpose of the request

I seek the information detailed below in order to better understand the extent to which your authority has developed a “**trauma-informed**” policy, strategy, guidance or equivalent document(s) that describes how your authority and its employees should best interact with individuals who have experienced psychological trauma.

Statutory cost compliance limit note

If your Authority considers that complying with this request in its entirety will exceed the statutory cost of compliance limit (specified in The Freedom of Information and Data Protection (Appropriate Limit and Fees) Regulations 2004) then I ask that you respond to the following requests in the order they appear until that limit is reached.

Requested Information

Please answer the following questions specified in (1) - (2) below concerning your (possible) involvement in the elaboration (and implementation) of a ‘trauma-informed’ strategy or equivalent within your Authority’s area.

Has your Authority taken any action to:

develop and/or adopt a ‘trauma-informed’ policy, strategy guidance or equivalent (as outlined above)? If so, please provide a copy (in printed or electronic form) of the relevant document(s); and

implement such a policy, strategy, guidance or equivalent? If so, please provide a brief summary of actions of this kind: examples of implementation work could include the development of a staff training programme; the development of a specific website and/or the appointment of staff to support such an implementation programme.

Has your Authority involved/consulted with families of disabled children in the development and/or adoption of such a policy, strategy, guidance or equivalent? If it has, please provide details of how such families were consulted and when the consultation took place.

I understand that under the Act I am entitled to a response within 20 working days of your receipt of this request.

If this request is denied in whole or in part, I ask that you justify all refusals by reference to specific exemptions specified by the Act.

If you require any clarification, please contact me via email at [Student’s University email] in accordance with your duty under section 16 to provide advice and assistance if you find any aspect of this Freedom of Information request problematic.

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

Appendix 3: Selected extracts from responses to the Cerebra survey question 7

- Delays and minimizing felt intentional in order to save money. – 11
- The LA are lawless and are more like terrorists in their treatment of children and young adults with disability. – 33
- That made her feel suicidal by age 9. – 34
- Becoming increasingly unwell in their care accused us of trying to poison our child as we had sent in his prescribed certrazine and dietician recommended breads. – 44
- Refused child because not disabled enough. – 49
- My daughter was suicidal and self-harming as she felt she did not 'fit' anywhere. – 61
- The teacher tried to practically drown my child by pushing them back under the water. Physically manhandled her and verbally abused her. – 65
- Years. Last years she was writing on the walls that she wanted to die because she didn't feel that any help was ever coming from anyone,' – 73
- They have made me lose faith in humanity – 77
- The social worker then said the reason the family is struggling is down to poor parenting. There's no rules or boundaries in our house. – 79
- He [paediatrician] went on to provoke me to tears through his brisk tone and then said "pull yourself together. This is not about you. Your emotions at the cause of your child's problems". – 89
- Causing great stress within a single parent family. Parent blaming, bullying and gaslighting. Deceitful behaviours when investigative procedures are ongoing as part of complaints process. Withholding information and vital reports so causing further damage to my YP. Denying my YP her rights to her education, fulfilling her aspirations and reaching her potential. Making my already vulnerable YP feel worthless, unheard and invisible. – 102
- For may suicide is a better option than what we have to manage. – 103
- Accused of FII and put on child protection with the threat of my children being removed from our care despite the condition being diagnosed twice privately. Refused care but forced me to sign consent for my child to be put in an inpatient unit. This threatened her life. Her health declined whilst forced to stay for a safeguarding assessment for 3 weeks over Christmas and New Year. My husband lost his job as a result of these accusations. 20 years as an outstanding Assistant head teacher. Depression and cPTSD remain. – 112
- They did not recognise or even consider that my 11-year-old may have asd or adhd and was having meltdowns. Instead, they labelled him as a domestic violence perpetrator." 131 - "One was - a ICB clinical lead...comment 'its fun' when speaking to colleague on returning to an adjourned hearing. My response this is not fun for my son, myself or my family. – 120

- He was smiling happily during a meal and she (the disability nurse) pointed at him, accusing him of being a master manipulator. – 139
- We were gaslit, told it was our fault, told my children didn't meet any criteria. – 136
- Being told I (the parent) was the reason for the waiting list. – 137
- If that is tedious to read, imagine that being your actual life. – 138
- I had literally pleaded on my knees to the consultant to help her and teach me how to help her, I got "no" as an answer and he left. – 149
- Mostly [council name] ignore ignore ignore, it must be their secret code! – 152
- Gaslighting child's needs and delaying provision. – 156
- Constantly sought to belittle me with oppressive behaviour. – 161
- After the hearing I drove home and spontaneously vomited in the shower from stress... It is endless. It put me in therapy. – 184
- Welfare officer asked her to lift her sleeves in front of other students walking past. – 201
- In a meeting with the headteacher I was told some children pretend to be suicidal so they can sit at home and play Xbox. – 230
- Poor understanding of SEN needs, not following individual learning plan, not managing EBSA so it spiralled, insisting a suicidal child should be in school. – 238
- Told us we had to make the home environment as uncomfortable and unpleasant as we could so they would return to school. – 239
- I am gaslit at every turn. – 242
- Organisations looking after themselves without focus on the real need –our child. – 244
- Constantly being investigated for child protection reasons we spoke up and asked for help. – 247
- I've spent the last 18months constantly chasing, complaining and fighting for my child's rights. – 250
- My son has paperwork in his file that it not ours with even a different name on it, when I addressed it they said we can only change the name nothing else. I said but that's describing a family that isn't ours and it has a different name on it they said they can't change it as it's a legal document. – 253
- Camhs and NHS England put in writing that they would remove her from my harmful care and section her and take her hundreds of miles away to a standard impatient unit for standard care and they would place a gagging order via the courts on me so I could not speak about it. – 254
- My child was subject to bullying (from staff and pupils) and neglect during her time in school. Both she and I were gaslighted after trying to highlight this and seek help. There were allegations made to social care about me... – 288

- I took an overdose believing from the social workers views that my children would be better off without me there. – 293
- No support in place, but pressure and expectation to attend. – 310
- Culture of silence with occasional aggression. – 314
- The tragedy is my son was an exceptionally gifted pupil at maths and science. [Name of Council] have ruined our health and my son's future. – 320
- I am devastated we have lost 2 years and that they bare face lied to me. – 321
- Basically, saying our child wouldn't amount to much. – 325
- Child has experienced far more trauma from professionals than from her existing SEN. – 331
- Basically, they made false allegations of my character and stole my child because I also have additional needs... they used this against me they removed my child and removed my child's human rights to silence my child. – 335
- School teacher also deputy head made hints at FII being the issue and not disability. – 336
- Reputation is more important than the child. – 338
- My son would have been removed into care due to an uneducated and untrained professional. – 354
- Systematic failures... let to series of events... which ended in death (by suicide of the disabled person). – 364
- I'm just horrified by all of this.'/' my child had lost so much academically and emotionally over the last 3 years. – 366
- It is an abusive situation for sure and we pay our taxes for this poor behaviour? – 369
- I cannot trust anyone and constantly hypervigilant in any interaction with school or services which exhausts me. – 371
- Oh, and apparently, she's [daughter] not got a disability. – 373
- Everything has been a distressing fight. – 374
- My children have been subjected to years of neglect from social services. – 375
- Being told "I am that difficult woman – 378
- A social worker wrote in a report that I was a gold digger... I have had to repeatedly complain about services, leading to FII accusations and being told I am vexatious. – 382
- Shortbreaks obstructive, view anything other than compliant 'grateful for anything thrown their way'. – 388
- They restrained him, he came home with scratches and bruises on him. – 392
- Looking back, these services have robbed me of years. – 400

- The things I did for my own wellbeing - therapy, pilates, writing - were cited as 'evidence' I must have mental health problems and therefore be an unfit parent. - 405
- Had to fight every agency for basic care. - 461
- PTSD not recognised so made trauma worse instead of better. - 472
- My daughter is autistic. She was academically able. Sept/Oct 2021 she was really struggling to access learning/mental health subsequently declined. Services wouldn't see her because she 'wasn't not accepting she was autistic'. Eventually when seen - psychologist said 'our services are causing this child mental harm'. Camhs continued to refuse to help. She now won't trust services. - 474
- Behavioral, use consequences, nothing wrong with child, her behaviour is a choice, Prosecution. Refusal to assess, refusal to offer alternative education despite child being on 9% attendance. Resulting in my attendance in court, fined over a thousand pound. Assessment ASD took over yrs. Then got independent specialist provision. - 476
- He was left in horrific pain. - 485
- They kept quoting cases such as Baby P and Victoria Climbié and made me feel like a criminal. I just wanted some help! - 487
- Informing me that my 16-year-old who has severe spastic quadriplegic cerebral palsy was not eligible for provision of wheelchair adapted transport to enable him to access post 16 education, because they decided... he should be able to get there himself. - 502
- Sole focus on attendance figures rather than child's condition and the impact on them and the rest of the family. - 503
- We were also left without a bathroom for 100 days and told to pour our faeces down the garden drains (I have an audio recording proving this). - 506
- Refused a request for social care assessment and had to make a second request, delayed assessment, refused to backdate even though they said they would, put me under immense pressure by asking for info again despite direct payments officer confirming the info was not required as the carer we had sourced had a db's certificate already. - 508
- If I had known what I was in for I might well have aborted my disabled child, not because they are too much to cope with, but because the attacks from the system have left me so wrecked. - 509
- You have to redo your child's EHCP every year and then it gets sent to the council for review. From submission to approval took 8 months! All this time I am stressed about his place at special school being withdrawn. I then go through this every year. Even on a good year the wait is about 6 months. It is unacceptable. - 519
- Parent shaming, belittling opinions of parent. Not seen as an equal in terms of attending meetings and given equal opportunity to be heard. Documents abstained written comments very derogatory about parents' opinions. Spoken to

as if you are the child yourself and you have no knowledge. No actions taken until parents didn't back down and had to fight to exhaustion. – 521

- Negligence from the paediatricians and camhld team- refusal to help my son who has severe Id when he was going through severe crisis. I believe it is discrimination on kids with profound autism and non-verbal severe Id. – 526
- Blaming of parenting, was the hardest, as though I was to blame for my son. – 529
- Refusal to assess my child's needs. Threatened with prosecution for non-attendance at school. Told there was nothing wrong with my child. Lies in reports. – 538
- Council housing refusing major adaptations then overturning but then delays of 3 years to implement. – 552
- In [year] [name of County] were found at fault following a complaint about how we were treated when asking for help from children's social care. The ombudsman told them to pay us compensation for what they did to myself, my eldest who was now an adult and my two younger children. The 2 younger children we were threatened they would be removed because we asked for help. – 559
- False accusations of FII, illegal child protection process, parent blaming, gaslighting by professionals, withheld services, professionals lying in reports/ meetings and colluding to cover up their own failings, failed to investigate real safeguarding concerns from institutional failings, failed to adhere to MCA, Human Rights Act, Equalities Act... – 561
- Poor recognition of need/not taking parental concerns seriously. Poor understanding/application of the law re both education provision and EHCP process. – 566
- Accused me of fabricating illness in myself and my children when I complained about a refusal to provide us healthcare and services. Have applied to remove my children from my care. Had me prosecuted for not sending my disabled son to school. Refused to amend false records used in the child protection investigation. – 579
- Too broad a question - however the condition my dtr developed is physical complex and badly treated - accused of FII unknowingly - years of bad treatment threat and her health getting wrong damaging treatment that made her worse - lost everything home career support of family fighting this 12 years later some recognition by those services and politicians but life destroyed and trust and all health issues not supported. – 609
- We were refused assessment for Adhd despite school constantly suspending her and treating her awfully. I paid privately and got a diagnosis now to be told it was a waste of time and now back to the bottom of the queue. My daughter took a massive overdose at 12 and still the school treat her like a criminal for doodling! – 614
- Social Services have put our children on the Child Protection Register for emotional abuse and neglect, rather than do a needs assessment and offer help. – 617

- It was only when I said it was discriminatory that they pulled out all the stops - i said the word discrimination at 9 am and by 2 Pm same day everything was put in place...with just one week to go and that was a half term... – 631
- Incorrect placement Huge delays with EHCP. No education for 2 years. – 639
- After many years battling for appropriate levels of physiotherapy and speech therapy for my child I raised a complaint through the health boards patients' complaints policy. It took a [sic] 4 years to conclude and during the investigation my child's physiotherapist accused myself of bullying behaviour on 2 occasions during my child's annual statement review. As a consequence of this complaint, I had to sit in a room with two health board directors and head of patient experience and was questioned for over 3 hours while they took notes of my responses. – 651
- Lots of parent blaming and gaslighting. Adopted daughter treated even worse!!!! Dumped by csmhs after waiting 4 years for therapy. – 680
- Refusal to accept that my child had any disabilities or trauma. I was reported to social services and accused of munchausen by proxy. Two years later my daughter was diagnosed was fasd, asd and adhd. – 721
- Staff member compared training a dog to training my son who has absolutely no cognition. – 767
- Led to suicidal ideation and my then 8-year-old son putting a belt around his neck. – 779
- No response to my chasing email. Not being listened to in CIN meetings, wasting my and other professionals time in repetitive meetings that achieve nothing. – 787
- I was accused of fii and emotional abuse/neglect of my autistic son when he was school refusing due to needs not being met. My character was defamed by multiple services based on opinion not fact via child protection. – 798
- We asked for help and were told she "was not disabled enough". – 834
- Huge delays on everything including setting up budgets, getting support in school and at home. Awful, insensitive comments about my daughter, how emotionally hard it is to work with disabled kids, staff constantly off with stress, avoiding phonecalls. All so difficult to navigate. – 836
- Removing information from EHCP and denying additions based on parental knowledge and information. Telling parents to "reconsider" their decisions despite being given the decision several times with rationale. – 842
- Brutal abusive treatment of an already traumatized child. My child considers their time in this place as the worst of their life and cannot even mention it. – 846
- The final tribunal regarding placement was traumatising for us as our sons needs were evidenced by a barrister funded by the LA, an EP and senco none of who knew our son and the judge ignored us as parents -the power imbalance was cruel. – 851
- It got so bad that I actually went and completed a diploma in education so the comment "your not qualified to make that comment" could not be used. Even now

I am having to fight for the right support for my lads and constantly being blamed.
– 854

- Threatened her when I wasn't there by saying they would write in the notes that she wasn't cooperating with them when she was unable to move. As a result, my daughter is terrified of health professionals which impacts on me as main carer as I need to give her so much more emotional support and we are always on edge until we see a clinician "gets it". – 856
- Social services continued to be vindictive towards us, accuse us if being bad parents and making us feel like we were begging for help and being incompetent. I have felt humiliated ever since and feel anxious with every review. – 858
- Social workers gaslighted me into believing I perhaps was an abusive and neglectful parent after all. – 861
- Social services have failed to offer support when daughter had been through difficulties with her paternal family and father as I was expected to safeguard without their help and we begged for help. My daughter is now in trauma therapy as a result. – 866
- Not listening to our experience of parenting our child & the impact of not having a break from them (as child out of school). Very resistant to providing direct payments & made us feel bad for asking for help. – 873
- EP's treatment of me - as a committed parent & professional - was degrading and condescending and humiliating. – 878
- Schools present said that 'our parenting skills are the reason for everything as we have no boundaries or offer our children guidance.' She is the first 'professional' who has repeatedly lied, cancelled visits, not attended her own arranged CINs. Has made us completely lose trust. – 879
- My child was constantly refused help. Initially because she was put on a never-ending waiting list for an autism assessment... After several extreme meltdowns (where she hurt herself and others and damaged property,) they have finally, reluctantly agreed to help us. Although there is no timescale on this. But they are still adamant that as she is not suicidal... she is not a priority. – 883
- When my child was unable to attend at all the headteacher phoned me and shouted "you need to get your child to school. You will be prosecuted ". My child was later diagnosed by CAMHS as having PTSD as a direct result of how he was treated at this school. – 887
- I emailed and spoke to school several times but it's not been dealt with, no apology from the staff involved, no support for the trauma and expectations to try harder and me keep encouraging him to attend; he distrusts everyone/ sees them as demons, school as a prison and never wants to go back/ or feels he need an education to learn. – 891
- Not being listened to. Allowing poor care and neglect. Restricting my visits. No long-term planning. Constant moves. Poor care management and total disrespect. – 893

- I finally got the funding from the CCG to be assessed privately and that's when I found someone who understood but this took around 4 years. She is now nearly 18 and still suffers but things have improved. Therefore, she will still need support as an adult due to the delays in her childhood. I suffered with my mental health as a result and became exhausted and had to take 6 months out of work. – 895
- In short, I had to get a solicitor in order to 'buy myself a voice' costing me my life savings (£40,000) and taking his case to the Court of Protection to get access to services that my son was entitled to by law. – 897
- But school does not meet the needs of our neurodivergent children. We caused our son trauma by forcing him to go to school. He became so ill he was suicidal. – 905
- We are dismissed, have to explain over and over, justify ourselves, are disbelieved or thought to be exaggerating. – 908
- In healthcare there is a lack of understanding of learning disabilities, I worked in the nhs for 40 yrs. staff can often not describe the difference between LD and learning difficulties and miss the low IQ element and life long global issues associated with LD. – 912
- LA & health making claims of FII & PP in order to avoid meeting needs of child with complex medical needs. Failure to acknowledge trauma caused to child by health care staff. – 916
- I spent many hours attending many parenting courses that seemed to not make much difference in my situation (in some cases making things worse). As time went on, this experience got worse where my family were being accused of abusing our children. – 919
- A nightmarish 7 years for us. I've given up my job to support my daughter due to being let down by the system. if we'd have had her autism identified in 2017 and supported then with IDP and specialist placement the awful life crippling trauma she has suffered and I by extension have suffered... would nor [not] have happened. – 923
- It's the inaction, gaslighting, and dismissal, the threatening letters for both of my girls' school absences for neurodiversity, the ignoring of repeated pleas for support. The feeling that you are a failure because your kids do not conform to 'normal'. – 927
- Removed support and then we battled for years to have it reinstated Continually failed to support daughter who developed FND, functional tics and PTSD. – 930
- The local authority then named a school over 8 miles away from home which was never even a preferences or choice of ours. – 931
- As a child health professional, I had sought advice from other professionals and as a result got a private psychologist and sensory OT who diagnosed SPD. We had a 9mnth long investigation from CSC in which time I was suspended from my job as working with children and my chronic health problems were acerbated by the stress and I ended up in hospital. – 932

- We were humiliated and racially discriminated in our own home and then we have been bullied and harassed throughout the years for requesting for support and equipment or a Disabled facilities grant for home adaptations etc. – 939
- The systematic abuse is happening daily and parents are not heard whilst our children are made to suffer at the hands of professionals representing the state. – 941
- They did not care about supporting my daughter - their sole aim was to avoid spending money. They continue to patronise, minimise and dismiss even though she is now on an EOTAS package, which is very limited. – 946
- The education professionals said internally that I engineered the situation and it could be munchausens by proxy for financial gain. – 947
- LA bullied us relentlessly. Had to instruct private Psychiatrist and solicitor. Son was at home in pants and a blanket unable to eat properly. Still having trauma therapy 14 months later. All support was obstructed and we experienced parental blame. Entire family has had to have counselling. – 961
- The annual review itself had already been delayed by 10 months, pretty much an entire school year, and my autistic child was in crisis, hardly attending school. – 963
- The social worker told me in front of my daughter that she was going to report me to the police for giving her melatonin. As a consequence, my daughter has said she will no longer talk openly to services/adults, as she doesn't know who to trust. – 967
- Being lied to about the law, and being told you're aggressive, or "have an appetite for conflict" when you ask the LA to follow the law. Being told "if you don't like it, complain!" And then being called names in emails for complaining. – 968
- The school also delayed completing paperwork for an autism referral for my daughter by 2 years. – 972
- I faced intense disability discrimination including being called a Deaf dog by [name of social worker]. – 974
- I asked for a carer's assessment. They shared my details with my ex-husband, the father of the children. He is a perpetrator of domestic abuse. It culminated in them trying to get care orders for both my children due to the emotional harm they were suffering due to "parental acrimony". – 978
- Got changed pretty quickly for social care and all over our notes is this is wrong but damage is done as they cannot retract judgement. Son is so traumatised and now disabled for life and they have all gone. – 983
- We were referred for EHCP but waited far too long (in breach of timescales by more than double) yet we got letters threatening court and fines despite them knowing the reason she was not attending. – 990
- Missing one appointment (didn't was cancelled by hospital due to Queens funeral) triggered a serious safeguarding meeting full of professionals stating I was either medically neglecting daughter or enjoying her being ill. Etc no one bit I sense

at meeting - a false narrative was pushed and no robust evidence presented changed this. - 992

- My life has been turned upside down, I was chair of the PTA at my daughter's school for nearly 10 years, I have lost friends, as has my daughter. It feels like we have been disowned by the community we have known and been part of for years. - 997
- The Head Teacher turned it into an extremely nasty, vindictive and absurd personal crusade. I was accused of "coaching" my daughter to appear autistic. - 999
- My daughter was interested by same two officers, with body cam on, and without an Appropriate Adult, parent or other. And my daughter is Autistic, already traumatised from her past School experiences. It went on and on, and to date, a living hell, they have turned our lives. - 1002
- Not listened to by school, school not on board with concerns and strategies, school denying any issues, CAMHs waiting list 2years, assessments take too long to have feedback from/be reported on, once diagnosed there's no support. Healthcare system won't see kids to diagnose SEN issues, have to go through camhs. - 1055
- The suspected fii we were accused of will always be on medical records though and it affects how we feel about medical professionals and adds to daughter's and my stress levels. Some GPs patronising and unhelpful and I think they read about fii on my record and don't take my concerns seriously enough. - 1073
- CAMHS waiting list over 18 months for adhd assessments and mental health assessments. - 1076
- Accused of fii due to one chronically ill child and one neurodiverse child. - 1080
- Accused of fabricated illness when I complained. - 1088
- I was accused of FII by the hospitals following a complaint and questions over her care and [name of children's social care service] placed our daughter on the Child protection register to 'err on the side of caution'. This is literally how it is written in the initial conference reports. This meant that our family were examined for the following 6 months and I was called an 'unsafe mother' as well as my daughter's father and grandparents being called 'colluding liars' because they all wrote independent statements stating they had witnessed her symptoms independently of me. - 1095
- Accused of fabricated illness by [name of Council]. Separated from my family for 7 months without evidence. Parental alienation and asking for help and an EHCP were the key causes. - 1104
- The school contacted social services without our knowledge and accused us of FII. This is because we were requesting our child to use the disabled toilet which was being supported by the school nurse. - 1105
- Textbook gaslighting by a senior doctor who said that my child was just a typical teenager who has to try harder. Psychologising of all physical symptoms. - 1111

- After requesting a disability needs assessment for my child, I was instead investigated as a child protection concern and accused of FII by both SW and child's former school (rehashing allegations dropped in 2021). – 1122
- Our son's ASD and ME/CFS co-morbidity (gastrointestinal, autonomic and immune dysregulation) treatment was significantly affected by social services and psychiatry. His life has been put at risk due to delays in treatment. – 1163
- My son has diagnosed ADHD and undiagnosed Autism (I have both). I was subjected to continuously being blamed fir[for] my son's behaviour, he was removed from my care and I was prevented from continuing my career as a professional childminder. My two other children were traumatised as well as my son and as a result we have been broken as a family. I've never recovered from the traumas I went through and tried to take legal action multiple times but failed... – 1200
- I have been through 2 safeguarding investigations, which resulted in a serious breach of GDPR where our confidential report was sent to another family and theirs to us. I have been accused/blamed by professionals of poor parenting, needing better discipline and boundaries and a better sleep routine. – 1201



*I thought about ending
my life to escape it. I now
understand why people do...
but if I did that who would
help my child? Nobody. So
you carry on fighting.*





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