

## **The prevalence and impact of allegations of Fabricated or Induced Illness (FII)**

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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.

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## Research overview note

This research report considers the prevalence and impact on families in England, Scotland and Wales of being accused of creating or exaggerating their child's difficulties – an extreme form of parent carer blame. Instances of this kind are referred to as 'Fabricated or Induced Illness' (FII).

## Key Messages

- FII allegations against parents of disabled children appear to be widespread. The research indicates that parents in at least 74 per cent of English children's services authorities have experienced FII allegations – and that authorities in Scotland and Wales were also reported as initiating allegations of this nature (para 4.08).
- The major finding of the research is one of family trauma. The making of an allegation often causes devastating and life-long trauma to those accused (para 5.02).
- Disabled parents appear to be four times more likely to be accused of FII than non-disabled parents – raising important questions concerning Equality Act 2010 compliance (paras 5.14).
- 50% of allegations of FII reported for this research were made after a parent carer had complained about the actions of the relevant public body (para 5.21).
- There is an urgent need for material revisions to be made to the Royal College of Paediatrics and Child Health (RCPCH) 2021 FII guidance<sup>1</sup> including revisions: (1) to address its failure to recognise the harm to parents and children caused by allegations of FII; (2) to address the danger that its 'alerting signs' may have an adverse discriminatory impact on disabled parents; and (3) to acknowledge that its 'alerting signs' are unsupported by any peer reviewed research.<sup>2</sup>
- It appears that most FII allegations (84 per cent) resulted in no follow up-action or were abandoned and that in 95 per cent of the cases the child(ren) remained living with the parent (paras 5.06 - 5.07) – which is unsurprising, given that FII is generally accepted as a very rare condition and research suggests that the RCPCH guidance is likely to give rise to a very high number of 'false positives' (paras 2.50 and 5.08).
- The research indicates that NHS practitioners were the source of most FII allegations, followed by schools and then local authority children's services (para 5.29).

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<sup>1</sup> 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/> (accessed 25 August 2023).

<sup>2</sup> Glaser and Davis (2019) noted that the 'alerting signs' had 'not been tested prospectively for specificity and sensitivity', and that their efficacy in preventing harm / FII was 'untested systematically' / 'unproven' - see D Glaser and P Davis 'Forty years of fabricated or induced illness (FII): where next for paediatricians? Paper 2: Management of perplexing presentations including FII' Archives of Disease in Childhood, 2019, 104(1), pp7–11 at p10.

## 1. Introduction

- 1.01 2021 research by the LEaP programme ('Institutionalising parent carer blame'<sup>3</sup>) concluded that national and local social care policies in England create a default position for those assessing disabled children, that assumes parental failings: an approach that locates the problems associated with a child's impairment in the family. The 2021 research noted that, as a consequence, many families describe their interactions with children's services as profoundly unhelpful, humiliating and intimidating.
- 1.02 Since the publication of the 2021 research, the LEaP programme has been contacted by families with disabled children who have experienced an extreme form of parent blame, namely that they have been accused of fabricating or inducing their child's illness / their impairments. Instances of this kind are referred to as 'Fabricated or Induced Illness' (FII).
- 1.03 The fact that significant numbers of parents have contacted the LEaP programme for support on this issue is surprising, given that FII is generally considered to be a very rare condition.<sup>4</sup> There is, however, evidence that suggests that there has been a significant increase in allegations of this kind being made against parents by public bodies. Appendix 1 to this report contains a brief summary of some recent reports, media articles and ombudsman findings relating to FII allegations.
- 1.04 This research seeks to better understand:
- the prevalence of FII allegations; the characteristics of the families against whom such allegations are made; the situations in which the allegations are made; and the nature of the impact on families so accused; and
  - the roles and practices of the public bodies whose practitioners make FII allegations as well as the relevant training and guidance provided for such practitioners.

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<sup>3</sup> 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).

<sup>4</sup> 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 Gullon-Scott and Long: FII and Perplexing Presentations: *British Journal of Social Work* (2022) 52, 4040 – 4056 at 4043.

## 2. The legal and policy context

### The legal context

- 2.01 This research is concerned with the use (and the potential misuse) of the powers and duties vested in statutory sector bodies in relation to the care, support and safeguarding of ‘children in need’. In England<sup>5</sup> these provisions are primarily located in the Children Acts of 1989 and 2004.
- 2.02 Section 17 of the 1989 Act places a general duty on Children’s Services authorities to (among other things) safeguard and promote the welfare of children<sup>6</sup> by providing a range and level of services appropriate to their needs.
- 2.03 Children are defined as being ‘in need’<sup>7</sup> if:
- (a) they are unlikely to achieve or maintain, or to have the opportunity of achieving or maintaining, a reasonable standard of health or development without the provision of services to them by a local authority ... or
  - (b) their health or development is likely to be significantly impaired, or further impaired, without the provision for him of such services; or
  - (c) they are disabled.<sup>8</sup>
- 2.04 Section 17(11) Children Act 1989 defines a ‘disabled child’ as one who:
- is blind, deaf or dumb or suffers from a mental disorder of any kind or is substantially and permanently<sup>9</sup> handicapped by illness, injury or congenital deformity or such other disability as may be prescribed; and ‘development’ means physical, intellectual, emotional, social or behavioural development; and ‘health’ means physical or mental health.
- 2.05 In England,<sup>10</sup> the Chronically Sick and Disabled Persons Act 1970 s2(4), places a specific duty on children’s services authorities to provide a wide range of support services for disabled children, once they are satisfied that these are necessary.<sup>11</sup>

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<sup>5</sup> In Wales the provisions are also contained in the Children Act 1989 – and in addition – in the Social Services and Well-being (Wales) Act 2014.

<sup>6</sup> In this report, a child is defined as anyone who has not yet reached their 18th birthday. ‘Children’ therefore means ‘children and young people’ throughout.

<sup>7</sup> Section 17(10) Children Act 1989.

<sup>8</sup> Section 17(11) of the 1989 Act defines a ‘disabled child’ as one who is ‘blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed; and ‘development’ means physical, intellectual, emotional, social or behavioural development; and ‘health’ means physical or mental health.

<sup>9</sup> The requirement that a child’s impairment be substantial and permanent does not apply to children who ‘suffer’ from a mental disorder.

<sup>10</sup> In Wales the 1970 Act has been repealed - and the relevant provisions of the 1970 Act replaced by the Social Services and Well-being (Wales) Act 2014.

<sup>11</sup> See generally S Broach and L Clements *Disabled children a legal handbook* 3<sup>rd</sup> edition Legal Action Group (2020) paras 3.66 – 3.78.

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

- 2.06 Children's services authorities have a duty to undertake assessments to decide if a disabled child is eligible for support under the 1989<sup>12</sup> and 1970<sup>13</sup> Acts. Where a disabled child may have special educational needs, the Children and Families Act 2014<sup>14</sup> reinforces this obligation to assess their social care needs.
- 2.07 Although an assessment of a disabled child's needs will not always give rise to a duty to meet their social care needs – authorities are obliged to make rational decisions as to what, if any, support is necessary and appropriate.<sup>15</sup> This means that they must focus on the child's and their family's specific impairment related needs.

## **Children Act 1989 duties to parent (and other family) carers**

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

## **Local authority duty to assess under the Children Act 1989 s47**

- 2.11 Section 47 of the 1989 Act requires Children's Services authorities to undertake enquiries if they believe a child in their area has suffered or is likely to suffer significant harm. As the statutory guidance 'Working Together 2018'<sup>16</sup> explains, the effective discharge of these duties can only occur with the full cooperation of partner authorities at all levels. Materially, for the purposes of this research,

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<sup>12</sup> *R (G) v Barnet LBC and others* [2003] UKHL 57; (2003) 6 CCLR 500 and see also *R (AC and SH) v Lambeth* [2017] EWHC 1796 (Admin); (2018) 21 CCL Rep 76.

<sup>13</sup> Disabled Persons (Services, Consultation and Representation) Act 1986 s4 and see Department of Health Circular Guidance LAC (87)6) para 4.

<sup>14</sup> Children and Families Act 2014 s36 and the SEN and Disability Regulations 2014 regs 3-10.

<sup>15</sup> *R (AC and SH) v Lambeth* [2017] EWHC 1796 (Admin); (2018) 21 CCL Rep 76 at [65].

<sup>16</sup> HM Government *Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children* (July 2018) p.6.



partner authorities are those within its area such as NHS integrated care boards, NHS trusts and foundation trusts, and the local policing body. A wide range of education establishments<sup>17</sup> are also subject to the duty to cooperate<sup>18</sup> and to ensure that their establishments are run in a way that that safeguards and promotes the welfare of their pupils.<sup>19</sup>

- 2.12 The 2018 guidance emphasises that social workers should lead section 47 assessments with support from the police, health practitioners, teachers, school staff and other relevant practitioners in undertaking relevant enquiries.<sup>20</sup> The general safeguarding principles in the statutory guidance are also supplemented by specific practice guidance concerning disabled children.<sup>21</sup>
- 2.13 When a Children's Services' authority receives information that it considers 'reasonably' suggests a child within its area has suffered or is likely to suffer significant harm it is obliged to make enquiries under section 47. In so doing, the authority must ensure its enquiries (and its subsequent action) are proportionate.<sup>22</sup>
- 2.14 The Courts have acknowledged the 'difficult and delicate'<sup>23</sup> role played by a public authority in cases where child protection concerns are raised but that 'nevertheless at the end of the day [it] still has to ask itself the right questions and arrive at conclusions in answering those questions which are not irrational'.<sup>24</sup>
- 2.15 The High Court has explained that the 'relatively high threshold' of evidence that must exist before an 'intrusive' section 47 enquiry is undertaken<sup>25</sup>, is important since such an enquiry can be:
- very damaging for the life, career and family relationships of many who are parenting or caring for the child being assessed. . . . . involvement in a section 47 enquiry may often result in the ending of a career involving contact with children. This will usually be for good reason but this is not always so and there

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<sup>17</sup> For example, schools maintained by the authority, city technology / arts colleges, academies, non-maintained schools providing education for pupils with special educational needs, and further education colleges.

<sup>18</sup> Section 10 Children Act 2004.

<sup>19</sup> Section 175 Education Act 2002.

<sup>20</sup> The Statutory Guidance HM Government *Working Together to Safeguard Children* [footnote 16] Chapter 1 para 85 'Initiating section 47 enquiries'.

<sup>21</sup> Department for Children, Schools and Families *Safeguarding disabled children – Practice Guidance* (DCSF 2009):para 1.11 explains that it is 'supplementary to, and should be used in conjunction with, the Government's statutory guidance Working Together to Safeguard Children' and para 1.12, that it is 'intended to provide a framework within which Local Safeguarding Children Boards, agencies and professionals at local level – individually and jointly – draw up and agree detailed ways of working together to safeguard disabled children'.

<sup>22</sup> Human Rights Act 1998 Schedule 1, Article 8 European Convention on Human Rights; see also in this respect para 2.33 – 2.35 L Clements and A Aiello [footnote 3].

<sup>23</sup> *R v Hampshire County Council ex p H* (1999) 2 FLR 359 at 362.

<sup>24</sup> *R (O)v Peterborough City Council & Cambridgeshire and Peterborough Foundation NHS Trust* [2016] EWHC 2717 (Admin) para 53.

<sup>25</sup> *R (AB & CD) v. Haringey LBC* [2013] EWHC 416 (Admin) paras 10 and 16.



will rarely be a means for those unfairly marked out by involvement in a section 47 enquiry to eradicate that stain on their professional and personal reputation.<sup>26</sup>

- 2.16 Depending on the outcome of the section 47 enquiry the authority has a range of options – from taking no further action, making the child the subject of a child protection plan, seeking an emergency protection order<sup>27</sup> and / or instituting care proceedings.<sup>28</sup>
- 2.17 By way of example as to how public bodies can make decisions that are irrational and incorrect, 2016 proceedings concerned a challenge by parents to a local authority decision to make their autistic child (who was refusing to eat or drink) the subject of a child protection plan. The court found no evidence of neglect and held that the mere fact that there was a dispute between the parents and the medical team over whether the child should be in a residential unit was not a proper basis for the imposition of the plan. The parents had done all they could reasonably do and the local authority's decision was irrational. In the Court's opinion, child protection plans exist for cases when there is evidence of substantial neglect and not, for example, to resolve a dispute in relation to the appropriate medical treatment for a child.<sup>29</sup>

### **The Human Rights Act 1998**

- 2.18 It is unlawful for a public authority to act in a way that is incompatible with (among others) Article 8 of the European Convention on Human Rights (ECHR).<sup>30</sup>

### **Article 8 ECHR**

- 2.19 Article 8 of the Convention requires public bodies to respect the rights of individuals to their private and family lives, their homes and correspondence. Any state sanctioned interference with this right must (among other things) be strictly necessary and pursue a legitimate aim (for example the protection of a child). There is an extensive body of European Court of Human Rights case law concerning the fundamental importance of States providing adequate safeguards to ensure that an individual's Article 8 rights are respected.

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<sup>26</sup> *R (AB & CD) v. Haringey LBC* [2013] EWHC 416 (Admin) para 11 and see also *R (O) v. Peterborough City Council & Cambridgeshire and Peterborough Foundation NHS Trust* [footnote 24] para 40 where the court referred to the potentially detrimental impact action of this kind could have on the parents' employment prospects – particularly parents involved working with children.

<sup>27</sup> Section 44 Children Act 1989 – the police have, in addition, powers to remove and accommodate children in cases of emergency.

<sup>28</sup> Section 31 Children Act 1989.

<sup>29</sup> *R (O) v. Peterborough City Council & Cambridgeshire and Peterborough Foundation NHS Trust* [footnote 24] paras 46 and 54.

<sup>30</sup> Human Rights Act 1998 section 6.

## Equality Act 2010

- 2.20 The Equality Act 2010 provides legal protection for disabled people from being treated adversely because of their disability. Section 6 of the Act states that a person has a disability if: (a) they have a physical or mental impairment, and (b) the impairment has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.
- 2.21 A 'mental impairment' includes autism.<sup>31</sup> An impairment is generally understood to be 'long term' if it is likely to last more than 12 months<sup>32</sup> and 'substantial adverse effect' is 'something which is more than a minor or trivial effect'.<sup>33</sup> Whether an individual meets this definition is decided on a case-by-case basis.

## Indirect Discrimination and the Equality Act

- 2.22 Indirect discrimination<sup>34</sup> arises when an apparently neutral provision, criterion or practice applied by (for example) a public body puts individuals with a particular protected characteristic (e.g. disability) at a disadvantage compared with others.
- 2.23 Indirect discrimination is capable of being justified if it is a 'proportionate means of achieving a legitimate aim'.

## Public Sector Equality Duty

- 2.24 Section 149 Equality Act 2010 contains what is referred to as the Public Sector Equality Duty (PSED). This requires public authorities to have (among other things) 'due regard to the need' to eliminate discrimination, to advance equality of opportunity between 'persons who share a relevant protected characteristic and persons who do not share it'.
- 2.25 When developing, applying or reviewing a policy or practice, a public body must be able to demonstrate that it has had due regard to the requirements of section 149. In *R (Brown) v Secretary of State for Work and Pensions*,<sup>35</sup> the court highlighted various principles<sup>36</sup> concerning the nature of the duty, namely that:
1. *It is a general obligation.* The duty is 'broad and wide ranging' (para 35) and arises in many routine situations, essentially whenever a public body is exercising a public function, including an exercise of judgment that might affect disabled people.<sup>37</sup>

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<sup>31</sup> See for example *C & C v The Governing Body of a School and others* (SEN) [2018] UKUT 269 (AAC); Equality and Human Rights Commission *What equality law means for you as an education provider – further and higher education* (EHRC 2014) p.54 and J Wadham, D Ruebain, A Robinson and S Uppal *Blackstone's Guide to the Equality Act 2010* (OUP 2016) p.15.

<sup>32</sup> Equality Act 2010 Sch 1 para 22(1).

<sup>33</sup> Equality Act 2010 s212(1).

<sup>34</sup> Equality Act 2010 s13.

<sup>35</sup> [2008] EWHC 3158 (Admin) at [84]–[96].

<sup>36</sup> Equality and Human Rights Commission *Technical Guidance on the Public Sector Equality Duty* (EHRC 2014).

<sup>37</sup> See also *Pieretti v Enfield LBC* [2010] EWCA Civ 1104.

2. *Consideration is required before a decision is made.* The consideration of the potential impact of the decision must take place ‘before and at the time that a particular policy that will or might affect disabled people is being considered by the public authority in question’.
3. *The duty is a substantial one.* It is a duty of ‘substance’ that must be exercised ‘with rigour and with an open mind’ (para 92).
4. *The duty is non-delegable.*
5. *It is a continuing duty.*
6. *It is a ‘duty of record’.* Public authorities must keep an adequate record showing that they had actually considered their disability equality duties and pondered relevant questions.

2.26 Technical Guidance issued by the Equality and Human Rights Commission addresses the use of criteria to guide decision making in individual cases. It explains that the use of criteria does not remove the responsibility of the decision-maker to have due regard to the requirements of section 149. In the context of this report, criteria of this kind would include professional guidance concerning alerting signs of FII.

2.27 If there is evidence that decisions taken by the public body ‘will have a detrimental impact upon or be disadvantageous to’ those protected under the Equality Act 2010, the Technical Guidance states that ‘the body will need to consider whether to review the policy’.<sup>38</sup>

## **FII and the policy context**

2.28 This research paper is concerned with the prevalence and impact of situations where health, social care and educational practitioners make known to a parent that they suspect them of fabricating or inducing their child’s illness.

2.29 Health professionals have developed a variety of terms to describe such clinical situations. These include ‘Munchausen Syndrome by Proxy’, ‘Factitious Disorder Imposed on Another’ and the current term adopted by the Royal College of Paediatrics and Child Health (RCPCH), namely ‘FII’, which it defines as:

a clinical situation in which a child is, or is very likely to be, harmed due to parent(s) behaviour and action, carried out in order to convince doctors that the child’s state of physical and/or mental health and neurodevelopment is impaired (or more impaired than it actually is).<sup>39</sup>

2.30 Allegations of FII can be seen as a severe form of parent blame. In 2021, the RCPCH published updated guidance that includes details of what it considers to be ‘alerting signs to possible FII’<sup>40</sup> and it developed a term ‘Perplexing

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<sup>38</sup> Paras 5.46 – 5.50.

<sup>39</sup> Royal College of Paediatrics and Child Health [footnote 1] p.11.

<sup>40</sup> Ibid p.18.

Presentations' that clinicians can use when they consider such signs to be present.

2.31 Alerting signs are not evidence of FII<sup>41</sup> and, indeed, FII is not a diagnosis:<sup>42</sup> it is not a condition listed in the current Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) produced by the American Psychiatric Association.<sup>43</sup>

2.32 There appears to be a general consensus:

- that the research evidence concerning accurate mechanisms to identify carers who are harming a dependent child by causing or exaggerating their illness is poor;<sup>44</sup>
- that the validity of the RCPCH's 'alerting signs' is unsupported by any peer reviewed research;<sup>45</sup>
- that conditions such as Munchausen Syndrome by Proxy and Factitious Disorder Imposed on Another are rare. 1996 research concerning Munchausen syndrome by proxy (and connected conditions) by McClure, Davis, Meadow and Sibert suggested a prevalence rate of 0.4 per 100,000 children;<sup>46</sup>
- that cases which involve 'intentional induction' or which have led to the death of the child are 'extremely rare'.<sup>47</sup>

2.33 A number of academic and practitioner papers have expressed concern about the potential adverse impact on families of the RCPCH 2021 guidance. In consequence in 2022 the British Association of Social Workers (BASW) published separate guidance for social workers.<sup>48</sup> The BASW guidance identifies a number of practical reasons and considerations that call into question the reliability of the RCPCH's alerting signs and (by implication) the

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<sup>41</sup> Ibid.

<sup>42</sup> FII is, in essence, a set of criteria the RCPCH have developed to help identify parents who are making up or exaggerating a child's difficulties. However, as Gullon-Scott and Long observe, the use of such criteria to identify rare conditions brings with it significant risks, not least the potential for 'high numbers of false-positive cases (see para 2.50 below) and see also 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 (The professional association for social work and social workers) (2022) p.3.

<sup>43</sup> Royal College of Paediatrics and Child Health [footnote 1] p.10.

<sup>44</sup> M Eichner, 'Bad Medicine: Parents, the State, and the Charge of 'Medical Child Abuse,' University of California Davis Law Review 50 (1) (2016): 205-320; J Langhinrichsen-Rohling, CL Lewis, S McCabe, EC Lathan, GA Agnew, CN Selwyn, ME Gigler, 'They've been BITTEN: reports of institutional and provider betrayal and links with Ehlers-Danlos Syndrome patients' current symptoms, unmet needs and healthcare expectations.' *Therapeutic Advances in Rare Diseases*, 2021 2 1-12; F Gullon-Scott and C Long [footnote 4] at 4040; KJ Benson 'Perplexing Presentations: Compulsory Neuronormativity and Cognitive Marginalisation in Social Work Practice with Autistic Mothers of Autistic Children' *British Journal of Social Work*, (2023) 53(3), 1445–1464; C Long, J Eaton, S Russell, F Gullon-Scott, A Bilson [footnote 42]; A Bilson and A Talia 'Fabricated or Induced Illness: The controversial history, missing evidence-base and iatrogenic harm' (publication pending).

<sup>45</sup> Glaser and Davis (2019) [footnote 2] at p. 10, noted that the 'alerting signs' had 'not been tested prospectively for specificity and sensitivity', and that their efficacy in preventing harm / FII was 'untested systematically' / 'unproven'.

<sup>46</sup> R J McClure, P M Davis, S R Meadow & J R Sibert [footnote 4] and see also F Gullon-Scott and C Long [footnote 4] at 4043.

<sup>47</sup> F Gullon-Scott and C Long [footnote 4] at 4043; and see also A Bilson and A Talia [footnote 44].

<sup>48</sup> C Long, J Eaton, S Russell, F Gullon-Scott, A Bilson [footnote 42].

harm that might result if social workers did not exercise caution in such cases.<sup>49</sup> These include the imprecise / subjective nature of its 'alerting signs'; its potential to discriminate; and, its uneven approach to the nature of 'harm' – in essence the 'proportionality' of its analysis on this issue.

- 2.34 The 'lack of clarity'<sup>50</sup> as to what precisely constitutes FII has also been seen as problematic by a number of researchers<sup>51</sup> – not least the risk that 'many families who are not harming their children' will find themselves being wrongly suspected of FII – including 'children and young people with disabilities and illnesses that are undiagnosed, or where their presentations have been misunderstood and subsequently misdiagnosed'.<sup>52</sup>
- 2.35 As noted below (para 5.10) the RCPCH guidance (i.e. including earlier RCPCH guidance)<sup>53</sup> has been widely disseminated and much cited. Its provisions appear to form the basis for extensive training programmes attended by health, social care and education practitioners.

### Discriminatory potential

- 2.36 The risk that the 2021 RCPCH guidance could result in disabled parents and disabled children experiencing adverse discrimination has been noted in a number of publications.<sup>54</sup> This has been a particular concern for autistic parents and autistic children: autism being a condition that has been poorly

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<sup>49</sup> Ibid at pp 7-11.

<sup>50</sup> A Lazenbatt, 'Fabricated or induced illness: A narrative review of the literature', *Child Care in Practice*, A. (2013) 19(1), pp. 61–7 at 63.

<sup>51</sup> See for example, F Gullon-Scott and C Long [footnote 4] at 4040; KJ Benson [footnote 44]; C Long, J Eaton, S Russell, F Gullon-Scott, A Bilson [footnote 42]; A Bilson and A Talia [footnote 44].

<sup>52</sup> C Long, J Eaton, S Russell, F Gullon-Scott, A Bilson [footnote 42] at p.4.

<sup>53</sup> Royal College of Paediatrics and Child Health *Fabricated or Induced Illness by Carers: Report of the Working Party of the Royal College of Paediatrics and Child Health* February 2002 (RCPCH 2002).

<sup>54</sup> See for example, C Long, J Eaton, S Russell, F Gullon-Scott, A Bilson [footnote 42]; KJ Benson [footnote 44]; A Bilson and A Talia [footnote 44]; and see also: Action for M.E. 'Families facing false accusations' June 2017 at <https://www.actionforme.org.uk/uploads/pdfs/families-facing-false-accusations-survey-results.pdf> (accessed 12 April 2023); Not Fine In School 'School Attendance Difficulties: Parent Survey Results' (May 2018) p.19 at <https://img1.wsimg.com/blobby/go/a41082e1-5561-438b-a6a2-16176f7570e9/NFIS%20Parent%20Survey%20Results%20May%202018.pdf> (accessed 18 July 2023); SE Connolly and SL Mullally 'School Distress in UK School Children: The Parental Lived Experience' (pre-print) at <https://www.medrxiv.org/content/10.1101/2023.02.16.23286034v1> (accessed 13 July 2023); R Blower 'Protecting Parents from False Allegations of Fabricated or Induced Illness (FII)' *Special Needs Jungle* March 8, 2021, at <https://www.specialneedsjungle.com/protecting-parents-from-false-allegations-of-fabricated-or-induced-illness-fii/> (accessed 12 April 2023); and C Long, T Coope, S Hughes & K Hindson 'PANS, PANDAS and Fabricated or Induced Illness: A Guide to Social Work, Healthcare and Education Professionals' (2023) p.7 at [https://www.panspandasuk.org/files/ugd/c803db\\_49948facc981415fbd715dd35ecca3b.pdf](https://www.panspandasuk.org/files/ugd/c803db_49948facc981415fbd715dd35ecca3b.pdf) (accessed 18 July 2023).



understood by some health and social welfare professionals<sup>55</sup> and, as Benson notes<sup>56</sup> is one 'long been considered 'a "perplexing" condition' in itself.

2.37 Gullon-Scott and Long<sup>57</sup> argue that the RCPCH 2021 guidelines concerning FII and Perplexing Presentation (PP):

have broadened the concept of abusive behaviour to scoop up anything that leads to a parent presenting frequently to professionals with concerns about their child and where the professionals are unable to identify a cause ... . FII and PP actively suggest that autism, Ehlers-Danlos syndrome, chronic fatigue syndrome, gastro-intestinal difficulties, gait disturbance and similar may be alerting signs in the child or a factor in the parent (without any evidence basis), and therefore immediately have bias against these parents. FII focuses on outcome and ignores the reason for the behaviour.

2.38 Gullon-Scott and Bass<sup>58</sup> have warned of the 'arguably very high danger' that a mother with diagnosed or undiagnosed autism and attendant 'social communication difficulties and a tendency for rigid thinking styles, potentially coupled with clinical levels of anxiety, may have her behaviours and intentions misinterpreted by professionals unfamiliar with the autistic presentation in adults and particularly in females'. They cite 2016 research<sup>59</sup> that suggests this concern may be well placed: it found that one in five mothers of an autistic child reported being assessed by children's services and that they were 100 times more likely to be investigated for FII.

2.39 A 2016 report<sup>60</sup> referred to the risks that autistic mothers ran when trying to get their children diagnosed and supported 'as social workers misinterpret the parent's autistic traits as indicating potential harm to the child'. This was particularly so when an autistic mother was undiagnosed, as their behaviour could 'put professionals backs up and [result in them being] accused of causing or fabricating their children's condition.' In similar vein in a 2020 report researchers<sup>61</sup> identified many issues that they considered 'could be attributed

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<sup>55</sup> See for example, K Corden, R Brewer & E Cage 'A Systematic Review of Healthcare Professionals' Knowledge, Self-Efficacy and Attitudes Towards Working with Autistic People' *Review Journal of Autism and Developmental Disorders* (2022) 9:386–399; House of Commons Health and Social Care Committee report *The treatment of autistic people and people with learning disabilities* Fifth Report of Session 2021–22, HC 21; and Department of Health and Social Care *Oliver McGowan draft code of practice on statutory learning disability and autism training* at <https://www.gov.uk/government/consultations/oliver-mcgowan-draft-code-of-practice/oliver-mcgowan-draft-code-of-practice-on-statutory-learning-disability-and-autism-training> (assessed 9 September 2023).

<sup>56</sup> KJ Benson [footnote 44] at 1447.

<sup>57</sup> F Gullon-Scott and C Long [footnote 4] at 4052-4053.

<sup>58</sup> FJ Gullon-Scott, C & Bass 'Munchausen by Proxy: Under-recognition of autism in women investigated for fabricated or induced illness', *Good Autism Practice* (2018) 19 (2), 6-11 at 7.

<sup>59</sup> AL Pohl, SK Crockford, C Allison and S Baron-Cohen 'Positive and negative experiences of mothers with autism poster presentation' (2016) International Society for Autism Research, Baltimore at <https://imfar.confex.com/imfar/2016/webprogram/Paper22166.html> (accessed 3 October 2023).

<sup>60</sup> Amelia Hill *Autism: 'hidden pool' of undiagnosed mothers with condition emerging* *Guardian* 2016 26 December at <https://www.theguardian.com/society/2016/dec/26/autism-hidden-pool-of-undiagnosed-mothers-with-condition-emerging> (accessed 3 October 2023).

<sup>61</sup> AL Pohl, SK Crockford, M Blakemore, C Allison & S Baron-Cohen 'A comparative study of autistic and non-autistic women's experience of motherhood' *Molecular Autism*. 2020 Jan 6;11(1) at 10.

to perceived stigma of autism, lack of awareness and unmet support' noting that 'communication difficulties with professionals, feelings of isolation and perceived judgment may create further barriers for autistic mothers to ask for the support they need'. The report cited 2010 evidence that autistic mothers may be subjected to 'higher scrutiny from social services and medical professionals' and in consequence 'be more likely to have their parental rights terminated resulting in the loss of their child'.<sup>62</sup>

**Proportionality and false positives: *primum non nocere***<sup>63</sup>

- 2.40 The RCPCH 2021 guidance uses the word 'harm' on 90 occasions and the context is, consistently, the harm (or the risk of harm) to a child resulting from action by a parent or carer. The phrase 'iatrogenic harm' is used on three occasions and again, culpability for this harm is directed at parents / carers – as in, for example, 'iatrogenic harm is caused by the doctor's need and wish to trust and work with parents, which is fundamental to most elements of paediatric practice, and not to miss any treatable cause of illness'.<sup>64</sup>
- 2.41 Iatrogenic harm is generally considered to have a broader, more neutral definition:<sup>65</sup> one that focuses on consequences rather than practitioner intentions. The Shorter Oxford English Dictionary definition, for example, is '[o]f a disease or disorder; induced by a physician or surgeon through his diagnosis or treatment'. It is thought that iatrogenic harm (i.e. including diagnostic / medical treatment errors and negligence) is not uncommon.<sup>66</sup>
- 2.42 Varley and Varma<sup>67</sup> argue that the medical literature concerning iatrogenesis 'routinely rationalizes and absolves itself of its harms'; 'overwhelmingly prioritize provider- and system-side concerns over patient experiences'; and that when 'things go awry, providers may hold [relatively powerless] individual patients responsible'. They call for a greater understanding by the medical establishment of 'the injustices that unfold from clinical processes, practices,

<sup>62</sup> E Lightfoot, K Hill and T LaLiberte 'The inclusion of disability as a condition for termination of parental rights' in *Child Abuse Neglect*, (2010) 34(12): 927–34.

<sup>63</sup> Above all, do no harm.

<sup>64</sup> Royal College of Paediatrics and Child Health [footnote 1] p.15.

<sup>65</sup> Peer and Shabir define iatrogenesis as 'The side effects and risks associated with the medical intervention are called iatrogenesis' including medical error and negligence - see RF Peer & N Shabir 'iatrogenesis: A review on nature, extent, and distribution of healthcare hazards', *Journal of Family Medicine and Primary Care* 2018 Mar-Apr;7(2) 309-314 and E Varley & S Varma 'Introduction: medicine's shadowside: revisiting clinical iatrogenesis' in *Anthropology & Medicine* (2021) 28(2) 141–155 refer to two additional definitions, namely: (1) 'any adverse condition resulting from treatment by a physician or allied health professional as well as the failure to provide adequate care when it is warranted' – see D Garner 'iatrogenesis in Anorexia Nervosa and Bulimia Nervosa' *International Journal of Eating Disorders* (1985) 4(4), 701–726; and (2) 'any illness [that] results from a diagnostic procedure or therapeutic intervention that is not a natural consequence of the patient's disease' – see T Suh & R Palmer 'Acute Care' in E Duthie, P Katz & M Malone (eds) *Practice of Geriatrics* (4<sup>th</sup> ed 2007 Elsevier).

<sup>66</sup> Peer and Shabir 2018 *ibid* at p.310, suggest that it is the fifth leading cause of death in the world. A recent USA study suggested that one in four people treated in a US hospital experiences some form of avoidable harm – see D Bates et al 'The Safety of Inpatient Health Care' *New England Journal of Medicine* (2023) 388:142-15 at <https://www.nejm.org/doi/full/10.1056/NEJMsa2206117> (accessed 11 September 2023).

<sup>67</sup> E Varley & S Varma [footnote 65].



and protocols that have far-reaching, reverberating effects into patient lifeworlds and subjectivities beyond the clinic’.

- 2.43 In the specific context of FII literature, Bilson and Talia<sup>68</sup> note that this too ‘mainly focuses on the potential for harm to be done by parents to children’. This unevenness of coverage exists despite the reports, papers and media articles concerning parents being found to have been wrongly accused of FII<sup>69</sup> – and in some cases imprisoned on the basis of evidence given by a paediatrician and (at the time) a leading FII researcher.<sup>70</sup>
- 2.44 One element present in a number of media reports concerns a parent being accused of FII when the root problem is subsequently discovered to be a misdiagnosis by a clinician. Errors of this kind are, of course, inevitable and accurate diagnoses in relation to disabled children can be particularly challenging given the range of potential impairments. Of the 800 medical conditions listed on the database of ‘Contact’ (the charity for families with disabled children) many are considered to be rare or very rare and difficult to diagnose.<sup>71</sup> Many parents of disabled children will be aware of this problem and, if their child’s health remains poor may in consequence undertake on-line research and /or seek a second opinion. Actions of this kind can result in a relationship breakdown between clinicians and families and fall within the ambit of the RCPCH’s 2021 guidance’s ‘alerting signs’. The blame in such cases will not always rest with the families and on occasions the failure to seek a second opinion – can, as Curtis and Wood observe,<sup>72</sup> ‘lead to deadly mistakes’ that are in fact attributable to ‘stubborn pockets of poor culture within hospitals and teams across the system’.

### Diagnostic procedures and false positives

- 2.45 Almost all diagnostic tests have a margin of error – even those involving the chemical analysis of blood or saliva or a sophisticated MRI scan. The error may be a failure to identify that a person has a particular condition or a ‘false

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<sup>68</sup> A Bilson and A Talia [footnote 44] cite research by D Rand & M Feldman ‘Misdiagnosis of Munchausen syndrome by proxy: A literature review and four new cases’ *Harvard Review of Psychiatry* (1999) 7(2), 94-101 who reviewed of more than 200 papers written concerning Munchausens (MSPB) syndrome by proxy published from 1966 to 1999 and found only seven reports of misdiagnosed MSBP. They express concern that ‘[i]ncreased efforts to identify and protect victims have sometimes resulted in misdiagnosis of MSBP, leading authorities to remove children from the home and/or bring criminal charges against an innocent parent.’

<sup>69</sup> See for example Appendix 1 to this report.

<sup>70</sup> See for example J Batt *Stolen Innocence: A Mother's Fight for Justice—The Story of Sally Clark* (Ebury Press 2004) and Thair Shaikh ‘Sally Clark, mother wrongly convicted of killing her sons, found dead at home’ *Guardian* 17 March 2007.

<sup>71</sup> Contact A-Z medical Conditions at <https://contact.org.uk/conditions/?filter-search=&filter-condition-az=a#conditions-archive> (accessed 10 September 2023).

<sup>72</sup> P Curtis and C Wood *Martha's Rule a New Policy to Amplify Patient Voice and Improve Safety in Hospitals* (Demos 2023) p.13 (accessed 10 September 2023) – a report that calls for families to have the right to ask a separate medical team for a review of treatment or diagnosis of a child or for a second opinion family to have a review. See also *R (O)v Peterborough City Council & Cambridgeshire and Peterborough Foundation NHS Trust* [footnote 24] and para 2.15 above.

- positive' where the individual is wrongly identified as having a particular condition.
- 2.46 False positives can cause psychological harm where a patient is told that they have tested positive for a particular condition – although this harm may be short-lived if a rapid and accurate second test is available. For example, in breast screening it appears that over 75 per cent of women who have an abnormal result are subsequently found not to have breast cancer.<sup>73</sup>
- 2.47 FII is not, of course, capable of being diagnosed by a chemical analysis or a scientific scan<sup>74</sup> and, indeed, it is a condition in relation to which there is considerable doubt as to the accuracy of the various diagnostic mechanisms used to identify it,<sup>75</sup> including the RCPCH's 'alerting signs'.<sup>76</sup>
- 2.48 This research study provides, however, strong evidence (see para 5.02 below) that where a parent is informed that they are suspected of FII – this can cause prolonged / life-long trauma, not only to the parent but also to their children: trauma that does not evaporate if the allegation is subsequently shown to be mistaken.
- 2.49 As Whitty notes,<sup>77</sup> '[f]alse positives matter because many treatments and even some diagnostic tests, can do harm', adding that they can lead to 'overtreatment, and in a few cases stigma' and that a 'screening programme which throws up very large numbers of false positives is therefore potentially very problematic'. This is particularly the case if the potential population to be screened is large.
- 2.50 Research has theorised that if the RCPCH's 'alerting signs' are superbly accurate and correctly identified all true cases of Munchausen syndrome by proxy or FDIoA, this would equate to between 53 and 376 individuals in England. It has also suggested that if the materials are 90 per cent accurate in rejecting non-cases, this would nevertheless result in 1,339,789 false positives.<sup>78</sup>

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<sup>73</sup> NHS Digital NHS Breast Screening Programme, England 2020-21 at <https://digital.nhs.uk/data-and-information/publications/statistical/breast-screening-programme/england---2020-21/qualitystatement3#accuracy-and-reliability> (accessed 2 October 2023).

<sup>74</sup> Not least because it is not a recognised diagnostic condition – see para 2.31 above.

<sup>75</sup> M Eichner [footnote 44]; J Langhinrichsen-Rohling, CL Lewis, S McCabe, EC Lathan, GA Agnew, CN Selwyn, ME Gigler [footnote 44]; F Gullon-Scott and C Long [footnote 4] at 4040; KJ Benson [footnote 44]; C Long, J Eaton, S Russell, F Gullon-Scott, A Bilson [footnote 42]; A Bilson and A Talia [footnote 44].

<sup>76</sup> Glaser and Davis (2019) [footnote 2] p10, noted that the 'alerting signs' had 'not been tested prospectively for specificity and sensitivity', and that their efficacy in preventing harm / FII was 'untested systematically' / 'unproven' – and see generally para 2.33 above.

<sup>77</sup> C Whitty, Screening. When is it useful, When is it not?, 2021 at [https://www.gresham.ac.uk/sites/default/files/2021-01-13-1800\\_WHITTY\\_Screening\\_T.pdf](https://www.gresham.ac.uk/sites/default/files/2021-01-13-1800_WHITTY_Screening_T.pdf) (accessed 2 October 2023).

<sup>78</sup> F Gullon-Scott and C Long [footnote 4] at 4043. See also: C Whitty (ibid); and B Jackson 'The dangers of false-positive and false-negative test results: false-positive results as a function of pretest probability'. Clinics in Laboratory Medicine (2008) Jun;28(2): 305-19.

## **UK National Screening Committee 2022 guidance**

- 2.51 The RCPCH 2021 guidance provides ‘a framework for earlier intervention to explore the concerns of children, families and professionals in order to ... address the issue of a perplexing presentation well before significant harm has come to the child or young person’ (page 4). Its purpose is to help clinicians identify individuals who may have a condition of concern, namely FII. Although FII is not a condition which is amenable to a screening test of the kind employed in relation to illnesses such as Covid or bowel cancer, it is arguable that the 2021 guidance serves a not dissimilar process.
- 2.52 Healthcare screening programmes can be of great value for patients and for society in general, but they can also be problematic. This is particularly so, if their accuracy is poor – such that individuals with the relevant condition are wrongly ‘screened out’ or vice versa – that individuals are the subject of a false positive. In consequence the UK National Screening Committee (UKNSC) has issued guidance as to when targeted or population-wide screening programmes are and are not, generally appropriate.<sup>79</sup>
- 2.53 The guidance details relevant considerations for a screening programme, including the criteria for appraising its viability, effectiveness and appropriateness. Materially these include a requirement that:
- ☐ the condition should be an important health problem as judged by its frequency and / or severity and its epidemiology, incidence, prevalence and natural history ... should be understood;
  - ☐ there should be a simple, safe, precise and validated screening test;
  - ☐ there should be evidence from high quality randomised controlled trials that the screening programme is effective in reducing mortality or morbidity;
  - ☐ there should be evidence that the complete screening programme (test, diagnostic procedures, treatment / intervention) is clinically, socially and ethically acceptable to health professionals and the public’;
  - ☐ the benefit gained by individuals from the screening programme should outweigh any harms, for example from overdiagnosis, overtreatment, false positives, false reassurance, uncertain findings and complications.

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<sup>79</sup> UK National Screening Committee, Criteria for a targeted screening programme (updated 29 September 2022) at <https://www.gov.uk/government/publications/evidence-review-criteria-national-screening-programmes/criteria-for-a-targeted-screening-programme> (accessed 17 September 2023).

## Data management

- 2.54 A number of respondents to the research survey described the trauma they were experiencing because their health and social care records (and those of their children) alerted practitioners to the fact that they had been accused of FII – even when it was accepted that the FII accusation was mistaken. This problem results, in part from (what is currently) 2022 NHS England guidance.<sup>80</sup> In relation to requests from families to have their records rectified, the relevant extract from the guidance states:

There may be times when information was correct at the time the entry was made but has since changed. For example, there may be an initial working diagnosis which was, at the time of entry, clinically possible, but is later ruled out with a different confirmed diagnosis. Retaining the original diagnosis does not make the record inaccurate, so it is important that this is not amended.

- 2.55 The NHS England guidance then states:

In case the patient / service user is unhappy with the health or care organisation's decision on retaining the information, the options for him / her are: (a) to present a formal complaint within the organisation, (b) if the complaint to the organisation is unsuccessful, to make a complaint to the Information Commissioner's Office (ICO) and (c) to contemplate legal action.

- 2.56 The 'processing'<sup>81</sup> of personal information of this kind is regulated by the Data Protection Act 2018 and the General Data Protection Regulation<sup>82</sup> (GDPR). These provisions embody a set of 'principles'<sup>83</sup> (GDPR Article 5) which require, among other things, that the information is 'processed lawfully, fairly and in a transparent manner' and in a way that is 'adequate, relevant and limited to what is necessary in relation to the purposes for which they are processed'.<sup>84</sup>
- 2.57 The Act and the GDPR permit the sharing of personal information where there is a lawful basis for so doing: provisions, in essence, designed to balance the rights of the individual with the need to share information about them. This would include, for example, sharing information (without the individual's consent) where it is necessary to safeguard and promote the welfare of a child.

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<sup>80</sup> NHS England *Amending patient and service user records* (2022) at <https://transform.england.nhs.uk/information-governance/guidance/amending-patient-and-service-user-records/> (accessed 17 September 2023).

<sup>81</sup> Which includes, among other things, the recording, storage, retrieval, disclosure, dissemination or otherwise making available of data.

<sup>82</sup> (EU) 2016/679.

<sup>83</sup> GDPR Article 5 and see also HM Government Data Protection at <https://www.gov.uk/data-protection> (accessed 11 April 2023).

<sup>84</sup> Articles 5(1)(a) and 5(1)(c) respectively.

2.58 A number of principles – the ‘Caldicott Principles’<sup>85</sup> – have been developed to determine when, and with whom, personal information can be shared. Principle 4 provides that:<sup>86</sup>

[o]nly those who need access to confidential information should have access to it, and then only to the items that they need to see. This may mean introducing access controls or splitting information flows where one flow is used for several purposes.

2.59 The sharing of personal information engages provisions in the Human Rights Act 1998, particularly those relating to the right of an individual to respect for their private and family life (Article 8). In this context the European Court of Human Rights has held that in difficult cases (i.e. where there are strong grounds for both sharing and not sharing personal information) the principle of proportionality requires that a decision be made as to where the balance of interests lies and if needs be, that there be recourse to an independent authority to make a final decision on this issue.<sup>87</sup>

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<sup>85</sup> The Eight Caldicott Principles

<sup>86</sup> National Data Guardian, *The Eight Caldicott Principles at , Principle 4: Access to confidential information should be on a strict need-to-know basis* (2020) 8 December 2020 at <https://www.gov.uk/government/publications/the-caldicott-principles> (accessed 20 October 2023).

<sup>87</sup> See for example *Gaskin v UK* 12 EHRR 36 (1989) para 49 and *Khelili v. Switzerland* 18 October 2011 (application no. 16188/07).

### 3. Research project methodology

- 3.01 The research involved three distinct dimensions: (1) analysis of anonymised survey data provided by Cerebra; (2) the making of Freedom of Information (Fol) requests and the subsequent analysis of the data provided; and (3) searches of local authority websites and the subsequent analysis of the data obtained.

#### The Cerebra Survey

- 3.02 An on-line survey (using an application called 'Survey Monkey') was posted by Cerebra in July / August 2022. The survey questions are detailed at Appendix 2 to this report.
- 3.03 A total of 415 replies were received by Cerebra. The data (anonymised) was then considered by the LEaP research team (including 51 *pro bono* student researchers) at Leeds University. The sample for detailed analysis was then reduced by discounting responses: (1) from jurisdictions outside of the UK and (2) from respondents who had not suffered an allegation of FII. As a result, the research team was left with a sample of 387 responses.
- 3.04 The survey comprised 10 questions. The analysis in this report focuses on the responses to Questions: Q1, Q2, Q3, Q4, Q6, Q8 and Q9.

#### Fol requests concerning FII training and guidance for children's services assessors

- 3.05 Fol requests were sent to a sample of 51 English children's services authorities seeking information concerning the training and written guidance that had been provided for their officers who were responsible for undertaking assessments of disabled children and their families for disability specific support services under the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970 and who were involved in initiating / managing allegations of FII with respect to these families.
- 3.06 The authorities comprised a geographically diverse range of unitary authorities, county councils and London boroughs.
- 3.07 The Fol requests were sent in October / November 2022 (via the local authority portals and / or via emails to the addresses specified for such requests) and the responses analysed between December 2022 and January 2022. Appendix 3 of this document includes the text of the Fol request used in each case.

#### Desk top analysis of local authority FII training and guidance for children's services assessors

- 3.08 To complement the information obtained as a result of the Fol requests, the websites of 51 authorities (the same authorities the subject of the Fol requests see para 3.05 above) were examined for evidence of FII training and guidance for children's services assessors.



## 4. Research findings

### Cerebra FII Survey analysis

Survey question Q1.

- 4.01 Q1 asked if the respondent was a parent caring for a disabled child and if they had approached their local authority and / or their local NHS for support to meet their child's needs. Of the 387 responses to this question, all but 13 respondents replied 'yes' (i.e. 97 per cent responded 'yes').
- 4.02 Respondents who answered 'no' to this question were directed to the final question – namely 'Please provide any other information which you consider relevant'.
- 4.03 Respondents who answered 'yes', were asked a supplemental question, namely (if willing) to identify their child's impairment and describe it briefly. The question included the prompt 'for example, physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness and various types of chronic disease'. 374 people responded to this question, and the five most common impairments were:
- (1) Autism / autistic / ASD (Autism Spectrum Disorder) / ASC (Autistic Spectrum Condition): mentioned by 245 respondents (65 per cent);
  - (2) Sensory [impairment]: mentioned by 116 respondents (31 per cent);
  - (3) ADHD (Attention deficit hyperactivity disorder): mentioned by 114 respondents (30 per cent);
  - (4) Anxiety: mentioned by 88 respondents (24 per cent);
  - (5) PDA (Pathological Demand Avoidance): mentioned by 59 respondents (16 per cent).
- 4.04 Many respondents responded to Q1 by listing several impairments / conditions, for example:
- (a) *Sensory issues, autism spectrum disorder, dyslexia, hyper mobility, various chronic health issues* (response no 15);
  - (b) *Autism, PDA, ADHD, Dyslexia* (response no 145);
  - (c) *My child has autism, anxiety and depression* (response no 373).

Survey question Q2.

- 4.05 Q2 asked if the respondent identified as a disabled person. Of the 387 responses to this question, 194 replied 'yes' (50 per cent).
- Respondents who answered 'yes', were asked a supplemental question, namely (if willing) to identify their impairment and describe it briefly. The question included the prompt 'for example, physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness and various types of chronic disease'. All 194 respondents responded to this question and the five most common impairments listed were:



- (1) Autism / autistic / ASD (Autism Spectrum Disorder) / ASC (Autistic Spectrum Condition): 82 respondents mentioned this – so 42 per cent of respondents to this question;
- (2) ADHD (Attention deficit hyperactivity disorder): 56 (29 per cent) respondents mentioned this;
- (3) Fibromyalgia: 27 (14 per cent) respondents mentioned this;
- (4) Anxiety: 22 (11 per cent) respondents mentioned this;
- (5) Chronic disease / fatigue / pain / illness / etc: 21 (11 per cent) parent carers mentioned this.

It was not unusual for respondents to list more than one impairment / condition in response to this question, for example:

- (a) *I am autistic, have ADHD, both diagnosed via NHS* (response no 23);
- (b) *Anxiety, fibromyalgia* (response no 28);
- (c) *Autism & suspected ADHD, fibromyalgia, chronic disease* (response no 150).

#### Survey question Q3.

- 4.06 Q3 asked if the respondent, during their 'interactions with the local authority and / or the NHS (for example, a GP or someone in a health clinic or hospital) had ever been accused of fabricating or causing or exaggerating [their] child's illness or have things been said by professionals that imply that this might be the case?' 387 respondents replied affirmatively.
- 4.07 Respondents who answered 'yes', were asked to 'describe briefly what happened, including the terms that were used when the allegation was made (i.e. FII – Fabricated or Induced Illness or PP – Perplexing Presentation)'. Of the 376 responses to this question:
  - (1) 124 (33 per cent) respondents did not provide sufficient information to enable the research team to determine if the initial allegation had been made by a healthcare, social services or education practitioner;
  - (2) 116 (31 per cent) allegations of FII were initiated by a health professional / NHS;
  - (3) 79 (21 per cent) allegations of FII were initiated by the child's school;
  - (4) 58 (15 per cent) allegations of FII were initiated by Children's Services.

#### Survey question Q4.

- 4.08 Q4 asked the respondent to 'name the local authority and / or the NHS body that made the allegation' of FII. Where an NHS body was named the research team then established the local authority area in which it was primarily located. Those who responded (387 respondents) named 112 English local authorities / health bodies (i.e. 74 per cent of English children's services authorities). Of this sample, five authorities were named 10 times or more (the highest number of mentions for two authorities respectively being 11). In addition, authorities / health bodies in Scotland were named on 19 occasions and those from Wales were named on 22 occasions.

#### Survey question Q6.

- 4.09 Q6 asked respondents if, 'before the allegation of FII or PP was made, they had made a complaint about the actions of the local authority and / or the NHS body'. Of the 387 responses to this question, 202 respondents replied 'yes' (52 per cent).

#### Survey question Q8.

- 4.10 Q8 asked for details of the outcome of the FII allegation that the respondents had experienced. It gave three 'tick box' options, namely 8.a 'No further action was taken by the local authority / NHS body'; 8.b 'Safeguarding action was commenced but then abandoned'; and 8.c 'Safeguarding action was pursued (please give details of the result in the box below)'. A comment box '8.d' was then provided for this purpose.
- 4.11 332 responses were considered for the analysis,<sup>88</sup> of which 184 (55 per cent) of the respondents only ticked boxes 8.a and / or 8.b,<sup>89</sup> confirming that for them, either no further action was taken concerning the FII allegation or that safeguarding action was commenced but then abandoned.
- 4.12 90 respondents ticked box 8.c indicating that safeguarding action had been pursued - and for these, the survey requested that they provide further details. An analysis of these responses suggests that: in 9 cases the safeguarding action was continuing; in 30 cases the safeguarding action had been abandoned; in 9 cases the safeguarding action had been replaced by a 'child in need' plan; in 7 cases the safeguarding action had resulted in a 'child protection plan'; in 3 cases a care order had been made; in 3 cases an adoption order had been made; and in two cases the children had moved to live with other family members. In the 8 cases where the children were no longer living with the parent accused of FII, it was not possible to determine from the responses, whether the children's removal was based in whole or in part on evidence relating to the FII allegation. In relation to the remaining 27 responses, it was not possible to determine what the outcome had been of the safeguarding action.
- 4.13 58 respondents did not tick any of the boxes 8(a), or 8(b) or 8(c), but did provide information in the comment box 8.d. An analysis of these responses suggests that: in 19 cases no safeguarding action had been taken; in 10 cases, that the FII allegations had been abandoned; in 14 cases that the allegations were on-going; and in one case the matter was now proceeding as a 'child in need' assessment. In 2 cases the children had been taken into care and, as with the cases in para 4.12 above, it was not possible to determine from the responses, whether the children's removal was based in whole or in part on evidence relating to the FII allegation. In relation to the remaining 13

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<sup>88</sup> 333 responses were received but one (response no 94) was discounted as it related to an adult 'child'. Several respondents ticked more than one box and / or provided information in response to the question 8.d.

<sup>89</sup> A number also entered information in the comment box 8.d.

responses, it was not possible to determine what the outcome had been for the family of the FII allegation.

Survey question Q9.

- 4.14 Q9 of the survey asked respondents to describe ‘the effect that [the] allegation of FII or PP has had upon yourself and your family’. The responses to this question are analysed at para 5.02 below and Appendix 4 of this report includes a summary of the replies.

## **Freedom of Information (Fol) requests and desk top analysis concerning FII training and guidance**

### **Fol requests**

- 4.15 As noted above (para 3.05) Fol requests were sent to 51 English children’s services authorities seeking information concerning the training and written guidance given to their staff members who were responsible for undertaking the assessments of disabled children and their families for disability specific support services under the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970 and are involved in initiating / managing allegations of FII with respect to these families.
- 4.16 45 (88 per cent) of the authorities provided a substantive response to the Fol.

Fol question Q1.

- 4.17 Q1 asked the authority for information concerning training courses that had been provided for its assessors (whether ‘in-house’ or externally funded), that specifically addressed the issue of FII (fabricated or induced illness). The information requested (which was limited to courses provided ‘since April 2019’) was as follows:
- (a) The name of the course or courses;
  - (b) Copies of the course programme or course programmes; and
  - (c) The number of staff who have attended the course, or if there was more than one course, the number of staff who have attended each of the courses.
- 4.18 22 of the 45 authorities (49 per cent) stated that they did provide training of this nature. One authority confirmed that it had provided training of this kind, but that it had taken place before April 2019. Two authorities stated that they did not hold this information and 20 authorities answered that they did not offer such training.
- 4.19 Of the 22 authorities who stated that they had arranged FII training since April 2019, 15 provided information about the number of staff attending the course / courses:

Local authority	Staff attendance	Local authority	Staff attendance
LA-FOI-10	5	LA-FOI-40	18
LA-FOI-11	46	LA-FOI-44	6
LA-FOI-17	42	LA-FOI-45	2
LA-FOI-18	40	LA-FOI-46	294
LA-FOI-22	245	LA-FOI-48	30
LA-FOI-24	7	LA-FOI-49	78
LA-FOI-29	11	LA-FOI-51	14
LA-FOI-39	11		

4.20 For these 15 authorities, a total of 849 of their staff had attended FII training – equating to an average per authority of 16 staff per year.

Fol question Q2.

- 4.21 Q2 asked that the authority provide a copy (in printed or electronic form) of the written policy / guidance that it provides to its assessors on how to deal with instances of FII.
- 4.22 Of the 45 authorities who replied to the Fol request: 26 (58 per cent) reported they had a written policy / guidance on FII; six stated that they did not have a local authority 'specific' / published policy / guidance but that their assessors adhered to external policies / guidance.<sup>90</sup> The remaining authorities either: indicated that their assessors did not have a policy / guidance to follow (three authorities); or that the requested information was 'exempt from release under FOIA section 31(1)(a)' (one authority); or that they did not hold the required information (two authorities); or they simply failed to answer the question (seven authorities).

### Desk top analysis

- 4.23 Web searches of 51 authorities also added relevant information to the data obtained via Fols and concerning FII policies / guidance.
- 4.24 In contrast to the data provided in response to the Fol requests (that 26 (58 per cent - out of 45) authorities had a 'specific' policy / guidance (see para 4.22 above) website searches revealed that 50 of the 51 authorities had published FII policy / guidance (98 per cent). The one authority (LA-FOI-18) for which the web search failed to identify a relevant policy / guidance, did however provide a response to the Fol request, stating:

The [local authority safeguarding partnership's] guidance in regard to Perplexing Presentations / Fabricated and Induced Illness has been under review since the publication of the updated Royal College of Paediatrics and Child Health (RCPCH) guidance in February 2021.

The response added that the updated 'guidance will be published imminently'.

<sup>90</sup> For example, citing 'The Royal College of Paediatrics and Child Health updated guidance' [footnote 1] and 'NICE Guidelines'.

## 5. Discussion and analysis

5.01 This chapter considers the data that has emerged from the research programme. The analysis is structured using the following subheadings:

- The impact of FII allegations’.
- The unequal incidence of FII allegations on persons with protected characteristics.
- Timing of FII allegations.
- Data access and the recording of FII allegations and PP

### The impact of FII allegations

5.02 No one reading the entirety of the research data could be in any doubt as to the study’s most disturbing finding, namely the harm suffered by families who have experienced FII allegations. Question 9 of the FII survey asked respondents to describe the effect on them and their family, of the FII or Perplexing Presentation allegation. Responses to this question (377) produced 41 pages of harrowing evidence – and at Appendix 4 we provide a 7 page summary of this data.

5.03 Time and time again, respondents described the impact of allegations 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. A striking characteristic of these impacts is the fact that they are generally described as long term / ongoing harms: harms from which the respondents believe that they and / or their partners and children will never recover.

*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.*

- 5.04 In the following discussion these severe and negative impacts are collectively referred to as 'trauma'.
- 5.05 Given the methodology underpinning the FII survey, it is not possible to state with precision how representative the individual survey responses are, concerning their experience of an FII allegation. Arguably, however, the responses should not be viewed in isolation, as the evidence suggests that there has been an increase in FII allegations made by public bodies against parents (see Appendix 1 to this report) and many of the responses echo concerns that prompted the research (see para 1.03 above).
- 5.06 Of the 291 responses to the FII survey that identified the outcome for the family of an FII allegation (see paras 4.10 – 4.13 above), in 243 of these cases (84%) it appears that the allegation either resulted in no follow up action or that any such action was subsequently abandoned. In all but 10 cases it appears that the children remained living with the parent who had been accused of FII. In these 10 cases it was not possible to determine from the responses, whether the children's move to live elsewhere, was due in whole or in part to evidence relating to the FII allegation.
- 5.07 On this basis, it would appear that at the time of the survey, the overwhelming majority of the families whose parent had faced an accusation of FII (possibly more than 95 per cent) were still living with that parent. The survey evidence also records that the traumatic consequences of the FII allegations were described in terms of their impact on the children – i.e. those in relation to whom the FII allegation had been made and their siblings.

*Traumatised me and my [child]. [s/he] no longer feels able to trust health professionals.*

*Devastating for me, but most importantly, delayed my child receiving the care and support needed.*

*Incredible physical and mental stress. The amount of care my [child] needed increased hugely. My [child's] words are it has permanently, emotionally, and physically scarred me, it has traumatized me probably permanently and it's given me a hell of a lot of anger.*

*Children traumatised anxious, nervous, distrustful, terrified of unknown faces and what they may do. Scared of any unknown vehicles that pull up outside the house.*

*I felt gaslighted for over [x] years, and that has had a huge impact on my mental health, but most importantly, has also meant that my [child] lived in constant pain for far longer than he needed to had I been believed from the start. It has had a huge and terrible impact on our family.*

*Shattered. Destroyed. [child] was sexually abused in care.*



## A proportionality review

- 5.08 *Prima facie* the research demonstrates that an allegation of FII can cause significant harm to children. It follows that even if the RCPCH materials on FII are ‘superbly accurate’ (see para 2.50 above), such that all FII allegations are correct, the adverse consequences on children of making them must be considered. Such a consideration is all the more important given the questionable accuracy of the identification measures, such as the RCPCH materials,<sup>91</sup> the potential scale of the ‘false positive’ consequences and the robustness of the evidence concerning the harm caused to children by a parent fabricating or inducing their illness (see para 2.32 above).
- 5.09 The research findings suggest therefore, that at a strategic level, there is an urgent need for the RCPCH guidance to be the subject of material revision to acknowledge and address these concerns.<sup>92</sup> At an individual level, however, the findings suggest that (in every case) there is a need for a proportionality review: an assessment as to whether the adverse consequences of making an allegation outweigh the potential consequence of it not being made.
- 5.10 The pressing need for revision stems in part from the widespread dissemination of the RCPCH guidance:<sup>93</sup> its ubiquitous citation by local authority safeguarding protocols and in the extensive FII training programmes provided for health, social care and education practitioners. As we note above (para 4.24), all but one of the 51 of the children’s services authorities in the research study had specific guidance concerning FII<sup>94</sup> and of those that responded to an FII request on the subject, 49 per cent had provided FII training for their practitioners in the previous three years. In one case over 245 staff had attended such training and during the course of the research we learned that this was not unusual. One local health body had, for example, trained over 350 practitioners concerning the risks of FII in just one year and another had trained over 550 at a single event: the publicity for which stated that it ‘wanted to raise awareness amongst the medical fraternity and our partner agencies’ that FII was ‘a massively undiagnosed condition’.<sup>95</sup>
- 5.11 In contrast to the extensive guidance and training concerning the harm caused by parents who fabricate or induce their child’s illness, 2022 research<sup>96</sup> revealed a troubling absence of appropriate guidance and training courses offered by children’s services authorities for practitioners concerning (among other things) their obligations under the Human Rights Act 1998 (including the making of ‘proportionate’ decisions) as well as awareness training concerning the disability related challenges that disabled children and their families encounter.

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<sup>91</sup> M Eichner [footnote 44]; J Langhinrichsen-Rohling, CL Lewis, S McCabe, EC Lathan, GA Agnew, CN Selwyn, ME Gigler [footnote 44]; F Gullon-Scott and C Long [footnote 4] at 4040; KJ Benson [footnote 44]; C Long, J Eaton, S Russell, F Gullon-Scott, A Bilson [footnote 42]; A Bilson and A Talia [footnote 44].

<sup>92</sup> As noted at para 2.40 above, the 2021 guidance is, to all intents and purposes, silent on this question.

<sup>93</sup> See for example Glaser and Davis [footnote 2] at p.10.

<sup>94</sup> The one authority that did not, stated that it was to publish such guidance ‘imminently’.

<sup>95</sup> An assertion for which the trust was unable to identify any supportive peer reviewed research.

<sup>96</sup> L. Clements & A. L. Aiello *Challenging Parent Carer Blame: Interim implementation research report 1: Disability and human rights training and guidance for disabled children’s assessors* (Cerebra 2022).



5.12 Any review of the RCPCH guidance and its use in practitioner training could usefully reflect on a number of the principles in the UK National Screening Committee (UKNSC) guidance<sup>97</sup> (considered at para 2.51 above). This guidance urges caution and requires cogent evidence before programmes analogous to the RCPCH's 'alerting signs' are applied in practice. In the light of this research study, there must be considerable doubt as to whether any of the UKNSC's necessary requirements are satisfied, for example:

- The condition should be an important health problem as judged by its frequency and / or severity' and its 'epidemiology, incidence, prevalence and natural history ... should be understood;
- there should be a simple, safe, precise and validated screening test;
- there should be evidence from high quality randomised controlled trials that the screening programme is effective in reducing mortality or morbidity;
- there should be evidence that the complete screening programme (test, diagnostic procedures, treatment/ intervention) is clinically, socially and ethically acceptable to health professionals and the public;
- the benefit gained by individuals from the screening programme should outweigh any harms, for example from overdiagnosis, overtreatment, false positives, false reassurance, uncertain findings and complications.

5.13 The evidence concerning the trauma experienced by parents and their children resulting from FII allegations is not new. It is a matter of significant concern that this risk is not addressed in detail in the 2021 RCPCH guidance. Guidance in which harm is conceptualised overwhelmingly from a 'parent blame' perspective and this view is reinforced by the guidance's 'weighted' interpretation of iatrogenic harm (see para 2.40 – 2.41 above). Even the brief mention of the possibility of doctors being 'off the mark' or 'dismissive' that appeared in the Royal College's earlier (2002) FII guidance<sup>98</sup> has been erased from the 2021 guidance.

### **The unequal incidence of FII allegations on persons with 'protected characteristics'**

5.14 Over 50 per cent of respondents who had experienced an accusation (or indication) of FII and who answered question 2 of the FII survey (387) identified as a disabled person (see para 4.05 above). Over 40 per cent of these respondents identified as autistic and the preponderance of all impairments cited could be classified as 'non-visible impairments': disability or health conditions that 'are not immediately obvious' – conditions that 'can defy stereotypes of what people might think disabled people look like'.<sup>99</sup> In this

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<sup>97</sup> UK National Screening Committee [footnote 79].

<sup>98</sup> Royal College of Paediatrics and Child Health (2002) [footnote 53].

<sup>99</sup> HM Government *Living with Non-Visible Disabilities* (2020) at <https://disabilityunit.blog.gov.uk/2020/12/17/living-with-non-visible-disabilities/> (accessed 3 October 2023).

category we include conditions such as ADHD, Fibromyalgia, Anxiety and Chronic disease.

- 5.15 In 2006 it was estimated that about 12 per cent of Britain's parents were disabled people<sup>100</sup> and it appears that the overall proportion of disabled people in the British population has not changed dramatically since that time.<sup>101</sup>
- 5.16 The data raises a disturbing equality question concerning the policies and practices of public bodies in relation to the making of FII allegations – namely that disabled parents are four times more likely to experience such allegations than parents who are not disabled. Without explanation or justification (i.e. that it is 'a proportionate means of achieving a legitimate aim') this difference in treatment has the potential to constitute indirect discrimination contrary to the Equality Act 2010 (see para 2.22 above). It is a risk to which a not insignificant body of literature has drawn attention (see para 2.36 above). It would appear to follow that any public body that has a statutory role in the children's safeguarding process should have ensured that its staff are aware of this risk and ensured that it has complied with its Public Sector Equality Duties under the 2010 Act (see paras 2.24 – 2.27 above).
- 5.17 The FII survey results raise an additional equality issue. As noted above (para 4.01) 97 per cent of the children in relation to which an FII allegation was made – were considered by their parent to be disabled, and of these, 65 per cent were considered by their parent to be autistic (and the preponderance of all impairments cited could be classified as 'non-visible impairments'). Although these findings are of potential concern (since it appears that only about 11 per cent of children in the UK are disabled<sup>102</sup>) methodological limitations to the study mean that little weight can be attached to them. This is principally due to the fact that, although the survey was widely disseminated, it was initially launched via the Cerebra website – which is an on-line portal directed at families with disabled children.

### **The timing of FII allegations.**

- 5.18 In 2018 the NGO Flightback undertook a survey of families who had been accused of FII. 58 per cent of the respondents<sup>103</sup> stated that their FII allegation followed a complaint that they had made about a school, a medical professional

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<sup>100</sup> J Morris & M Wates *Supporting disabled parents and parents with additional support needs*. Adults' Services Knowledge Review 11 (Policy Press 2006) p15.

<sup>101</sup> Between 2011 and 2021 there was a slight decrease in the proportion of disabled people in England and Wales (1.6 per cent and 2.3 per cent respectively) Office of National Statistics *Disability, England and Wales: Census 2021* (2023) at <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/disabilityenglandandwales/census2021> (accessed 3 October 2023) whereas in Scotland it appears that (in the working age population) there was an increase between 2014 and 2021 (of 6 per cent) Scottish Parliament Information Centre *Disability Employment in Scotland: Initial Findings* (2023) at <https://spice-spotlight.scot/2023/09/26/guest-blog-disability-employment-in-scotland-initial-findings/> (accessed 3 October 2023).

<sup>102</sup> Department for Work and Pensions (2023), *Family Resources Survey, 2021/22* at <https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2021-to-2022/family-resources-survey-financial-year-2021-to-2022#disability-1> (accessed 30 October 2023).

<sup>103</sup> Flightback (2019) *False accusations of FII: A report by flightback - March 2019: a survey involving 191 families*.

or other professional. The survey also noted that 57 per cent of those so accused, identified as having an additional need, chronic illness or disability.

- 5.19 A number of respondents to the survey analysed in the 2021 'Institutionalising Parent Carer Blame' report<sup>104</sup> also referred to hostile action that they had experienced after making a complaint. The report referred to official recognition of the 'power imbalance'<sup>105</sup> that exists between individuals seeking support from statutory agencies and the statutory agencies themselves – leading to a widespread 'reluctance to complain': a hesitancy attributed to (among other things), a 'fear of the consequences' (i.e. fear of retaliatory action).<sup>106</sup> A 2021 Department of Health and Social Care publication<sup>107</sup> acknowledges this reality by referring to the 'repeated concern' voiced by parents and carers that they 'had been brought into the child protection process because of disagreements with practitioners'. This issue is also highlighted by the BASW guidance (p.10), which refers to families reporting that 'concerns about FII are raised in the context of them requesting more support for their child or when raising a complaint'.
- 5.20 In order to explore the incidence of allegations of FII and PP following a complaint by a family, question 6 of the FII survey asked respondents to state whether they had made a complaint about the actions of the local authority and / or the NHS body, before they had experienced such an allegation.
- 5.21 As noted above (para 4.09) over 50 per cent of the respondents reported that the allegations they had experienced were made after they had complained about actions of the relevant public body.
- 5.22 The FII survey, allied to the reports cited above, suggests that there is a strong correlation between the making of a complaint by a parent and that parent then facing an FII or PP allegation. This finding is of concern and warrants further research, although on the basis of the current evidence the following observations are relevant.
- 5.23 First and foremost, it is important to acknowledge that 'asymmetry' is a major theme that runs through the research study and its findings. Asymmetry in the sense of the power imbalance between practitioners and parents; asymmetry in terms of the dependency of parents on practitioners who hold the keys to social care, health care and educational resources; and asymmetry in the treatment of 'risk' in the Royal College's guidance (see para 2.40 above). In the context of the linkage between parental complaints and practitioner allegations – the asymmetry is particularly pronounced in terms of available remedies / sanctions. Being accused of FII, as this research demonstrates, can often result in life changing trauma: trauma for parents and children alike. The evidence strongly suggests that this trauma remains even when the allegation is shown to have been made in error. The making of an FII allegation, however, appears to be a virtually risk-free exercise. In practice, families do

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<sup>104</sup> L. Clements & A. L. Aiello [footnote 3] at para 4.15..

<sup>105</sup> Joint Committee on Human Rights *The human rights of older people in healthcare* HL Paper 156-I HC 378-I (2007) para 234 et seq.

<sup>106</sup> K Simons *I'm Not Complaining, but ...* (Joseph Rowntree Foundation 1995).

<sup>107</sup> Chief Social Workers for Adults and the Chief Social Worker for Children and Families *A spectrum of opportunity: an exploratory study of social work practice with autistic young adults and their families* (Department of Health and Social Care 2021).

not appear to have access to any effective remedies to challenge inappropriate allegations of this kind. Indeed, a family making a complaint about being wrongly accused, will in itself, risk being seen as a further 'alerting sign' and further evidence of FII. The Royal College guidance contains no meaningful warnings to practitioners about the harm families can experience in such cases and if cases do proceed to the relevant ombudsman, none appear to have resulted in meaningful disciplinary action or wider inquiry as to whether the experience was symptomatic of a wider organisational failing.

- 5.24 Although one would hope that all FII allegations made by practitioners would be based on cogent evidence that had been validated by an appropriately qualified professional, it is inevitable that this will not always be the case. This concern is given credence by the number of reports of inappropriate FII allegations (see for example Appendix 1 below). It is reinforced by the responses of many parents to question 6 of the FII survey: responses that suggest the allegations were effectively punitive and / or vindictive – resulting from a complaint or a request for a second opinion or for additional support etc.

*Very angry, we felt like the paediatrician was gaslighting us as we complained about sub par services.*

*The inference of Fii /exaggeration was in direct response to me asking for more social work support ...*

*Formal complaint about Head Teacher - head teacher then made the retaliatory "safeguarding" referral.*

*All accusations of FII tie in with [SEN] Tribunal dates and there is even reference to them being made as a result of me "taking school to court."*

*I had received a response from the service I complained about- this was starting to raise FII allegations*

*Head teacher retaliated with a "safeguarding concern" of Fii*

*I believe the complaint was what initiated the backlash of a referral to social services.*

- 5.25 One explanation for the linkage between parental complaints and practitioner allegations is, as noted above, the fact that the Royal College guidance identifies 'Frequent vexatious complaints about professionals' as an 'alerting sign' of possible FII (at para 4.4.2). The guidance provides no definition as to how (or by whom) it is to be determined that a complaint is 'vexatious' nor does it contain any qualifying comment of the kind found in the more recent BASW guidance, that, for example (page 10):

where 'parents are concerned for their child's health and treatments offered are ineffective, it is unsurprising that they will attempt to get further medical opinions, scour the internet for information and make complaints'.

### **Complaints made by disabled parents**

- 5.26 In their analysis of the FII survey data, the research team considered whether FII allegations were more likely to be made against disabled parents who had made a complaint rather than against non-disabled parents who had made a complaint.<sup>108</sup> The analysis suggested a comparatively small difference in this respect: 114 (56 per cent - out of 202) disabled respondents had made a complaint before being accused of FII, as opposed to 88 (44 per cent) non-disabled respondents. Given the FII survey sample size, we do not consider it possible to draw significant conclusions from this finding.

### **Regions with a disproportionate number of FII allegations?**

- 5.27 The FII survey data was analysed to see if there were regions in the UK where there appeared to be a disproportionate number of FII allegations being made. The analysis used the answers to question 4 – which asked respondents to name the local authority and / or the NHS body that made the allegation.<sup>109</sup> We found that there were no statistically significant regions in which disproportionate number of FII allegations were being made. Given the differences in the population sizes of local authorities (and a number of other variables) a larger survey would be required to provide a definitive answer to this question.
- 5.28 The data does, however, strongly suggest that the making of FII allegations is a widespread local phenomena. Respondents to question 4 identified 112 English local authority areas (74 per cent of English children's services authorities). Five of these were mentioned by 10 or more respondents - the highest number for an individual authority being 11. These five authorities were, in population terms, all larger than the average English authority. 19 respondents named authorities in Scotland and 22 identified named authorities in Wales.

### **Practitioner professions and the making of FII allegations**

- 5.29 The FII survey did not include a specific question concerning the public sector from which the FII allegation first emerged. A detailed examination of each survey response has, however, enabled this information to be identified in 253 cases. The analysis reveals that NHS practitioners made the most allegations (116 – i.e. 31 per cent of sample) followed by education practitioners (79 – i.e. 21 per cent of sample) and then children's services practitioners (58 – i.e. per 15 per cent of sample).

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<sup>108</sup> ie comparing the results of questions 2 and 6 of the FII survey.

<sup>109</sup> Where an NHS body was named we then established the local authority area in which it was based.



## **FII allegations, data access and potential for ‘re-traumatisation’**

- 5.30 As noted above (para 2.54) a number of respondents to the FII survey described the trauma they were experiencing because their health and social care records (and those of their children) alerted practitioners to the fact that they had been accused of FII – even when it was subsequently accepted that the accusation was mistaken. Several families stated that their NHS records, including details of the FII allegation, remained ‘available to all’. Respondents described this experience in terms of being ‘re-traumatised’ each time they encountered a professional who had access to these records. Comments included:

*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.*

*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.*

*There is a note on my doctor’s screen that pops up sometimes when I or my children visit the doctor saying something about safeguarding.*

*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!)*

- 5.31 As we note above (para 2.54) this problem is, in part, a consequence of the issue highlighted in 2022 NHS England guidance concerning when it is (and is not) appropriate to amend a patient’s records.<sup>110</sup> The guidance states 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’. There is, of course, a certain logic to this approach: a logic illustrated by the example it then provides – namely ‘there may be an initial working diagnosis which was, at the time of entry, clinically possible, but is later ruled out with a different confirmed diagnosis. Retaining the original diagnosis does not make the record inaccurate’.
- 5.32 The guidance appears, however, to be materially defective in two respects. Firstly, it fails to address, in appropriate detail, the fact that in some situations the prejudicial effect of retaining ‘accurate’ information may materially outweigh and invalidate the retention of that information; and secondly, that, even if retention of the prejudicial material can be justified, it fails to address the question of whether this information should be ‘available to all’.
- 5.33 There are well established principles as to how the privacy rights of individuals should be balanced against wider considerations<sup>111</sup> as well as principles as to

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<sup>110</sup> NHS England [footnote 80].

<sup>111</sup> In relation to the retention of data concerning allegations of child neglect / abuse US states have developed a wide array of mechanisms to determine when expunging / screening out ...etc etc – see for example Child Welfare Information Gateway *Review and expunction of central registries and reporting records* U.S. (2018) Department of Health and Human Services, Children’s Bureau at <https://www.childwelfare.gov/topics/systemwide/laws-policies/statutes/registry/> (accessed 14 October 2023).

when the prejudicial effect of information renders its use inappropriate<sup>112</sup> – even when that information may be ‘factually’ accurate.<sup>113</sup> As we note above (para 2.58 - 2.59): (1) the European Court of Human Rights has held that the doctrine of ‘proportionality’ provides a relevant mechanism for determining such questions. It has also stressed the need for independent review in difficult cases; and (2) domestically the Caldicott rules<sup>114</sup> stipulate (among other things) that ‘[o]nly those who need access to confidential information should have access to it, and then only to the items that they need to see. This may mean introducing access controls or splitting information flows where one flow is used for several purposes’.<sup>115</sup>

- 5.34 It would appear to follow that where an FII allegation has been found to be wrong, misguided, unfounded or unsupported by the evidence, then the relevant public body should take the initiative to ensure that: (1) either the record is expunged; or, at the very least, (2) that the fact that an FII allegation has been made, is placed in a secure part of the records to which access can only be granted in exceptional circumstances. It would also appear to follow that public bodies must, in this respect, be proactive and (regardless of a request by the person who has been inappropriately accused of FII) take the initiative to determine whether such data should be expunged or ‘split’ from the general record.

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<sup>112</sup> The ‘prejudice rule’ concerning the use of certain evidence in courts has, indeed, ‘ancient roots’ – see for example, J A Tanford ‘A Political-choice Approach to Limiting Prejudicial Evidence’ *Indiana Law Journal* 64(4) 831-872 at 834.

<sup>113</sup> See for example *Z v Finland* 25 E.H.R.R. 371 (1997) where the disclosure of ‘fact’ that the applicant was HIV positive was held to violate Article 8 of the European Convention on Human Rights.

<sup>114</sup> National Data Guardian, *The Eight Caldicott Principles* 8 December 2020 at <https://www.gov.uk/government/publications/the-caldicott-principles> (accessed 20 October 2023).

<sup>115</sup> *Ibid*, Principle 4: Access to confidential information should be on a strict need-to-know basis.



## 6. Appendices

### Appendix 1: Reports, papers and articles that suggest an increased prevalence of FII allegations

#### *Reports*

A 2014 article in 'Autism Eye',<sup>116</sup> that referred to 'increasing numbers of parents are being accused of exaggerating their autistic child's problems, with reports that it is happening after the parents request more support for their offspring'.

A 2017 'Action for M.E.' survey<sup>117</sup> of 270 families found (among much else) that 90% of respondents were concerned that professionals involved with their child did not believe them; one in five (22%) said a safeguarding / child protection referral had been made against them; nearly half of these referrals related to claims of fabricated/induced illness or FII and of which 70% were dropped within a year.

A 2018 survey by the Family Support Group 'Not Fine In School'<sup>118</sup> completed by 1,661 parents concerning the consequences of a child not attending school, recorded that over 18 per cent of respondents had been accused of Fabricating or Inducing Illness in relation to their child's difficulty with school attendance.

A 2021 article in Special Needs Jungle<sup>119</sup> (a specialist Special Educational Needs NGO) that referred to the fact that it had 'heard from so many families who have found themselves at the wrong end of an accusation of Fabricated or Induced Illness (FII) or child protection proceedings following a request for help or a complaint about a service'. It additionally noted that allegations of this kind are 'one of the most frightening situations that anyone can face and parents often don't know where to turn' and that it was 'vital that families are aware of the rising number of allegations being experienced throughout the SEND community, so they realise that no one should consider themselves immune and take appropriate steps to protect themselves and their children'.

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<sup>116</sup> Autism Eye (2014) 'Parents accused of fabricated illness' at: <https://www.autismeye.com/parents-accused-of-fabricated-illness/> (accessed 8 August 2023).

<sup>117</sup> Action for M.E. 'Families facing false accusations' June 2017 at <https://www.actionforme.org.uk/uploads/pdfs/families-facing-false-accusations-survey-results.pdf> (accessed 12 April 2023).

<sup>118</sup> Not Fine In School 'School Attendance Difficulties: Parent Survey Results' (May 2018) p.19 at <https://img1.wsimg.com/blobby/go/a41082e1-5561-438b-a6a2-16176f7570e9/NFIS%20Parent%20Survey%20Results%20May%202018.pdf> (accessed 18 July 2023); and see also SE Connolly and SL Mullally 'School Distress in UK School Children: The Parental Lived Experience' (pre-print) at <https://www.medrxiv.org/content/10.1101/2023.02.16.23286034v1> (accessed 13 July 2023).

<sup>119</sup> R Blower 'Protecting Parents from False Allegations of Fabricated or Induced Illness (FII)' Special Needs Jungle March 8, 2021, at <https://www.specialneedsjungle.com/protecting-parents-from-false-allegations-of-fabricated-or-induced-illness-fii/> (accessed 12 April 2023).

2022 research by the NGO PANS PANDAS<sup>120</sup> that found (from a survey of 217 parents of children with these conditions<sup>121</sup>) that ‘approximately 1 in 5 parents’ had been accused of FII and / or threatened with ‘safeguarding’. In a 2022 ‘position statement’<sup>122</sup> the organisation stated:

We are aware that many families with children with PANS and PANDAS are currently subject to accusations regarding safeguarding and/or Fabricated Induced Illness (FII). ... The impact on caregivers of false accusations of FII is immense. Desperate to secure medical treatment for their children, families can quickly find themselves in a position where the very professionals who they rely on for support are the ones raising safeguarding concerns. It is a devastating situation.

The 2022 BASW guidance<sup>123</sup> refers (p.5) to ‘an increase in the prevalence of FII referrals made to social care’.

A 2023 report<sup>124</sup> concerning a survey of 1,016 parents of children with Pathological Demand Avoidance (PDA) in which over 87% of the respondents reported that they had felt blamed by professionals for some aspect of their child’s ‘presentation or “lack of progress”’ with a number commenting that they had experienced allegations of FII.

A 2023 Report concerning the actions of Herefordshire Council’s Children’s Services<sup>125</sup> referred to a ‘fixation of the “FII” label, contrary to independent medical and education reports’ which ‘resulted in some families spending years trying to get social work files corrected via freedom of information and subject access requests, to show how inaccurate records were or are and that the “FII” label permeated throughout professional opinion, completely losing sight of needs of the child(ren).

### *News items and other publications*

2006: an article where a family succeeded in having an erroneous FII allegation referred to the General Medical Council.<sup>126</sup>

2019: an article concerning a parent whose child was removed as a result of an FII allegation made by the Royal Aberdeen Children's Hospital, and the child was

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<sup>120</sup> C Long, T Coope, S Hughes & K Hindson ‘PANS, PANDAS and Fabricated or Induced Illness: A Guide to Social Work, Healthcare and Education Professionals’ (2023) p.7 at [https://www.panspandasuk.org/\\_files/ugd/c803db\\_49948facc981415fbd715dd35ecca3b.pdf](https://www.panspandasuk.org/_files/ugd/c803db_49948facc981415fbd715dd35ecca3b.pdf) (accessed 18 July 2023)

<sup>121</sup> PANS and PANDAS are post-infectious disorders in which severe symptoms of obsessive-compulsive behaviours, tics or eating restrictions develop suddenly.

<sup>122</sup> PANS and PANDA UK ‘Fabricated or Induced Illness Position Statement’ November 2022 at <https://www.panspandasuk.org/fii-position-statement> (accessed 12 April 2023).

<sup>123</sup> C Long, J Eaton, S Russell, F Gullon-Scott, A Bilson [footnote 42].

<sup>124</sup> A Running & D Jata-Hall ‘Parental Blame and the Pathological Demand Avoidance (PDA) Profile of Autism’ (2023) at <https://www.pdasociety.org.uk/resources/parental-blame-and-the-pda-profile-of-autism/> (accessed 23 April 2023). Over 90% of the respondents were from the UK.

<sup>125</sup> Report of the Commission to Consider Families’ Experience of Children’s Services in Herefordshire (June 2023) at <https://www.herefordshiresafeguardingboards.org.uk/documents/report-of-the-commission-to-consider-families-experience-of-childrens-services-in-herefordshire> (accessed 17 July 2023) at paras 3.3.6, 3.4.2, and 3.4.3.

<sup>126</sup> C Dyer ‘Parents win ruling to send doctors back to GMC over misdiagnosis’ Guardian 1 May 2006 at <https://www.theguardian.com/society/2006/may/01/childrenservices.uknews> (accessed 18 July 2023).

subsequently allowed to return home to live with her siblings without any conditions attached.<sup>127</sup>

2019: an article concerning a parent who was accused by social workers of inventing her daughter's symptoms (of severe pain) and who was then sent to a psychiatric unit almost 100 miles away where she stayed for 10 months. It transpired that the NHS had failed to correctly diagnose the child's condition and had also used the wrong clinical notes. The same article referred to the fact that this was 'one of 12 families in Gloucestershire suspected of having invented their children's symptoms' and of which 'all the allegations of FII' were subsequently dropped.<sup>128</sup>

2021 Mary Kidson 'Legally Abducted' (Amazon 2021) written by a mother who spent six months in prison 'on remand' pending her prosecution based on allegations of FII (by Hereford Social Services) which were then dismissed by the judge on the basis that there was no case to answer.

2022: a Special Investigation report<sup>129</sup> by School Week that referred to the phenomenon of parents 'frequently not feeling believed by schools' and in this context to accusations of causing a 'fabricated or induced illness'.

#### *Local Government and Social Care Ombudsman reports*

A 2019 report<sup>130</sup> concerned a parent who was wrongly accused of FII and who was subjected the distress of prolonged uncertainty about the allegation, before it was held to be unfounded. The ombudsman, in addition upheld her complaints that incorrect information about her family was presented to a case Conference and that the NHS Trust failed to provide the necessary evidence to substantiate the allegations.

A 2020 report<sup>131</sup> where the authority's own investigation found that a social worker 'seems to have been actively trying to make this case fit the FII criteria and it appears from the evidence looked at that information was sought only to fit her hypothesis. It is unclear why this was the case, but it could be suggested that it was a relatively inexperienced social worker being overzealous.'

A 2021 report<sup>132</sup> concerned an allegation that a family had fabricated evidence that their child suffered from an autism spectrum disorder, and it was only after a court

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<sup>127</sup> L Adams 'I was suspected of causing my child's illness' BBC on-line 27 June 2019 at <https://www.bbc.com/news/uk-scotland-48770748> (accessed 18 July 2023) and see also P Grant 'False allegations of fabricated illness 'ripped family apart' BBC on-line 5 May 2019 at <https://www.bbc.com/news/health-48151355> (accessed 18 July 2023).

<sup>128</sup> R Cave 'I was accused of pretending that my daughter was sick' BBC on-line 11 March 2019 at <https://www.bbc.com/news/health-47500686> (accessed 18 July 2023). See also D Siret *The Impact of FII allegations on parents* Parent & Carers Alliance (2019) at <https://www.parentandcareralliance.org.uk/wp-content/uploads/2019/03/PCA-FII-Summary-final-shared.pdf> (accessed 18 July 2023).

<sup>129</sup> J Staufenberg & S Booth 'Kids in Crisis: The Toll of our Collapsing CAMHS' (276) 11/2/22 School Week at <https://schoolweek.co.uk/wp-content/uploads/2022/02/kids-in-crisis-digi.pdf> (accessed 10 February 2023).

<sup>130</sup> Complaint no. 18 013 505a against Leicestershire Partnership NHS Trust and Leicestershire County Council 4 September 2019.

<sup>131</sup> Complaint no 19 004 566 against Gloucestershire County Council, 25 February 2020 (para 17).

<sup>132</sup> Complaint no 20 000 544 against East Riding of Yorkshire Council, 22 Dec 2021.

recommendation that the child was then diagnosed with a condition frequently linked to autism. As a result of the ombudsman's intervention the authority accepted (among other things) that there was no evidence on file to establish why the accusation of FII had been made and that the accusation 'resulted in distress for the family and a breakdown in their relationship with the social worker. This may have built towards their sense of being 'blacklisted' by the Council'.

## Appendix 2: The Cerebra online FII Survey questions

1. Are you a parent caring for a disabled child who has approached your local authority and / or your local NHS for support to help meet your child's needs?  
Yes  
No

If you have answered 'Yes' and you are willing to identify your child's impairment, could you please describe it briefly in the box below (this includes, for example, physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness and various types of chronic disease).

2. Do you identify as a disabled person?  
Yes  
No

If you have answered 'Yes' and you are willing to identify your impairment, could you please describe it briefly in the box below (this includes, for example, physical impairment, sensory impairment, cognitive impairment, intellectual impairment, mental illness and various types of chronic disease).

3. During your interactions with your local authority and / or the NHS (for example, your GP or someone in a health clinic or hospital), have you ever been accused of fabricating or causing or exaggerating your child's illness or have things been said by professionals that imply that this might be the case?  
Yes  
No

If 'Yes' – In the box below, please describe briefly what happened, including the terms that were used when the allegation was made (i.e. FII - Fabricated or Induced Illness; PP - Perplexing Presentation).

If you have answered '**No**' to this question, **please skip questions 4 – 9 and go directly to question 10 below.**

4. Please name the local authority and / or the NHS body that made the allegation.
5. When did the allegation of FII or PP take place? Please give the year (and if you are able) the month.
6. Before the allegation of FII or PP was made, had you made a complaint about the actions of the local authority and / or the NHS body?  
Yes  
No

If 'Yes' – please provide brief details in the box below.

7. Have you made a formal complaint or taken any other action as the result of the allegation of FII or PP?

Yes

No

In the box below, please add any further information you think relevant concerning your decision to complain / take action (or your decision not to). This could include what the result was of your action and (for example) whether you decided to consult with a solicitor to take court action etc.

8. What was the outcome of the allegation?
- a. No further action was taken by the local authority / NHS body.
  - b. Safeguarding action was commenced but then abandoned.
  - c. Safeguarding action was pursued (please give details of the result in the box below)
  - d. Other (please give details in the box below)

Please add any further information which you think is relevant in the box below.

9. Please describe the effect that this allegation of FII or PP has had upon yourself and your family.
10. Please provide any other information which you consider relevant.



### Appendix 3: Copy of the Formal Freedom of Information Request on FII Training and Guidance

#### Formal Freedom of Information Request

Dear

I request that you provide 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 ascertain the level of training and written policy / guidance received by the those working for your authority who are responsible for undertaking the assessments of disabled children and their families for disability specific support services under the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970 and are involved in initiating / managing allegations of FII (fabricated or induced illness) with respect to these families.

#### **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**

1. Please provide the details specified in (a) - (c) below concerning training courses provided by your authority (whether 'in-house' or externally funded) that specifically addressed the issue of FII (fabricated or induced illness). This request is limited to those courses that have been provided since April 2019 for your staff members (including agency staff) who were involved in the assessment of disabled children and their families for disability specific support services under the Children Act 1989 and the Chronically Sick and Disabled Persons Act 1970.
  - a. The name of the course or courses;
  - b. Copies of the course programme or course programmes; and
  - c. The number of staff who have attended the course, or if there was more than one course, the number of staff who have attended each of the courses.
2. Please provide a copy (in printed or electronic form) of the written policy / guidance that your authority provides to its assessors, for dealing with instances of FII.

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 of the Act. I will also expect you to release all non-exempt material. I reserve the right to appeal your decision to withhold any information or to charge excessive fees.

If you require any clarification, please contact [email specified] 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 4: Summary of findings about trauma from the online Cerebra FII Survey

- ☐ I am not the person I was. I have lost myself. Who I was and who I am now are, sad reflections. I do not have a life space to be free of this ever and I worry for the future of not just me but all the mothers to come. (Response no 1)
- ☐ At the worst time of our lives, when our child was desperately ill. (Response no 2)
- ☐ I was paranoid and scared as I knew the consequences of an FII allegation (as I had seen them when I worked [in social care]). (Response no 3)
- ☐ Traumatise me and my [child]. [s/he] no longer feels able to trust health professionals. (Response no 4)
- ☐ Trauma. It has caused us PTSD and worse it delayed getting the right help and medications for our [child]. It was over a year sheer fear and spending every waking hour working out who had done what. We are still waiting for a written apology. (Response no 5)
- ☐ Devastated. (Response no 7)
- ☐ We are sick and tired of being treated with complete disrespect and lack of understanding. (Response no 9)
- ☐ Too scared to visit doctor or minor injuries as it is still on health records as 'active'. (Response no 10)
- ☐ It was devastating. (Response no 18)
- ☐ Devastating. I lost everything. (Response no 22)
- ☐ Massive. Almost [x] years later I still make my [spouse] do all the GP visits and medical appointments for our children. I only go to the GP when I absolutely have to. (Response no 23)
- ☐ As a parent and a human being, being accused of such a heinous form of child abuse, has undoubtedly left long-standing, emotional/psychological scars which will remain until the day I die. Just hearing and seeing the words MSBP/FII reignite the trauma and injustice of it all. (Response no 24)
- ☐ Destroyed us all. I fear professionals and completely distrust everyone. (Response no 25)
- ☐ Trauma. (Response no 26)
- ☐ Traumatizing scary, lost faith in the system, cannot trust anyone now. (Response no 27)
- ☐ It's upsetting and caused a lack of trust. Stress, sleepless nights, not being believed at school. (Response no 29)
- ☐ Depression, anxiety. (Response no 30)
- ☐ Feeling abandoned by the system. Gaslit into believing symptoms were not as bad as they were. (Response no 32)
- ☐ The impact on my health was horrendous. I think it is PTSD! (Response no 33)
- ☐ Devastating effects on confidence, emotionally. Unbelievable. Someone would suggest that. (Response no 34)
- ☐ Annihilated [partner] dead. (Response no 38)
- ☐ Had to have trauma therapy. (Response no 39)
- ☐ Furious! Stressed! (Response no 40)
- ☐ It has caused massive issues and I have no support whatsoever from the local authority. (Response no 41)
- ☐ Devastating. (Response no 42)
- ☐ Legacy of anxiety and mistrust. (Response no 44)
- ☐ Devastating. My [spouse] is mentally broken and withdrawn. (Response no 45)
- ☐ Stress, exhaustion, and lack of faith in the system. (Response no 47)
- ☐ It was stressful and time-consuming, and left me outraged. (Response no 50)

- ☐ My anxiety levels are through the roof. My hair has fallen out at times, and it has been the most stressful experience in my entire life. (Response no 52)
- ☐ It is depressing. (Response no 55)
- ☐ 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. (Response no 56)
- ☐ Made me very defensive and hypervigilant. (Response no 57)
- ☐ I have cried myself to sleep many times and felt traumatised that anyone could think and say such awful things about me. It's put me off schools in entirely. (Response no 58)
- ☐ I appealed and they refused to remove [allegation] 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 or they were present in the meeting so I feel like they are judging me. I feel physically and mentally violated. (Response no 59)
- ☐ I am too scared to take my youngest to the GP. (Response no 60)
- ☐ Severe distress and mental anguish. (Response no 61)
- ☐ Devastated, depressed, exhausted, wondering if I was good enough, angry, devastated, not to get the urgent help desperately needed. (Response no 62)
- ☐ I have been subjected to nothing short of emotional torture for [x] years. (Response no 63)
- ☐ We were very anxious about this escalating. (Response no 69)
- ☐ Absolute immense sustained stress. (Response no 72)
- ☐ Crucified us. (Response no 74)
- ☐ We don't trust the establishment. (Response no 75)
- ☐ Untrusting of professionals. (Response no 79)
- ☐ Devastating. My [child's] needs are not understood and I cannot even openly say what they are! Every day brings fresh pain. I am frightened of having any contact with professionals. Yet I am a [professional]. (Response no 80)
- ☐ It has been devastating. I am burned out. (Response no 81)
- ☐ Fear and exhaustion. (Response no 82)
- ☐ I am now a broken woman. (Response no 83)
- ☐ Both myself and my child now have diagnoses of either PTSD or CPTSD. I could go on, but the scars are deep and unfading. What we have been put through, has changed our outlook and our lives forever, we will never be the same as we were before. (Response no 84)
- ☐ We can never trust institutions ever again. My [spouse] had to have therapy for PTSD and developed a sleep disorder. (Response no 86)
- ☐ Often feeling like I can't go on. (Response no 88)
- ☐ Stress/upset/lack of support for child. (Response no 90)
- ☐ It broke us. (Response no 92)
- ☐ Ruined my life. (Response no 95)
- ☐ It devastated us. We very nearly lost our home and our careers. (Response no 96)
- ☐ Extremely stressful and worrying. Pushed us to breaking point. Made us less likely to attempt to try and get much-needed help for the family, further disadvantaging in us and putting pressure on the family. (Response no 97)
- ☐ Destroyed all of our ability to trust professionals and led to our needs for support massively increasing. (Response no 98)
- ☐ Devastating for me, but most importantly, delayed my child receiving the care and support needed. (Response no 100)
- ☐ We lost everything. (Response no 103)
- ☐ It has caused lifelong trauma for all of us, especially my disabled [child] who as an adult is afraid to seek the help [s/he] needs. (Response no 105)
- ☐ It has caused trauma and blocked access to care. How can we ever trust them? (Response no 107)

- ☐ Traumatic, stressful and constantly fearful. (Response no 108)
- ☐ It has been stressful and it has delayed my child getting the support. (Response no 109)
- ☐ Depression, panic, worry on entire family. (Response no 112)
- ☐ This has had a massive effect on us all. The schools have shared between themselves ... some highly confidential information. (Response no 114)
- ☐ Incredible physical and mental stress. The amount of care my [child] needed increased hugely. My [child's] words are "it has permanently, emotionally, and physically scarred me, it has traumatized me probably permanently and it's given me a hell of a lot of anger". (Response no 116)
- ☐ It was an added layer of stress in what was already horrific. (Response no 118)
- ☐ This has caused a huge amount of distress for our family, it was so unnecessary. We have no relationship with the school. (Response no 119)
- ☐ Destroyed us all. Enhanced massive trauma to [child]. (Response no 120)
- ☐ Devastating. (Response no 121)
- ☐ It has devastated us. I worked in the healthcare industry, but I am too afraid to think of going back into it. I no longer trust doctors. (Response no 123)
- ☐ It has torn me apart. (Response no 124)
- ☐ PTSD. (Response no 126)
- ☐ It has been very worrying and the school were very obviously just covering their backs. (Response no 127)
- ☐ Absolutely devastating. Children have severe separation anxiety and nightmares. (Response no 131)
- ☐ Made us feel awful, stressed, lack of sleep. Fearful of hospital involvement. It ended my career, [social care]. (Response no 133)
- ☐ Destroyed our family. (Response no 134)
- ☐ Traumatized both me and my child. (Response no 135)
- ☐ It destroyed me. I came close to ending my life. (Response no 136)
- ☐ I am a mere shell of what I was. I will never dare seek help from the NHS for my [children] again. I would never dare be assertive with schools or fight for any proper support or diagnosis. We will live in fear for ever I dare not even go to the doctors myself at present. (Response no 137)
- ☐ Unbelievably stressful. I feel I can never again seek help for any medical conditions. (Response no 141)
- ☐ I used to be confident now I feel weak and scared. (Response no 143)
- ☐ Trauma and anxiety. (Response no 144)
- ☐ Caused anxiety, PTSD, stress fighting the allegations. (Response no 145)
- ☐ I am traumatised by it. I feel punished and threatened because I asked for help. (Response no 146)
- ☐ Broke us. Made us think we were going crazy. (Response no 150)
- ☐ From this, I stopped pursuing support for my daughter. She went on to self harm and have suicidal thoughts. (Response no 151)
- ☐ Anxiety, fear of doctors, PTSD. (Response no 153)
- ☐ Made us scared to ever approach services for support. (Response no 154)
- ☐ Trauma. Living in fear for so long that someone is coming to take your child away. (Response no 155)
- ☐ It has destroyed my mental health. (Response no 156)
- ☐ Made me feel scared to ask for help or trust any professionals. (Response no 159)
- ☐ Too much to list. Unable to work in [NHS]. (Response no 160)
- ☐ Cause severe depression in me. (Response no 161)
- ☐ Caused huge amount of upset and anxiety. (Response no 163)
- ☐ It is by far the worst thing that ever happened to my family. (Response no 164)

- ☐ It destroys you as a family, it means you live in fear of someone else making up a false allegation. (Response no 168)
- ☐ Horrific. (Response no 169)
- ☐ It's so destroying to think that I would ever make up what my daughter is struggling with. (Response no 171)
- ☐ Extremely stressful, expensive to fight. (Response no 173)
- ☐ I was devastated, and it caused me to struggle with stress and depression. (Response no 174)
- ☐ I became very depressed, attempted suicide. (Response no 175)
- ☐ Panic attacks for me. Depression with my youngest who wasn't believed. (Response no 176)
- ☐ I feel traumatised by the system. Scared to answer the phone, scared to attend meetings with staff that were parent blaming. (Response no 177)
- ☐ Immense stress. Emotional and physical damage. (Response no 178)
- ☐ It completely devastated, the whole family and it has taken years to heal, and we still have a long way to go. (Response no 179)
- ☐ It destroyed our lives. We had to give up a home and move away to another county where the accusation of FII was overturned. (Response no 180)
- ☐ The trauma of the multiple experiences continues to impact our mental health [x] years on. (Response no 181)
- ☐ Distress and upset and a feeling of total distrust towards government organisations. (Response no 182)
- ☐ Ended my career. (Response no 184)
- ☐ I was devastated and suffered intrusive thoughts. (Response no 185)
- ☐ Trauma. (Response no 187)
- ☐ No longer go to any NHS appointments. (Response no 189)
- ☐ Worried to ask for help. Felt alone and isolated and unsure what to do. (Response no 190)
- ☐ Trauma. Trauma. Trauma. Total distrust of all professionals. (Response no 191)
- ☐ I felt gaslighted for over [x] years, and that has had a huge impact on my mental health, but most importantly, has also meant that my [child] lived in constant pain for far longer than he needed to had I been believed from the start. It has had a huge and terrible impact on our family. (Response no 193)
- ☐ It was horrendous. Nearly caused me to have a breakdown as it was the final straw. (Response no 196)
- ☐ It has destroyed my belief in my parenting. (Response no 197)
- ☐ Shattered me. Confidence, physical illness, mental health difficulties. (Response no 199)
- ☐ It destroyed us completely. (Response no 201)
- ☐ It's like abuse-gaslighting. (Response no 203)
- ☐ Pure stress. Anxiety. I feel reluctant now to go to the doctors and such like with any issues. (Response no 204)
- ☐ Devastating: the worst you can imagine. (Response no 205)
- ☐ I had a breakdown. There was a point when I felt suicidal. (Response no 206)
- ☐ Destroyed my family. I've been slandered and my daughter now has no help. (Response no 209)
- ☐ Extremely stressful. (Response no 211)
- ☐ Destroyed our family and traumatised our children. (Response no 213)
- ☐ Devastated. Made to feel like a criminal for being the best parent I could be and advocating for my child. (Response no 216)
- ☐ Devastating. (Response no 218)
- ☐ Triggered post traumatic stress. (Response no 219)

- ☐ Fear, abuse, stress, distress, exhaustion, declining health, loss of childhood, loss of a family, loss of education, financial impact, isolation, gaslighting. (Response no 220)
- ☐ The consequences of being put on child protection destroyed our family and put everyone on edge and worried about every time the doorbell rang. (Response no 229)
- ☐ Family in distress. Lost trust in all. (Response no 231)
- ☐ Devastating at the time and has made me aware of something so harmful to families who are already struggling. (Response no 232)
- ☐ I still feel I can't trust people. (Response no 233)
- ☐ Now broken family vulnerable in crisis [parent] diagnosed with complex PTSD. (Response no 234)
- ☐ It destroyed us. I will never get over it. Caused my [spouse] to collapse with stress. (Response no 239)
- ☐ Absolutely devastating. I suffer from PTSD and anxiety. I cried all the time (Response no 240)
- ☐ It was the worst [x] years of my life. (Response no 242)
- ☐ We are both still working through the trauma of their time at school, but for me, it's the trauma of those accusations. (Response no 244)
- ☐ To be reported to SS absolutely gutted us. I ended up sobbing on the floor. For a time I just wanted to curl up and die. (Response no 245)
- ☐ The psychological impact of finding out that professionals have been writing lies and totally unfounded allegations about you is traumatising. (Response no 248)
- ☐ I then was catapulted into a world of trauma. I lost faith in the NHS. (Response no 250)
- ☐ It made me very very ill. (Response no 251)
- ☐ I have PTSD. Still now every time I have to go to the GP I know they will have it on the system. (Response no 258)
- ☐ Devastating and negatively reinforcing. (Response no 259)
- ☐ Stopped seeking professional help. (Response no 261)
- ☐ It nearly destroyed us and severely traumatised us. I felt suicidal. (Response no 264)
- ☐ I still have nightmares [x] years on. You cannot get things removed from medical records even if you can prove they are wrong and that it is not right and worries me hugely. (Response no 266)
- ☐ It made me feel like I was mad. (Response no 267)
- ☐ I have been diagnosed with PTSD. (Response no 268)
- ☐ Now I am too scared to ask for anything. (Response no 269)
- ☐ I went into a mental break. (Response no 270)
- ☐ Destroyed, all trust in services, with all the family. (Response no 271)
- ☐ We are not the same people. We are broken and traumatised. We cannot trust anyone anymore. (Response no 272)
- ☐ I have been diagnosed with PTSD, my children remain scared, and we live in fear of it starting again. (Response no 273)
- ☐ I'm terrified to ask for help now. (Response no 275)
- ☐ I believe the stress was so severe that it contributed to cancer. (Response no 276)
- ☐ It nearly tore our family apart, because of how stressful things got for us. (Response no 277)
- ☐ Child won't attend doctors. (Response no 279)
- ☐ Trauma. (Response no 281)
- ☐ Devastated still don't feel listened to or believed. (Response no 283)



- ☐ Stressed, feel like can't trust professionals and have to watch what I say, isolated. (Response no 284)
- ☐ I am suffering from PTSD. (Response no 285)
- ☐ Near family break up. (Response no 286)
- ☐ I was so anxious and depressed I wanted to die, but had to be strong for my [children]. (Response no 287)
- ☐ Oh it's huge. My [child] was hospitalised in [number] hospitals over [number] weeks with reams of medical evidence and you got told you're making stuff up. It's devastating. You end up not trusting anyone and the isolation is awful. The knowledge that the lack of services is having on your child's recovery. (Response no 291)
- ☐ Utter devastation. (Response no 293)
- ☐ Severe anxiety. Struggle to ask for help. Scared to complain. (Response no 294)
- ☐ Not being believed is harrowing and soul destroying. (Response no 297)
- ☐ Child is without proper support and will be for the foreseeable future. (Response no 298)
- ☐ Devastating. Humiliating. Unfounded. (Response no 299)
- ☐ It was devastating. We became too scared to access help. (Response no 302)
- ☐ Catastrophic. (Response no 303)
- ☐ Mistrust of NHS. (Response no 307)
- ☐ Huge trauma. Physical symptoms, nightmares, high heart rate, hair loss. Feeling of helplessness. Anger that being gaslighted by [NHS] was common practice. (Response no 310)
- ☐ Devastating. (Response no 311)
- ☐ Traumatic, hugely traumatic. Destructive and damaging for everyone involved. (Response no 312)
- ☐ We all have severe PTSD from everything we have been through, and we will never ever be the same again, we live in fear of something happening again. (Response no 315)
- ☐ Trauma. Lack of treatment for my [child]. (Response no 318)
- ☐ I now have such a deep-seated mistrust of professionals that I can't bring myself to go to a doctor, even when I'm sick. (Response no 319)
- ☐ We are still affected, my kids have no trust in anything or anyone. I've had my parental rights stamped over, my [child] still talks about being abuse there, and my [child] is beyond help because [child] has also been abused while not in my care. (Response no 321)
- ☐ Made me trust the school less. (Response no 322)
- ☐ Devastating. My child's life. My health, mental, health, dental, etc, financial, zero human rights, defamation, physical, health, friendships, relationships, the lot. Traumatized. Totally. (Response no 325)
- ☐ It's impossible to say how much it affected us. It nearly broke us. (Response no 331)
- ☐ Shattered. Destroyed. [child] was sexually abused in care. (Response no 334)
- ☐ My family have been to hell and back. I don't even know how to answer this. Asking for help should not lead to accusations because the school wants to save money. (Response no 339)
- ☐ Several years down the line, [child] is a happy confident ... . Unfortunately, my mental and physical health has never recovered from the FII insinuation and being treated as an abuser. (Response no 341)
- ☐ Increased stress levels, anxiety made wary of wanting to get any medical help. (Response no 342)

- ☐ This massively affected my mental health. (Response no 343)
- ☐ It nearly destroyed us. We are constantly terrified if our children are ill. (Response no 344)
- ☐ The allegation has destroyed me I don't trust anyone now. (Response no 347)
- ☐ Paranoia, lack of self-worth, thinking we weren't good parents. (Response no 348)
- ☐ This allegation completely destroyed me. (Response no 351)
- ☐ Totally floored us as a family and completely knocked her confidence. (Response no 354)
- ☐ It put a child's life at extreme risk. (Response no 356)
- ☐ I'm really struggling feeling so alone. (Response no 358)
- ☐ [x] year-old ASD child now refuses to discuss any issues with any healthcare practitioners following these encounters. (Response no 362)
- ☐ My poor child needed me I'm not a vindictive head teacher, trying to score points for their schools failings! (Response no 364)
- ☐ It took nearly [x] years before we felt able to ask for social care support. (Response no 365)
- ☐ It has made me feel I can't raise concerns about my [child's] health, [child] has very complex needs, and I'm afraid to ask for help or support. (Response no 366)
- ☐ Devastated. Can't sleep, eat. Feel sick. Stigma. (Response no 368)
- ☐ We both have CPTSD, severe anxiety and fear of authority stemming from this. We get panic attacks when anyone 'official' or with lanyard badge comes to our door. (Response no 372)
- ☐ I'm fearful of asking for help as it can be taken the wrong way. My daughter is in therapy due to the stress. (Response no 373)
- ☐ I felt broken, I mentally fell apart. I felt suicidal. (Response no 374)
- ☐ Myself and my children all suffer with PTSD. (Response no 375)
- ☐ Destroyed us all. (Response no 376)
- ☐ 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'm going to die. (Response no 379)
- ☐ My [spouse] and I separated due to stress. (Response no 380)
- ☐ Terrified to take child to GP. (Response no 382)
- ☐ This has caused shame, embarrassment, confusion, devastating impact, it's traumatic. I can barely eat, sleep. (Response no 383)
- ☐ It has changed how I am as a person completely. (Response no 386)
- ☐ All deeply traumatised and left unable to trust professionals. (Response no 387)
- ☐ This allegation has ruined our lives ... the lack of trust created by those professionals we rely on. (Response no 393)
- ☐ I am reluctant to approach my GP for anything for fear of triggering any further action. (Response no 395)
- ☐ Beyond stressful and put the most incredible stress upon her family. Made me very distrustful of professionals. (Response no 396)
- ☐ Destroyed me. I will never be the same again. (Response no 397)
- ☐ In the years since this happened, we have been too afraid to ask for any help for our younger children in education, because we are aware of the consequences. (Response no 398)
- ☐ My [child] experienced massive trauma and myself. (Response no 401)
- ☐ There is a note on my doctor's screen that pops up sometimes when I or my children visit the doctor saying something about safeguarding. (Response no 403)
- ☐ I have extreme distrust for the NHS and medical profession ... It has prevented me from asking for further diagnosis and support. (Response no 404)

- ☐ Even though this experience was short, and no action was taken against me, it actually is one of the most upsetting experiences in my life as a parent. (Response no 406)
- ☐ Broken. (Response no 407)
- ☐ Frightened to ask for help for my son in case this happens again. (Response no 410)
- ☐ Abuse by services. One made serious attempt in [date]. (Response no 412)
- ☐ My [children] are also suicidal due to Huge mental health implications for family so much that [parent] tried to commit suicide. (Response no 415)