

PRESS RELEASE

Royal College of Paediatrics and Child Health refuses to withdraw its 2021 guidance concerning Fabricated or induced illness (FII) by carers.¹

On the 16 July 2024 we the undersigned researchers and non-governmental organisations wrote to the President and Chief Executive Officer of the Royal College of Paediatrics and Child Health and called for the College to withdraw, with immediate effect, the above publicly available guidance that it had issued in 2021 (**copy letter attached**).

The letter to the Royal College explained that we considered this to be necessary in view of the evidence as to its discriminatory impact on disabled parents and the traumatic experiences of disabled children and their families when unwarranted and inappropriate allegations of FII are made.

The letter suggested that the weight of independent research and evidence from practice was such that no reasonable body (let alone one exercising public functions) could fail to take such urgent action.

In its response of 1st August 2024, the Royal College declined to withdraw its guidance (**copy letter attached**).

Discriminatory impact

A number of scholars have highlighted the potential for the Royal College's guidance to have an adverse and discriminatory impact on disabled parents, and the College is aware that research evidence suggests that this is happening in practice: that disabled parents are four times more likely to face FII allegations than non-disabled parents.

The Royal College's response to this evidence is, in our opinion, frankly inadequate – indeed it could be characterised as a 'non-response'.

We have accordingly drawn our concerns to the attention of the Equality and Human Rights Commission.

Disproportionate impact on families' right to respect for their private and family lives.

There is a duty on us all (individuals and organisations) to do our best to protect children from harm. The research evidence and the experiences of many non-governmental organisations strongly suggests that where parents are wrongly accused of FII, that they – and their children – can experience life-long and devastating trauma.

The British Association of Social Workers (BASW) was sufficiently concerned about an 'increase in the prevalence of FII referrals made to social care' that in 2022 it

¹ [Perplexing Presentations \(PP\) / Fabricated or induced illness by carers: A practical guide for paediatricians](#) (2021)

issued guidance² on this issue with a view to (among other things) ensuring that ‘parents/caregivers are appropriately supported, rather than them being subjected to unnecessary child protection proceedings, when inappropriate and wrongful accusations of FII are made’.

The BASW guidance noted that the Royal College’s guidance is ‘not founded on solid, indisputable evidence’ and expressed the importance of ‘an interprofessional consensus’. In this context, it noted that of those who agreed to be listed as consultees to the Royal College’s guidance ‘there is an absence of organisations representing key safeguarding bodies including social work, education, and the police’. It added:

If social workers were to follow the RCPCH guidance, the proposed assessment criterion for FII is likely to cast suspicion on many families who are not harming their children, including children and young people with disabilities and illnesses that are undiagnosed, or where their presentations have been misunderstood and subsequently misdiagnosed.

We are profoundly troubled by the failure of the Royal College’s guidance to warn practitioners (or even to mention) that an erroneous identification of FII can have tragic consequences for the family and child.

Dr Ana Laura Aiello³

Dr Peter Baker⁴

Professor Andy Bilson⁵

Sonya Chowdhury (Chief Executive, Action for ME)⁶

Professor Luke Clements⁷

Dr Judy Eaton (Clinical Director, Help for Psychology Services)⁸

Dr Fiona Gullon-Scott⁹

Beverley Hitchcock (Head of Research and Information, Cerebra)¹⁰

Cathleen Long (Vivacity Independent Social Work (West Wales))¹¹

Tammy Mayes (Co-chair, Parents, Families and Allies Network)¹²

Diana Skelton (National Coordination, ATD Fourth World)¹³

ENDS

7 August 2024

² BASW [Fabricated or Induced Illness and Perplexing Presentations Abbreviated Practice Guide for Social Work Practitioners](#) 2022

³ School of Law University of Leeds LS1 9JT: email A.L.Aiello@leeds.ac.uk.

⁴ Tizard Centre, University of Kent, CT2 7NF P.A.Baker@kent.ac.uk

⁵ Emeritus Professor of Social Work, School of Health, Social Work and Sport University of Central Lancashire, Preston PR1 2HE andy@bilson.org.uk.

⁶ Chief Executive, Action for ME, 2 Temple Street, Keynsham BS31 1EH sonya@actionforme.org.uk.

⁷ School of Law University of Leeds LS1 9JT: email l.j.clements@leeds.ac.uk.

⁸ Clinical Director, Help for Psychology Services, drjudyeaton@help4psychology.co.uk.

⁹ School of Psychology, Newcastle University, NE2 4DR fiona.gullon-scott@ncl.ac.uk

¹⁰ Head of Research and Information, Cerebra, The MacGregor Suite, Jolly Tar Lane, Carmarthen, SA31 3LW. beverleyh@cerebra.org.uk.

¹¹ Vivacity Independent Social Work (West Wales) info@vivacitysocialwork.co.uk.

¹² Co-chair, Parents, Families and Allies Network, 33 Serpentine Rd, Kendal, LA9 4PE tammy@pfan.uk

¹³ National Coordination, ATD Fourth World, 48 Addington Square, London SE5 7LB diana.skelton@atd-fourthworld.org

Commenting on the Royal College's 1st August 2024 response:

Dr Ana Laura Aiello¹⁴ said

This reply provided by the Royal College is very disappointing. Despite the solid research evidence demonstrating how their 2021 Guidance could damage and traumatise disabled children and their families, the Royal College has not taken any immediate action to look properly into this.

Professor Andy Bilson said:¹⁵

With no basis in research, the Royal College's guidance has significantly widened the alerting signs of possible FII, making it likely that many more parents and children with hard to diagnose conditions are put through the trauma of unnecessary suspicion of FII. It also removed the warnings about harm to children caused by misidentification found in earlier guidance.

Sonya Chowdhury (Chief Executive, Action for ME) said:¹⁶

We are extremely disappointed to see that, despite a clear evidence-base existing for how their 2021 guidance could cause damage and trauma to children with ME and their families, the Royal College has refused to take any urgent action to address our concerns.

Professor Luke Clements¹⁷ said:

Where research evidence concerning a policy suggests that it may result in severe and adverse trauma and disability discrimination (against both disabled parents and disabled children), and research then finds that this appears to be happening in practice, the author of that policy is duty bound to take urgent action to assess and, if needs be, to address this impact. In the present case the Royal College has known of this problem for a considerable period of time and yet it has decided to delay taking action until a convenient moment arises (ie a periodic review). In my opinion this is unacceptable.

Dr Judy Eaton (Clinical Director, Help for Psychology Services) said:¹⁸

I have worked for many years in a clinical setting and have first-hand experience of supporting families who are facing accusations of Fabricated and Induced Illness simply because they have fought to access appropriate expertise in identifying complex, and often under-researched, clinical presentations. This can have a devastating impact upon both young people and their families, particularly neurodivergent mothers who are simply seeking the best support for their children. Even when these allegations are subsequently found to be untrue, the stigma and anxiety remains.

¹⁴ School of Law University of Leeds LS1 9JT: email A.L.Aiello@leeds.ac.uk.

¹⁵ Emeritus Professor of Social Work, School of Health, Social Work and Sport University of Central Lancashire, Preston PR1 2HE andy@bilson.org.uk.

¹⁶ Chief Executive, Action for ME, 2 Temple Street, Keynsham BS31 1EH sonya@actionforme.org.uk.

¹⁷ School of Law University of Leeds LS1 9JT: email l.j.clements@leeds.ac.uk.

¹⁸ Clinical Director, Help for Psychology Services, drjudyeaton@help4psychology.co.uk.

Dr Fiona Gullon-Scott said:¹⁹

I am saddened that the RCPCH has chosen to reject the call to withdraw its FII guidance. In their own words the RCPCH confirm the “absence of published evidence” around FII, yet when presented with published evidence demonstrating the discriminatory and traumatic impacts of erroneous FII allegations has chosen to dismiss this. The RCPCH state that their guidance was drafted “in a manner so as to avoid discrimination”, yet research has shown that discrimination of disabled families is rife and the guidance has not, therefore, avoided discrimination. Being presented with such evidence I am stunned that the RCPCH have not sought to redress this.

Beverley Hitchcock (Head of Research and Information, Cerebra) said:²⁰

It is of great concern and disappointment to Cerebra that the Royal College came to the conclusion that they would not withdraw their 2021 FII guidance despite the evidence that was presented to them. This is in despite of the overwhelming fact that allegations of this nature can have such a devastating effect on parents and children which can cause harm resulting in a lifelong impact on families.

Cathleen Long (Vivacity Independent Social Work (West Wales) said:²¹

As a registered social worker, I am dutybound to protect children and young people from the risk of harm. We therefore need robust, evidence-based safeguarding policies that proactively encourage professionals to consider and reflect on the unique characteristics of every child within their family and wider community, without inadvertently causing them any harm. Whilst acknowledging that the RCPCH guidance was written with the intention of protecting children from having misdiagnoses imposed on them by their parents/caregivers, the guidance is not sufficiently fine-tuned to discern the genuine (and very rare) cases of Fabricated or Induced Illness from honest and legitimate parental concerns about their child’s wellbeing. Research reveals that a high proportion of neurodivergent mothers are accused of FII, which is indicative of disability and gender discrimination. During the consultation stages prior to the RCPCH 2021 publication, I raised these concerns which were subsequently ignored. I am aware that the trauma families feel when accused of FII is immense and long-lasting, and their experiences are repeatedly being minimised and discounted.

Diana Skelton (National Coordination, ATD Fourth World) said:²²

In addition to all of the above issues, ATD Fourth World is deeply concerned that the widespread lack of understanding of the multidimensional nature of poverty can mean that the discriminatory impact of this guidance is often heightened for families in poverty.

¹⁹ School of Psychology, Newcastle University, NE2 4DR fiona.gullon-scott@ncl.ac.uk

²⁰ Head of Research and Information, Cerebra, The MacGregor Suite, Jolly Tar Lane, Carmarthen, SA31 3LW. beverleyh@cerebra.org.uk.

²¹ Vivacity Independent Social Work (West Wales) info@vivacitysocialwork.co.uk.

²² National Coordination, ATD Fourth World, 48 Addington Square, London SE5 7LB diana.skelton@atd-fourthworld.org

Background research information:

Research by Action for ME found:

2017 research - Action for M.E. '[Families facing false accusations: results of Action for M.E.'s survey](#)'. The survey ran for 3 months and received 270 responses. Key findings: 1) Half of the families subjected to child protection proceedings told us these were instigated by a teacher, with 70% of these citing FII as a factor. 2) 90% of respondents agreed they were concerned that professionals involved with their child did not believe them. 3) 1 in 5 said a safeguarding/child protection referral had been made against them, with nearly half of these referrals related to FII claims – 70% of these cases were dropped within a year.

Research by Professor Andy Bilson:

2020 response to RCPCH draft guidance [Comments on Perplexing Presentations \(PP\) / Fabricated or Induced Illness \(FII\) by carers: RCPCH guidance](#) warned that the proposed alerting signs would mean many more children with legitimate medical conditions whose parents have not harmed their children would be suspected of FII than those who fabricated illnesses.

Research by Professor Luke Clements and Dr Ana Laura Aiello funded by Cerebra:

2023 research (Clements, L & Aiello, L A [The prevalence and impact of allegations of Fabricated or Induced Illness \(FII\)](#) (Cerebra 2023)) included an analysis of a sample of 387 responses to a survey concerning the nature and impact of FII allegations. The major finding was that the making of a FII allegation often causes devastating and life-long trauma to those accused. The analysis also found that: (1) Disabled parents were four times more likely to be accused of FII than non-disabled parents; (2) 50 per cent of FII allegations were made after a parent carer had complained about the actions of the relevant public body; (3) most FII allegations (84 per cent) resulted in no follow up-action or were abandoned and in 95 per cent of the cases, the child(ren) remained living with the parent; (4) that NHS practitioners were the source of most FII allegations, followed by schools and then local authority children's services.

Research by Dr Fiona Gullon-Scott:

2018 research (Gullon-Scott, F.J. & Bass, C., Muchausen by Proxy: Under-recognition of autism in women investigated for fabricated or induced illness, *Good Autism Practice*, 19 (2), 6-11) presented case study evidence for inappropriate mis-interpretation of autistic communication and interaction as 'evidence' for FII, and cautioning professionals to think about alternative (non-abusive) explanations for behaviours (e.g., diagnosed or undiagnosed autism) before assuming FII.

2022 research article (Gullon-Scott, F.J & Long, C., FII and Perplexing Presentations: What is the Evidence Base for and against Current Guidelines, and What are the Implications for Social Services?, *British Journal of Social Work*, 52, 4040-4056) outlined that an increasing number of families of children with neurodevelopmental presentations (such as autism), or presentations of complex or less well-known conditions such as Ehlers–Danlos syndrome, were finding themselves being investigated for FII by Social Services, and consequently labelled as potential 'perpetrators' of child abuse, on the basis of FII guidelines. The article discusses how current guidelines are creating implicit and explicit bias against certain kinds of families.

Research/publications by Cathleen Long:

2022 research (Gullon-Scott, F.J., & Long, C. 'FII and Perplexing Presentations: What is the Evidence Base for and against Current Guidelines, and What are the Implications for Social Services?' *British Journal of Social Work*, 52, 4040-4056).

2023 research Long, C., Coope, T., Hughes, S., & Hindson, K. 'PANS, PANDAS and Fabricated or Induced Illness: A Guide for Social Work, Healthcare and Education Professionals', PANS PANDAS UK,.

2022 guidance BASW, 'Fabricated or Induced Illness and Perplexing Presentations - Practice Guidance for Social Work Practitioners', Long, C., Eaton, J., Russell, S., Gullon-Scott, F.J., and Bilson, A.

2023 chapter Long, C. 'Social Work Practice, Neurodivergence and Fabricated or Induced Illness' (Chapter 9) in Eaton, J. (2023). 'Autism Missed and Misdiagnosed: Identifying, Understanding and Supporting Diverse Autistic Identities'. Jessica Kingsley Publishers.