Witness Name: Dr Nick Lessof
Statement No.: NL/1
Dated: 29/07/2024

THIRLWALL INQUIRY

WITNESS STATEMENT OF Dr Nick Lessof

I, Nick Lessof, will say as follows: -

1. I am a consultant paediatrician currently working as Designated Doctor for Safeguarding Children (since 2014) for North East London NHS and I have previously worked as Named Doctor for Safeguarding Children at Great Ormond St Hospital for Children and at Homerton Hospital (between 2003 and 2014).

   I would like to offer my sincere condolences to the affected families.

2. The key question (at least from a Safeguarding Children perspective) arising from the murders and attempted murders of infants on the Neonatal Unit at the Countess of Chester Hospital is whether or not this is a safeguarding problem. It is my understanding that the concerns raised by staff were not treated as a safeguarding issue.

3. NHS England have just published the "Safeguarding children, young people and adults at risk in the NHS: Safeguarding Accountability and Assurance Framework" which is explicit in stating that all Health organisations must adhere to the United Nations Convention on the Rights of the Child (UNCRC). In discussing the Duty of Candour it states that a safeguarding incident may be because of a clinical procedure or practice that could have contributed to death, physical or psychological harm. It states that information must be shared with the Local Authority Designated Officer (LADO) where it is considered that a member of health staff poses a risk to children or might have committed a criminal offence against one or more children.

4. The Framework presumes that harm caused to children in a clinical setting is indeed a Safeguarding issue but public discourse has focused on the roles of senior managers and human resources staff. Any problem is framed as an 'allegation against a member of staff', and the response concentrates on the regulation of managers. I do not believe that health system or HR managers have the skills required to investigate serious child abuse.

5. I would like to reframe the problem as one of keeping children safe in hospital. If we are prepared to take this perspective, then we can address more appropriately why there was such a catastrophic failure of safeguarding systems. My belief is that Safeguarding Children Teams are excluded both implicitly and explicitly, from the management of children coming to harm in hospital settings *unless* it can be demonstrated that the parent or carer is to blame. The prioritisation of determining adult fault over child wellbeing leads us to fail many children at great cost to all involved.

6. Every hospital trust has a children's safeguarding team, including at least a Named Doctor for Safeguarding Children, a Named Nurse for Safeguarding Children, a Named Midwife and administrative support. This is a significant resource. Included in the role of the safeguarding team is the management of cases where children are poisoned or smothered in hospital by a parent. Cases where a child is harmed by a member of staff are excluded from the work of the safeguarding team.

7. It is recognised by paediatricians that children can suffer abuse in hospital and the Royal College of Paediatrics and Child Health (RCPCH) has produced guidance, "Perplexing Presentations (PP) / Fabricated or Induced Illness (FII) in Children. RCPCH guidance. Subtitled 'Fabricated or Induced Illness by Carers: A practical guide for paediatricians' – last published in 2009. Updated February 2021.

8. The guidance on FII is written by paediatricians for paediatricians, from the viewpoint that we know the doctor has the best interest of the patient at heart, and that Hospital is a safe place. There is no acknowledgement in the guidance that a child may be harmed by a member of staff, or of the huge power differential between staff and patients. This is reflected in the case definition of FII:

   "FII is 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 or neurodevelopment is impaired (or more impaired than is actually the case). FII results in emotional and physical abuse and neglect including iatrogenic harm."

9. This is the only Professional Guidance on keeping children safe in hospital and contains no mention of the possibility of harm being caused by a member of staff and no mention of the need to refer to the LADO. It does not therefore align with the NHS Safeguarding and Accountability Framework.

10. The current Guidance needs to be updated to admit the possibility of harm caused by a member of staff and to stipulate that referral to the LADO is mandatory. This would remove the unacceptable delays in police referral, enable more effective police investigation and prevent ongoing harm.

11. FII is said to be rare and hard to recognise and the NHS response focuses on determining parental guilt. This approach is inherently adversarial and causes great stress to families and to professionals. These problems are compounded by the fact that much of the terminology is poorly understood. There is no shared understanding across the system and it is entirely possible for a child to be referred to Children's Social Care only for the parent to explain to the social worker that s/he is following the doctors' instruction and for this to be taken at face value meaning little changes for the child.

12. As worryingly, the assumption of parental fault means that harm caused by a member of staff is excluded from practice guidance (see also 9 above). Professional sensitivities have protected this 'doctors and nurses do no harm to children' perspective and the current confusing terminology contributes to the obfuscation. It would be better to follow the lead of the American Academy of Paediatrics and name Medical Child Abuse. In my view we should go further and remove the presumption underpinning FII definitions – that it must be the parents' fault. This has no place in the case definition of abuse. The term Perplexing Presentations, which refers to the state of mind of the doctor, has no clinical value. A term which would be more useful would be Overmedicalisation (consisting of Overdiagnosis and Overtreatment), that would centre the terminology on the health and wellbeing of the child.

13. The vast majority of children coming to harm in hospital settings are those 'Perplexing Presentations' where overmedicalisation has led to children being told they are sick. They suffer unnecessary and harmful medical interventions and lose out educationally, emotionally and socially as a result.

14. The critical failing in our current system, however, is not about terminology or assumptions but the absence of resources to de-medicalise and rehabilitate affected children. Change is always challenging and will be especially difficult for families that have centred around a sick child for a long time. Current professional attitudes also 'trap' professionals in a treatment loop. The care of children who have become overmedicalized is unlikely to evolve without an exit strategy acceptable to both families and professionals, and a rehabilitation programme is an essential resource in these

cases. Where multidisciplinary rehabilitation services are available the results are excellent for most children.

15. Rather than addressing how to break an abusive cycle, it feels as if there is a 'standard operating procedure' for covering up patient harm. On one hand attack the bearer of bad news (see the GMC Hooper review, 2015, and the testimony of whistle-blowers nationwide). On the other hand, order serial invited reviews at 2- to 3-year intervals, thus deferring admission of the problem (often by as much as a decade).

16. A set of anecdotes or mini case studies illustrate this and some important points around the role of safeguarding professionals and institutional resistance to their involvement.

17. At Great Ormond St Hospital for Children the department of Paediatric Gastroenterology over-diagnosed and overtreated hundreds of children over many years for a condition called Eosinophilic Enterocolitis. Significant harm was done to many children by the 'nocebo' effect of being told they had a serious disease, by unnecessary dietary restrictions including tube feeds and intravenous nutrition, by high doses of steroids and other immunosuppressant medication and by unnecessary surgeries. The affected children were often from families with a past history of trauma or abuse and / or with neurodivergence or other vulnerabilities. Eventually, the department was closed to new admissions for two years. The disease is no longer diagnosed or managed at the hospital but the Trust has never admitted that any child was harmed. As Named Doctor for Safeguarding Children at the time I was removed from my post.
    The Care Quality Commission accepted that no child had been harmed. The Duty of Candour was not fulfilled and there has been no attempt to learn from the experiences of these children.

18. At the Tavistock Gender Identity clinic large numbers of children were treated with unevidenced medical interventions with irreversible side effects on fertility and sexual function. The Named Safeguarding Professional was side-lined. Significant harm was done to vulnerable children. Children who had suffered sexual abuse, children experiencing homophobia and neurodivergent children were particularly affected. The service was closed and the Cass review proposed a better model of care. Excluded from the terms of reference of the review, and indeed from the response of the Tavistock and broader NHS, was an acknowledgement of the harm done to children by the treatments they received. The Named Safeguarding Professional won her Employment Tribunal case against the Trust.

19. There have been other examples of doctors over-diagnosing children with disastrous consequences – some dating back many years. A Leicester paediatrician overtreated children for epilepsy in the 1990s with the affected families eventually receiving significant compensation. The Cleveland scandal concerned children being removed from their families although in this instance because a safeguarding children paediatrician overinterpreted a physical examination finding, reflex anal dilatation, as being diagnostic of sexual abuse – demonstrating that there is a need for checks and balances.

20. The system of Invited Reviews by the Royal Colleges offers a route for the consensual improvement of paediatric services. However, where there is a problem of systemic abuse a consensual solution may not be appropriate. There is a real risk of collusion in perpetuating dangerous medical practice.

21. The terms of reference of a recent Invited Review by the RCPCH addressed 14 cases of suspected FII. Insufficient preparation led to the review team excluding the cases and concentrating instead on departmental culture. There was no subsequent attempt to investigate the details or to learn from the cases as a group.

22. There is an institutional refusal to acknowledge that children have come to harm which explains the dearth of research in this area. Nonetheless, it is clear that the long-term outcomes of affected children are poor and that there are significant ongoing economic costs of Continuing Care packages.

23. There are also issues that arise because Patient Safety and Bullying are seen as two separate agendas within the NHS. A bullying culture though is a prerequisite to and enabler of systemically dangerous practice.

24. Abuse in hospital settings continues to be thought of as an unpredictable exception rather than as an expected and preventable consequence of the power differentials within an institution. The Church and Football Coaching have both been forced to acknowledge this reality and the medical profession needs to catch up.

25. The examples that follow illustrate how institutional attitudes can hamper child protection.

    - A mental health nurse wrote that “mother’s all-pervasive sense of catastrophe in relation to P's feeding, while a natural response to the situation, is an obstacle to

viewing the situation clearly. For example, during our first meeting we were struck by mother's certainty that P never drinks more than about 2 oz of milk per day, while P drank some 7 oz of milk from a bottle during the hour-long meeting." Ten years later the press reported that this mother of 6 had been jailed for benefit fraud and child abuse, having duped doctors, convincing them to insert feeding tubes into her son and daughter's stomachs. In that interim period doctors had overlooked the nurse's clear diagnosis of the situation and the environmental issues that had prevented the child from thriving. They stayed within the confines of their own professional pool / attitudes and failed to make the correct diagnosis – and despite the press reporting it was they and not the mother who had inserted the feeding tubes.

- I was referred to the GMC by a parent because, as Named Doctor for Safeguarding Children, I tried to prevent a child having unnecessary major surgery. The GMC found that I had not harmed the child. After a further five years of intensive medical treatment, missed education and social isolation a court judgement described the mother's treatment of the child as so abusive as to be life threatening. This abuse had been evident to me and many colleagues. It was enabled by some doctors and by the system. The GMC, in investigating the complaint, failed to speak to the child and failed to speak to the Child Protection doctor. Failure to listen to the voice of the child is a recurring theme in Serious Case Reviews.

- Another Serious Case Review found systemic failings by the health service leading to a 10-year old boy spending 5 years in a wheelchair on high dose fentanyl. Though rehabilitation was successful in weaning the boy off harmful opiates and helping him to regain independent mobility, the lack of a dedicated rehabilitation resource and the system's inability to foster proper multidisciplinary working means that he is still unable to eat or urinate normally, continues to rely on unnecessary, harmful and expensive intravenous nutrition and remains educationally and socially isolated.

- The system fails children through entrenched, siloed working and an institutional inability to respond to past failings. It also displays institutional difficulties in dealing with parents despite the FFI guidance about harm "due to parent(s') behaviour and action". For example, a health worker may manage to help a child

achieve a positive change in their life, such as no longer wearing nappies, or no longer needing a wheelchair. If the change is unwelcome to a parent and they complain about the health worker, the response of the hospital complaints department may well be to ask the health worker to apologise. The child is thus returned to her previous state of dependence.

26. The current version of the RCPCH guidance on FII does represent progress in some key regards. Crucially, it acknowledges the importance of a Child Rights based approach to the safeguarding of children in the NHS, though the concept is underdeveloped. There are still weaknesses, the child for example is still said to "collude" with an abusive parent. I also have concerns about invoking the Right to Privacy to support the medical profession's consensus position that the police should not use video surveillance in hospitals when (if the safeguarding of the child is central) this should be a police led decision.

27. The UNCRC states that a child rights-based approach to child caregiving and protection requires a paradigm shift towards respecting and promoting the human dignity and physical and psychological integrity of children as rights-bearing individuals rather than perceiving them primarily as victims.

28. The updated guidance acknowledges this. It also (its second significant step forward) describes Health and Education Rehabilitation Plans as a model for managing over-medicalised children. This is an essential development but demands dedicated service provision, which does not currently exist.

29. I would like to illustrate the complex way the above points combine with the example of a 'notional' child who has leg pains, has started to use a wheelchair and is seen in the specialist paediatric rheumatology service (a setting in which I have worked). The child's pain may be due to inflammatory arthritis, which will be diagnosed and treated with appropriate medication. Muscle weakness is an inevitable consequence of restricted activity and weakness will make pain more severe. Other natural responses that make pain worse are being frightened of the pain and thinking about it all the time. The child can be helped to return to normal mobility and school attendance through effective management in a multidisciplinary rehabilitation programme. Support by physiotherapists will help the child strengthen their muscles, occupational therapists will liaise with school and psychologists will teach pain management techniques.

It may also be that the child's pain is 'non-inflammatory' or 'biomechanical': that is the pain may not be caused by an organic disease process but maintained by other complex factors. In these instances drug treatments are unnecessary and, apart from simple pain killers, unhelpful. Nevertheless, the child is in a wheelchair and missing school. Children in this group did extremely well in the same rehabilitation programme that had been designed for children with inflammatory arthritis (what doctors understand as 'real' disease) and were almost always able to regain mobility and normal school attendance. However, the hospital made the decision to exclude the group of children whose muscle weakness was not linked to a clear diagnosis of inflammatory arthritis from the rehab service.

The decision to exclude wheelchair bound children from access to rehabilitation reflects the prevailing attitudes and culture of the medical profession. The children are seen as not having a 'proper' disease. Many of the affected families have vulnerabilities to overmedicalisation (the same vulnerabilities we have already discussed). They were often felt to be difficult to deal with and the cause of professional discomfort or dispute. This is, to some extent, a reflection of the fact that within the group of children with non-inflammatory pain, there are a small number of cases of Medical Child Abuse where families will not allow the child to regain mobility and independence. The complexity of managing these particular cases and our inability to maintain boundaries with those families mean that they use enormous NHS resources, cause huge staff distress and make frequent complaints. It was this which prompted the decision to close the service, an easier option than having the difficult conversations required to manage the most challenging cases. It excluded the children facing Medical Child Abuse but also left those suffering pain because of complex fears and vulnerabilities without the help that would allow them to rehabilitate.

30. I have spoken to colleagues in the USA where they have recognised specialists in Child Abuse Paediatrics and where Medical Child Abuse is named for what it is. These developments should clearly be a step forward yet they are not sufficient, on their own, to resolve the problem. Child Abuse Paediatricians in the USA I have spoken with are refusing to continue to manage cases of Medical Child Abuse. Key concerns for them are the attitudes of the medical profession and the lack of dedicated Rehabilitation Services. The situation in the UK is no better.

31. There is however a model that has been shown to work. The Hasbro Children's Partial Hospital Program in New England is an effective rehabilitation service for children

suffering from overmedicalisation and Medical Child Abuse, and is described in detail in 'Medical Child Abuse: Beyond Munchausen by Proxy' by Roesler and Jenny, American Academy of Paediatrics 2009 and could be a useful template for change.

32. There are important next steps that the Inquiry could recommend:

    1. Co-produce multiagency and multidisciplinary child rights based professional guidance for the management of over-medicalised children and children suffering Medical Child Abuse. This guidance should offer a co-ordinated and supportive approach to the challenges experienced by over-medicalised children and recognise the importance of education and the damage caused by social isolation.

    2. Commission the specialised multidisciplinary rehabilitation services that children and families need to achieve lasting change.

    3. Commission an academic study of the health, educational and economic outcomes of children diagnosed with Eosinophilic Enterocolitis.

Statement of Truth

I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: Nick Lessof

Dated: 29 July 2024