

Written evidence from A7 (PHS 23)

Public Administration and Constitutional Affairs Committee Parliamentary and Health Service Ombudsman Scrutiny 2019-20 inquiry

Summary of Concerns

This document summarises key issues and concerns as briefly as possible in a lengthy and complex case. I am happy to provide further evidence both in writing and orally and supporting documentation.

Although my concerns relate specifically to my own son's case, I am aware from other parents of disabled children who I know through both my professional work and personal contacts, who have had to refer cases to the PHSO, that the concerns we found seem to be common to families of disabled children. There is a concern that there is a lack of awareness throughout the PHSO from Mr Behrens down of the systemic discrimination disabled children potentially face in accessing healthcare, despite this being well documented in individual, national and international reports and in academic research. Indeed, systemic discrimination against disabled children seems to be a problem at the PHSO itself. There are many echoes between the experiences of parents' of disabled children trying to get issues addressed concerning their children's healthcare and deaths by the PHSO, with the systemic racism found within the police force by the McPherson (1999) report following the death of Stephen Lawrence. This includes evidence provided by parents being ignored; parents' credibility as witnesses being unreasonably questioned; and a failure to consider at all the potential that disability discrimination, prejudice and unconscious bias on the part of some health professionals could have played a part in the treatment and death of their children.

The concerns addressed in this paper are:

1. The unacceptable delay (over three years) on the part of the PHSO to investigate my son's death and the healthcare that preceded it. My son's case was referred to the PHSO in July 2017; due to an internal re-organisation it was not allocated to officers until Spring 2018. The officers did not complete their terms of reference until Autumn 2018 and have repeatedly extended their deadline for their report. Their investigation is still not complete.
2. The PHSO's unreasonable and disproportionate refusal to investigate my son's clinical and nursing care, insisting instead that we take legal action despite (i) litigation and the investigation were only concurrent due to the PHSO's long delay, but for the PHSO's delay litigation would not have been considered until after the PHSO completed their investigation; (ii) the litigation only relates to the period Nov 2014-March 2015 whereas the PHSO investigation relates to the period September 2013-March 2015 and the PHSO is refusing to investigate the whole period; (iii) no litigation is live, litigation was withdrawn when the Trust indicated their intention to defend it, making it unreasonable to continue as any potential sum recoverable would be far smaller than the costs to us and the public purse of the litigation; (iv) the global pandemic makes obtaining independent evidence difficult if not impossible and disproportionately costly compared with any possible recovery; (v) the PHSO officer assured us the investigation would be restarted should the litigation not provide us

with the remedy we wanted: (vi) litigation can only provide a financial remedy and not address potential on-going issues impacting on other families and (vii) continuing the litigation would have had a detrimental and potentially dangerous impact on our and the mental health of the relevant health professionals, especially during a global pandemic, when we are all subject to exceptional strain.

3. The PHSO's failure to exercise their s.149 Equality Act duty and consider the impact of potential disability discrimination, prejudice and unconscious bias in cases concerning the deaths of disabled children, despite families flagging up clear concerns related to detrimental treatment due to the child's disability or assumed disability.
4. Lack of diligence by PHSO staff in reviewing evidence provided by families of disabled children; failing to fully review documentation provided and accepting health professionals' accounts, even when there is clear evidence showing their accounts are flawed.
5. Repeating the errors made by Trusts which families believe contributed to their children's deaths, by refusing to obtain expert opinions from health professionals other than those from the same sub-specialisms who are the subject of the complaint, even when the main cause for concern is lack of input from appropriate sub-specialists, in our son's case paediatric neurologist, which we believe contributed to the diagnostic overshadowing which we believed caused his death.

Background to referral to PHSO

The PHSO were asked to investigate my son's hospital care in July 2017. We had been advised by a nurse director at NHS England to refer our son's case to the PHSO as we and that director believed there had been serious failings in the investigation into our son's death commissioned by the hospital concerned. Most significantly, the investigation failed to consider whether disability discrimination played any part in our son's death.

Our only son died aged 15 years, on 24th March 2015. His post-mortem showed very severe infection of his pancreas, very severe sepsis, and very severe internal bleeding. Several months before our son's death an on-call doctor had informed us that blood tests showed possible infection of the pancreas which needed urgent investigation. The on-call doctor had reviewed our son because he reported severe pain. The on-call doctor referred the matter back to our son's regular consultant Dr. C. Dr. C refused to investigate claiming the extreme health problems our son was facing were all due to our son's disability. Dr. C refused to involve a neurologist or other doctors in our son's care or talk with doctors who had treated him successfully for many years in another region and who had offered to talk with him. Dr. C stated categorically that it was 100% impossible that our son had infection anywhere in his body and that children did not get infection of the pancreas.

Our son was an in-patient at a large tertiary hospital from September 2013 in a region we had moved to a few months before our son was admitted to hospital. A large part of this stay was due to our son waiting for his home nursing package to be put in place, rather than due to ill health. The intention was always that he would return home and go back to school.

Our son had very severe cerebral palsy due to birth hypoxia and associated health problems. He was intellectually able and had won numerous national and international awards for writing, which he did by blinking, using a spelling chart and computer software. He was often asked by national bodies to write pieces for them or to give his views from a child patient perspective. He had lived with serious health problems all his life with frequent short hospital admissions. Between hospital admissions he had a good life; attending mainstream school, where he did well educationally (top of the class in all subjects); being part of the local community, with a wide circle of friends; always busy going out and about visiting people, places and cultural and other events around the UK.

Our son became critically ill with infection but his consultant, Dr C repeatedly insisted he was not ill. Our son's vital signs were all extreme for prolonged periods of time. His presentation was exactly as it had been in the past when he had a significant infection, except more extreme as he was not receiving appropriate treatment. In other hospitals our son had received appropriate care and been discharge home well for him. Dr. C became increasingly unpleasant as we repeatedly asked that our son get the treatment, he needed and that appropriate specialists, (most notably neurologists who would recognise our son's presentation as signs of infection) be involved in his care. Dr C repeatedly shouted verbal abuse at us in front of our son.

In February 2015 our son was so ill he had lost consciousness. The Trust had appointed another consultant (new to our son) by now to be his lead consultant, but he was an honorary consultant and academic expert in enuresis (bed wetting), not a neurologist, endocrinologist or respiratory specialist, being the three sub-specialisms who had cared for our son in other regions, with his care always being led by neurologists. He continued to insist our son had severe cognitive impairment and told us wrongly that our son (who when well attended mainstream school and excelled academically) had been unconscious since birth. It was clear our concerns about our son's serious condition were being dismissed due to diagnostic overshadowing.

Following our son's death, due to external pressure (our son and I worked closely with senior health professionals nationally) the Trust commissioned an 'independent' investigation. That investigation was seriously flawed, so much so that the NHS England nurse director described it as the '*worst and most biased investigation*' she had ever seen and advised us to refer our son's case to the PHSO.

Referral to PHSO

I referred our son's case to the PHSO in July 2017 but due to internal changes being made the PHSO did not allocate officers to the case until Spring 2018. They did not start working on the case until Summer 2018 and only produced terms of reference in Autumn 2018. I always replied immediately to requests from the PHSO but I understand from them the Trust often delayed in replying and the PHSO also repeatedly missed promised deadlines. As of 30 October 2020 the PHSO are still investigating the case.

It was made clear to the PHSO in my initial letter to them that they were being asked to address the issues which the Trust's 'independent' investigation had not addressed. I

provided the PHSO with copious written evidence including the Trust report and my detailed comments highlighting the issues I believed the report had not addressed. This expressly referenced the failure to consider the implications of the Human Rights Act 1998 and the Equalities Act 2010. The document also made clear that I believed diagnostic overshadowing (doctors mistakenly attributing clear evidence of serious and critical illness to my son's impairment) played a significant part in my son's death. The fact that doctors repeatedly wrongly claimed our son was unresponsive and could not communicate due to learning disabilities (he did not have learning disabilities) was also a key factor.

The PHSO were also aware from documentation provided to them that one of our key concerns was the Trust's failure to properly involve a neurologist in our son's care, leading we believe to misdiagnosis and his eventual death. They were aware that we had expressly asked that a neurologist be part of the independent review team.

All these factors were discussed with PHSO officers repeatedly, including providing them with evidence that rather than having learning disabilities, when well our son was educationally gifted and exceptionally talented for his age.

I was aware that both the PHSO and the hospital trust were public bodies pursuant to Schedule 19 Equalities Act 2010 and as such they had a public sector duty pursuant to s.149 of the Act to have due regard to eliminating discrimination, including disability discrimination. I took it in good faith that in the circumstances and particularly in light of the numerous inquiries and reports in recent years reporting systemic problems of discrimination in the health care of disabled people, especially those labelled (as our son wrongly was by the Trust) as having learning disabilities, the PHSO would automatically consider the potential of disability discrimination in relation to each and everyone of the issues they included in their scope. Potential disability discrimination was such a clear and obvious issue in the treatment our son received and in the conduct and findings of the Trust's 'independent' review, it never occurred to me that the PHSO would not recognise it as a significant factor, if not the most significant factor in our son's care.

Concerns about the PHSO

Unacceptable Delay

The long delay in investigating our son's case is a serious concern especially as it is still ongoing. This has had a very serious detrimental impact on both my and my husband's mental and physical health, causing significant depression, trauma and anxiety. I, in particular am under constant stress of having to deal with the issues and readdress the very distressing details of our son's death. There has been a lack of parity of esteem with the Trust repeatedly being given time to complete tasks whilst we are expected to meet tight deadlines, despite ill-health, working full time and demanding family commitments. Trust staff have also been given full support including psychological support. We requested support to help us through the trauma of the investigations but received none.

Unreasonable refusal to investigate clinical issues

At the time of our son's death litigation was issued and stayed to protect the right to litigate in relation to the clinical negligence in the last weeks of my son's life. The PHSO took legal advice and confirmed this did not stop them investigating our son's clinical care. The delays by the PHSO in their investigation meant the Court time limit was about to expire so solicitors acting for my son's estate issued proceedings. The PHSO told us they would be

able to return to their investigation should the litigation not resolve our concerns. The decision by the PHSO to not continue the investigation seems disproportionate as the litigation only related to the last weeks of my son's life. The PHSO was investigating his clinical care from September 2013 to his death, a period of a year more than that covered by the litigation.

The Trust indicated their intention to defend the litigation. After careful consideration we decided it would be unreasonable to continue with the litigation. We wrote to the PHSO explaining why the litigation was not continuing as follows:

[Correspondence redacted for publication]

Despite the PHSO being legally permitted to investigate when it would not be reasonable for a family to pursue a legal remedy; this problem only arising because of long delays on the part of the PHSO; the litigation in question only being concerned with the last five months of the 18 months our son was in the hospital (the whole of which the PHSO was investigating); the PHSO telling me they would pick up the investigation into our son's clinical care should the litigation not resolve things to our satisfaction; and the PHSO investigation being close to completion, they are now refusing to look into issues related to our son's clinical care.

This is a particular concern as I am aware from other families with disabled children that the clinical care problems we faced and which we believe contributed to if not caused our son's premature death continue at the hospital. A report by the PHSO could impact these preventing future harm or deaths, in a way litigation for our son's avoidable death could not.

When I raised concerns directly with Mr Behrens about this matter, he did offer £1,000 in compensation for the delays, but this fails to address our concerns. It will not prevent on-going harm to and potential death of other disabled children at the hospital concerned.

Unlawful disregard for s.149 Equalities Act Public Sector Duty

In my letter to Mr Behren's I also raised my concern with the PHSO's complete failure to address the potential impact of disability discrimination on my son's treatment and death, despite this being repeatedly flagged up to them in conversations and documents as a central concern. I had also repeatedly expressed my concern that the PHSO had not sought an opinion from a paediatric neurologist.

Mr. Behren's reply shocked me. He wrote:

[Correspondence redacted for publication]

It is untrue to say we did not flag up the importance of disability discrimination. I mentioned it repeatedly in my conversations with PHSO officers, including in our meeting on 13 June. I spoke to them of my concern that my son's death resulted from diagnostic overshadowing and my concern that doctors responsible for his care repeatedly claimed his obvious serious and then critical illness was attributable to his disability.

This is referenced repeatedly throughout the detailed chronology provided to the PHSO. I put a lot of stress on the huge gap between the two consultant's prejudicial assumptions about my son's cognitive ability and his actual cognitive ability, including providing school reports and exam results, as well as my son's blog and educational films he had made for child rights

organisations to investigators to evidence this gap. I repeatedly expressly stated I believed my son had been denied access to PICU until too late (when he was admitted due to external pressure being put on the Trust) because of his assumed learning disabilities.

Moreover, the PHSO were expressly addressing the failings in the investigation commission by the Trust. The PHSO received that report with my comments on it. These comments made express reference of the failure to address the implications of the Equalities Act 2010 as well as the Human Rights Act 1998.

I did not question why disability discrimination was not mentioned in the scope, because I reasonably assumed this would be considered as a factor in every item on the scope, as it was intrinsic to every element of my son's care and the subsequent investigation. Disability discrimination is not a discrete added extra needing separate investigation, but permeated through everything, relating to my son's healthcare at the Trust, his death, and the subsequent investigations.

I note also that the PHSO's statutory Equality Duty paper on its website references addressing discrimination only in relation to their staff, not those using their service or who are deceased subjects of their investigations. Failure to recognise disability discrimination in plain sight, suggests serious failings in the PHSO's ability to comply with their legal duties under the Equalities Act and Human Rights Act and also that systemic disability discrimination exists within the PHSO's functioning.

Lack of diligence in investigation

At their request I provided the PHSO with volumes of evidence included detailed contemporaneous notes made through out my son's stay and my detailed comments on the Trust's 'independent' investigation.

Their draft report suggested despite taking over three years these documents had not been reviewed, at least not with any level of diligence. Indeed, when I spoke to the officer investigating after I received the draft report, she confirmed that she and her colleagues had not conducted a detailed review of the evidence I had provided.

Moreover, Mr Behren's claim in his letter to me that the PHSO officers were unaware that disability discrimination was an issue of concern is further evidence of the lack of due diligence in reviewing the documentation we provided. Had the documents provided been reviewed with anywhere near the level of diligence required, one in which the reasons for the death of a child are the subject of the investigation, the officers would have seen the multiple references to our concerns that disability discrimination in multiple forms was a central factor in our son's poor care, death and the subsequent inquiry. They would have also read the express references to the Equalities Act 2010 and Human Rights Act 1998 in the documents provided.

There was clear evidence through out the PHSO draft report that rather than checking facts they had simply accepted accounts given to them by the health professionals involved. There were many examples, but this paragraph from my comments on the PHSO draft report concerning an incident when a locum respiratory consultant prescribed our son a 10 times overdose for midazolam, illustrates one such example:

[Correspondence redacted for publication]

Copy of reply received:

[Correspondence redacted for publication]

In my and the experience of other parents of disabled children, rather than impartially investigating concerns concerning disabled children, with parity of esteem, investigations seem to be focused on justifying the actions of health professionals, however, unreasonable that behaviour is. A common concern is a failure by the PHSO to seek clinical advice from sub-specialists with the relevant expertise. In our and other cases a key concern, as mentioned earlier, was that the Trust did not (contrary to national guidance and common good practice elsewhere) allow sub-specialist with the relevant expertise to be involved in a child's care. In our son's case care was led by a respiratory and then an academic enuresis specialist, who repeatedly wrongly attributed our son's serious infection to his disability, leaving him without appropriate treatment and care. The PHSO repeats the failings of the Trusts as they insist on using the same type of sub-specialist as the Trust had used, rather than the type of sub-specialist parents with decades of experience caring for their child and even significant relevant professional expertise believe should have been leading their child's care. This seems to be a manifestation of the systemic disability discrimination found in poor parts of the NHS spreading to the PHSO office, echoing the findings of the MacPherson report (1999) about the police, that due to systemic discrimination and unconscious bias evidence from parents about their child's death were dismissed inappropriately and not taken seriously, missing the opportunity for a full and just investigation into the death of a child from a marginalised and vulnerable group within society.

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