LGB Alliance response to the Call for Evidence of the Health and Social Care Committee inquiry into NHS litigation reform
15 October 2021

LGB Alliance welcomes the opportunity to respond to the Committee's call for evidence on NHS litigation reform. If you have any questions regarding our response, please contact kate.harris@lgballiance.org.uk

LGB Alliance is a charity that represents the interests of a rapidly growing number of lesbian, gay and bisexual people. We represent thousands of LGB people who have grave concerns about the loss of our rights, specifically in relation to moves to replace, in law and elsewhere, the category of 'sex' with 'gender identity', 'gender expression' or 'sex characteristics'.

We are long-time gay and lesbian activists who fought for the rights of people with a same-sex sexual orientation. These hard-won rights are now under serious threat.

The context for our submission

One of our areas of interest is to protect children who may grow up to be lesbian, gay or bisexual. We work to protect children from harmful, unscientific ideologies that may lead them to believe either their personality or their body is in need of changing. Any child growing up to be lesbian, gay or bisexual has the right to be happy and confident about their sexuality and who they are.

In the course of this work, we have encountered issues that are of direct relevance to litigation in healthcare settings and, although they do not relate directly to most of the questions set out in the call for evidence, we hope the Committee finds this submission of interest.

Risks in specialist tertiary healthcare settings

There are a number of disturbing issues surrounding the treatment of children at the Gender and Identity Development Service (GIDS) at the Tavistock and Portman NHS Hospital Trust that are coming to light as a result of a recent Care Quality Commission (CQC) report[1].

GIDS is a small specialised tertiary unit treating children referred to them with gender dysphoria. The issue is that treatments administered to these children – many of whom later turn out to be lesbian or gay – may have significant adverse effects which do not become evident for a number of years. The treatment pathway for children under the care approach adopted by GIDS involved initially medicating with puberty blockers before (in the vast majority of cases) moving on to cross-sex hormones. There is growing evidence that puberty blockers carry with them raised risks of future bone density depletion and increased cancer risks related to cross-sex hormones. However, these effects do not become evident until many years after treatment. We believe that, unfortunately, we are already in the situation where we can expect that there will be a large number of medical negligence claims from detransitioners (disproportionately lesbians) who in later life no longer wish to transition, but having been given puberty-blockers and cross-sex hormones will find themselves suffering from serious long term health implications.

The recent CQC report found significant failings at the unit, awarding it an overall 'inadequate' rating. James Kirkup summarised the CQC findings in a Spectator piece[2] as follows: "The CQC

[1] See Care Quality Commission report Tavistock and Portman NHS Foundation Trust (cqc.org.uk).
[2] James Kirkup, The Spectator, 20 January 2021 Tavistock gender clinic whistleblowers have been vindicated | The Spectator

describes an NHS facility that — until last month — put vulnerable children on a pathway to the use of untested medicines and life-changing interventions, sometimes without keeping proper records proving consent for treatment or demonstrating the reasons for that treatment. An NHS service where staff were afraid to raise concerns about procedure and practice for fear of 'retribution' from their employers. An NHS service that failed to ask fundamental questions about the growing number of vulnerable children being presented for treatment."

Like many other specialist tertiary healthcare services, GIDS is a small specialised unit without peers for benchmarking against and it is delivering novel treatments without an established evidence base or protocol with potentially very long time lags before harms become clear. This has the potential to generate a large number of medical negligence claims in the distant future when it is too late to use lessons learnt to adjust treatments and prevent many further adverse outcomes.

While this evidence is specific to GIDS, we believe that there is a read across to other specialist tertiary care settings deploying novel treatments. There are certain parallels with historical medical scandals that have emerged in similar specialist or 'trailblazer' centres; for example:

- The Bristol Royal Infirmary[3] where babies died at high rates after cardiac surgery and an inquiry found numerous leadership and culture issues that led to concerns raised by staff not being addressed.
- The Gastroenterology unit at Great Ormond Street Hospital[4] where staff had concerns, but felt too scared to speak out about aggressive treatments leading to children being misdiagnosed and given unnecessary drugs with potentially serious side effects.

We believe this is revealing a gap in the current healthcare oversight and scrutiny framework when it comes to specialist tertiary care providers.

Options to address the issue and prevent setting up future negligence claims

The Committee asks for information on how to address NHS litigation issues. The issues we observe indicate that there is a need for a stronger mechanism that allows for early scrutiny and heightened responsiveness to whistleblowers in tertiary healthcare settings like GIDS, in order to avert a potential future wave of medical negligence claims. Waiting for a disproportionate number of medical negligence claims to be observed before action is taken does not work in these situations.

We have two suggestions:

1. An enhanced focus on 'lesson learning' through 'no blame' culture

Evidence from the Sonia Appleby case suggests that the culture prevailing at GIDS did not encourage challenges to the protocols being pursued and there was a general lack of responsiveness to any concerns that were raised or even desire to learn, given the poor record-keeping that has been revealed. Given the experimental nature of treatment and long lead times between treatment and emergence of serious adverse consequences, a setting like GIDS should have been operating in a culture even more 'open' than more 'standard' secondary healthcare settings, where benchmarking between units is possible. Specialist units need specific mechanisms in place to allow staff and

[3] Bristol heart scandal

[4] Seven year saga of Great Ormond Street department that over-treated some children — The Bureau of Investigative Journalism (en-GB) (thebureauinvestigates.com)

practitioners to raise questions about safety and appropriateness to allow treatment protocols to be adjusted rapidly even in the absence of medical negligence claims.

2. *An enhanced independent 'whistleblower' investigation unit*

An enhanced independent body that can investigate concerns raised by whistleblowers about issues in specialist units could address the concerns where there are no other equivalent units in the country to benchmark against. This body would need to take a very strong evidence-based approach and make sure protocols have been developed based on a rigorous scientific approach and not devised by maverick individual practitioners or unduly influenced by lobby groups with specific ideological aims. The new Healthcare Safety Investigation Branch could potentially act in this capacity.

3. *A more extensive role for the Healthcare Safety Investigation Branch in the oversight of specialist tertiary care units*

Alternatively, the new Healthcare Safety Investigation Branch could oversee small specialist units in tertiary care that do not have many (or any) similar units to benchmark or comparator which makes it harder to pick up issues early. Evidence from the recent past suggests that these units may be particularly vulnerable to falling under the influence of either a maverick leader creating an atmosphere that prevents concerns being raised, or a unit being unduly influenced by lobby groups and patient advocacy groups rather than adhering to good scientific practise and actively assessing all their outcomes through strong record keeping and analysis. Self scrutiny by all specialist units following and developing new protocols should be the norm but it is clear that at times this fails and any scrutiny is seen as an unwanted challenge rather than a mechanism to improve patient outcome. The Healthcare Safety Investigation Branch could step in here.