

Dr Hilary Cass Chair Independent review of gender identity services for children and young people

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Sent by email

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Dear John and James,

# INDEPENDENT REVIEW OF GENDER IDENTITY SERVICES FOR CHILDREN AND YOUNG PEOPLE – ADULT GENDER DYSPHORIA CLINICS

As set out in my final report, a number of clinicians who currently or who have previously worked in adult gender services approached me to express concern about both the clinical practice and model of care. Their experiences cover several Gender Dysphoria Clinics (GDCs) across the country. I have also heard concerns from clinicians in other settings, most specifically general practice, about patients under their care.

It was outside the Review's remit to attempt to validate the accounts I received, or to determine whether all the issues are still current. In addition, practice and standards may be markedly different between different clinics. However, there were common themes which I hope will be explored in the upcoming review of adult gender services that NHS England is planning to undertake.

### Patient cohort and assessment

The most common concern was the very limited time for assessment and the
expectation that patients would be put on hormones by their second visit. In most
instances, the individuals described a first appointment with a non-medical
practitioner who was not necessarily clinically trained, and usually a medical
practitioner seeing patients at the second visit.

- Clinicians who spoke to me felt that, in common with the population that is
  presenting to children and young people's services, the majority of patient
  presentations were extremely complex, with a mix of trauma, abuse, mental health
  diagnoses, past forensic history, ASD and ADHD, and therefore this limited
  assessment was inadequate. These other clinical issues were not addressed or taken
  into account in decisions to prescribe masculinising or feminising hormones.
- It was difficult for clinicians to defend a decision not to prescribe hormones except in exceptional cases; for example, patients who were sectioned or had multiple personalities. It was reported that if a patient was self-harming or had significantly unstable mental health, it was not viewed as a contraindication to treatment.
- One clinician told me they would be subject to complaints if they delayed putting
  patients on hormones and another told me their practice was monitored and if they
  offered a patient too many appointments this was 'clamped down on'. Because of
  this approach, further issues sometimes became apparent a few months after
  hormone treatment had been started.
- Both medical and non-medical practitioners in at least two clinics had raised concerns about the marked change in the case-mix, from predominantly older birthregistered males to predominantly birth-registered females in their early 20s with complex presentations. One person told me that during their time in the service they saw only a handful of the more 'traditional' cohort for these services (older birth registered males).

## Consent

- I was told that consent procedures were inadequate, with limited explanation of risks such as vaginal atrophy, osteoporosis, etc. The rapidity of the action of testosterone was not reliably explained, nor the irreversibility of some of the effects.
- Several described 'magical thinking' (i.e. unrealistic beliefs about what could be achieved through medical transition) which was not corrected or challenged.
   Sometimes this seemed to be related to watching social media videos, and not having the cognitive ability to appreciate the limitations of hormones and surgery. In some instances, this led to patients expressing dissatisfaction with their medical transition.

# **Clinical protocols**

- I was told that there are no national treatment guidelines regarding use of hormones, and access to endocrine advice was variable between clinics.
- I heard that the psychiatrist who provided second opinions for surgery for one of the clinics writes 'boilerplate' letters which do not reliably reflect the individual patient under consideration.

#### Administration

- Administrative processes were described as chaotic by several of the individuals who spoke to me, with waiting lists out of control, a lack of systematic processes for follow-up, and rapid discharge.
- I was told that some patients had extended periods without monitoring blood tests. Of those who were followed up, there was a high rate of fall out, and no system for prioritising re-referrals compared to primary referrals.

#### Adverse outcomes

- Clinicians informed me that suicides of patients on treatment were not formally discussed in Morbidity and Mortality meetings, with no clear strategy for determining whether there were lessons to be learnt for future cases.
- I heard that detransitioners tended to move between clinics, often not returning to their clinic of origin, and there was no system for informing the originating clinic about them. In one clinic regret was treated as a new episode of dysphoria.

# **Culture and safety**

- There was a perception from some that the approach was ideologically driven and polarised and it was difficult to question the approach or discuss concerns. Clinicians described a philosophy that it was up to patients to make their own mistakes.
- There was a view that clinical supervision and training was inadequate, and there
  were marked inconsistencies in clinical practice. They described nurses who had
  been in the clinic for many years having unmanageable workloads, with
  responsibility for many risky patients, and some left the service as a result.
- Medical practitioners who left the service described doing so because they were worried that they could not defend their clinical practice.

I hope this is helpful to NHS England as it embarks on the review of adult services.

Yours sincerely

**Dr Hilary Cass** 

Chair, Independent Review into Gender Identity Services for Children and Young People