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## Services for children with gender dysphoria need fundamental reform, says interim review

For the past 16 months the eminent paediatrician Hilary Cass has been investigating the care needs of children and teenagers who question their gender identity. **Clare Dyer** reports on her initial findings

Clare Dyer

A “fundamentally different” service model should replace the current system for assessing, caring for, and treating children and teenagers with gender identity problems, a review set up by NHS England has concluded.<sup>1</sup>

Its interim report recommends that regional hubs should replace the current sole service provider for England, the gender identity development service (GIDS) at the Tavistock and Portman NHS Trust in London, which has a waiting list of more than two years.

The review, chaired by Hilary Cass, a former president of the Royal College of Paediatrics and Child Health, calls for children and adolescents with gender incongruence or dysphoria to receive the “same standards of clinical care, assessment, and treatment as every other child or young person accessing health services.”

It highlights major gaps in research on outcomes of treatment for gender dysphoria and a lack of routine and consistent data collection, making it difficult to design an evidence based assessment and treatment model. The small studies that have been done were mainly on birth registered boys displaying gender incongruence from an early age, who used to be the main cohort seeking treatment.

But from about 2015 there has been a steep rise in the number of birth registered girls coming forward in their early teens, who now form the main cohort. Many of the young people referred to GIDS have other mental health conditions, a third have autism or other types of neurodiversity, and looked-after children (those in local authority homes or foster care) are over-represented.

The GIDS model requires it to decide whether young people with gender dysphoria should receive puberty blockers and, later, cross sex hormones and, if so, to refer them to paediatric endocrinologists to deliver the treatment. Some staff who have left GIDS accused it of being too ready to prescribe life changing physical treatments while leaving other aspects of the young people’s distress unexplored.

After concerns about informed consent, a multiprofessional review group set up by NHS England now reviews cases being referred by GIDS to endocrinologists to ensure that procedures are being properly followed. The Cass review recommends that this should continue in the immediate term.

The review has been hearing from—and intends to continue to hear from—people with lived experience, professionals, and advocacy groups. It says that “its outcomes are not being developed in isolation or by committee but rather through an ongoing dialogue aimed at building a shared understanding of the current situation and how it can and should be improved.”

In the longer term, it calls on service users, support groups, and professionals to collaborate with the review to reach an agreed way forward. To ensure that the new model is based on evidence, the review team has commissioned a literature review and a programme of qualitative and quantitative research and has called for standardised data collection on cases.

### Regional centres

The review advises that the regional centres be developed as soon as feasibly possible to assess and treat young people who might need specialist care as part of a wider pathway. Each would work with a range of local services to “ensure that appropriate clinical, psychological and social support is made available to children and young people who are in early stages of experiencing gender distress.” Regional training programmes should be run for clinical practitioners at all levels, it says.

The aim is to develop a formalised assessment process, including differential diagnosis. “The assessment should be able to accurately identify those children or young people for whom physical intervention is going to be the best course of action, but it is equally important that it identifies those who need an alternative pathway or treatment,” says the interim report. Paediatric endocrinologists would participate in the multidisciplinary team meeting that discusses the young people being considered for treatment.

The review cites the example of autism as a condition for which standardisation of the process over time, together with an improved evidence base, made diagnosis more reliable and consistent.

GIDS came under the spotlight in 2019 when Keira Bell, who regretted taking puberty blockers and male hormones as a teenager and detransitioned back to her original female gender, took a case to the High Court, along with the mother of a 15 year old girl with autism who was on the waiting list. The court ruled that it was “very doubtful” that children under 16 would be able to understand the immediate and long term consequences of the treatment and to give

informed consent, and it said doctors might want to consider court authorisation before giving over 16s the “experimental” treatment.<sup>2</sup>

That decision was later overturned by the Court of Appeal, which held that it was for doctors, not judges, to take such decisions.<sup>3</sup> David Bell, an adult psychiatrist who worked at the Tavistock for 24 years, applied to intervene in the appeal court case and told the court he had investigated the concerns of 10 clinicians who had worked or were working in GIDS. His report found “very serious ethical concerns as regards the modes of practice and the inadequacy of consent.”

#### Timeline of events

##### 2011

- As part of a study, GIDS offers puberty blockers, previously available from age 16, to a group of children aged 12-15. From 2014 this became routine clinical practice

##### 2020

- January—Policy working group is established by NHS England, chaired by Hilary Cass, to review the published evidence on use of puberty blockers and cross sex hormones, but available evidence is not strong enough to form the basis of a policy position
- Autumn—Cass review is set up by NHS England and NHS Improvement to make recommendations about services for children and teenagers who question their gender identity
- November—Care Quality Commission takes enforcement action after an inspection rating of GIDS overall as “inadequate,” highlighting overwhelming caseloads, deficient record keeping, and poor leadership
- December—High Court ruling in Keira Bell case questions under 16s’ ability to give informed consent to use of puberty blockers and suggests court approval may need to be sought

##### 2021

- March—High Court decides in a separate case that parents can consent on behalf of under-16s
- March—National Institute of Health and Care Excellence (NICE) reviews puberty blockers to treat children and adolescents struggling with their gender identity and concludes that the evidence for their use is “very low”
- September—Court of Appeal overturns Keira Bell judgment and rules that doctors, not judges, can decide whether a child under 16 can give informed consent to the use of puberty blockers

##### 2022

- March—Cass review publishes interim report

1 Cass H. Independent review into gender identity services for children and young people: interim report. 2022. <https://cass.independent-review.uk/publications/>

2 Dyer C. Puberty blockers: children under 16 should not be referred without court order, says NHS England. *BMJ* 2020;371:m4717. doi: 10.1136/bmj.m4717 pmid: 33268453

3 Dyer C. Doctors can decide if children are able to consent to puberty blockers, say judges. *BMJ* 2021;374:n2307. doi: 10.1136/bmj.n2307 pmid: 34544798