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Review of gender identity services for children and young people

Hilary Cass chairIndependent Review into Gender Identity Services for Children and Young People

Contemporary clinical practice presents us with day-to-day challenges which are a far cry from many of the didactic topics we covered at medical school. These include advising on treatment options when the underpinning evidence base is weak, complex issues of risk and safeguarding, ethical dilemmas about how to ensure best interests of vulnerable individuals, service safety in the face of workforce shortages, and polarised societal views on what the NHS can and should do. Clinicians working with children and young people with gender-related distress face every one of these dilemmas.

In 2019, I was asked by NHS England to chair a policy working group to review the published evidence on the use of hormone treatments in children and young people with gender dysphoria, and in 2020 to extend that remit to conduct an independent review into the broader clinical approach and service model for this group.¹

The context for the commissioning of this broader review was the weak evidence base underpinning the current practice of prescribing gonadotropin-releasing hormone analogues to pause puberty in children and young people with gender dysphoria, as well as the uncertainties about the subsequent prescription of cross-sex hormones.²³ The preceding decade had seen a dramatic increase in the numbers of referrals to the Gender Identity Development Service, at Tavistock and Portman (the only commissioned specialist service for this population in England), from around 50 in 2009 to over 2700 in 2019/20.45 This was accompanied by a change in the case-mix from predominantly birth registered males presenting with gender incongruence from an early age, to predominantly birth registered females presenting with teenage onset of reported gender-related distress.4 In addition, approximately one third of children and young people referred to GIDS had autism or other types of neurodiversity. The reasons for these changes were not adequately investigated or understood. These questions were being played out against the backdrop of the Bell vs Tavistock case, and polarised debates within society about the rights and protections of transgender adults.6

My interim report sets out my initial findings and advice. Here I set out my more specific reflections for clinical colleagues.⁷

Children and young people with gender dysphoria must receive the same standards of care as every other child or young person accessing NHS services

Primary and secondary care clinicians have reported to the Review that they are nervous about seeing children and young people with gender-related distress because of lack of evidence and guidance about appropriate management, and the toxicity of the societal debates.⁸

Some clinicians also reported feeling unable to undertake the process of assessment and differential diagnosis that would be the norm in their clinical practice because they perceived that there is an expectation of an unquestioning affirmative approach. They felt that this was at odds with a more open and holistic evaluation of the factors underpinning the young person's presentation, and consideration of the full range of possible support and treatment options.

As a result, a majority refer directly to GIDS, where the waiting list now exceeds 2 1/2 years. This means that these patients are not receiving the same level of care and support as other similarly distressed young people, despite being at high risk of mental health and safeguarding issues.

Support, training and guidance for clinical staff at all levels will be essential if this inequity is to be addressed.

Children, young people and their parents must have access to the best possible evidence to inform their care

Much of the existing research base is observational, and there is a lack of longer term follow-up data on outcomes for children and young people receiving hormone treatment. In addition, the focus on medical treatment has meant that the impact of non-medical interventions such as social transition and therapeutic support are ill understood.

At present the professional community does not have a shared understanding about the meaning of gender dysphoria in young people, and the extent to which it can be an inherent and immutable phenomenon, or a more fluid and temporal response to a range of developmental, social, and psychological factors. In the absence of more open discussion about this fundamental question, the research that is available will continue to be interpreted from varying ideological standpoints.

The Review has commissioned a broad qualitative and quantitative research programme to try and address some of the gaps in the evidence base, and its success will be dependent on widespread engagement from all interested parties.

The care of children and young people with gender dysphoria is everyone's business

I have provided advice to NHS England on how services and access might be improved, recognising that a single specialist provider is not a sustainable long term option for care of this complex group of children and young people. I have also made recommendations about how care can be made safer

pending the fuller findings of the Review and its research programme.

However, with the best will in the world, the commissioner cannot effect change without strong support from clinical staff at all levels in the NHS. It is particularly important that Medical Royal Colleges and other professional organisations support their members to engage in meaningful and respectful debate about the underlying issues, to work with the Review team to develop consensus solutions to some of the thornier questions about assessment and treatment, and to take on the care of this important and under-served group of children and young people.

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