

Guest Editorial

Gender identity services for children and young people: navigating uncertainty through communication, collaboration and care

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Summary

This editorial describes the Cass Review findings and the extraordinary challenge we all face in managing uncertainty amid a toxic and highly polarised debate. Children and young people will only get the best care if patients and professionals join forces to seek answers collaboratively and respectfully.

Keywords

Gender identity; uncertainty; puberty; consent; ethics.

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*'Medicine's ground state is uncertainty. And wisdom – for both the patients and doctors – is defined by how one copes with it.'*¹

In April 2024 I published the final report of my 4-year independent review (Review) of gender identity services for children and young people.² It is a report about uncertainty, complexity and the need to listen, to learn and above all to discuss and collaborate.

Multiple different truths exist within this space, and views are often more aggressively voiced than in any other area of clinical care, such that many people are afraid to express an opinion; this is a dangerous situation for both doctors and patients. Indeed, in my 40 years of medical practice it proved to be the first time that it was not even possible to get individuals with the most polarised views into a room together.

In this editorial I discuss some of the most difficult dilemmas I encountered, which underpin the profound disagreements and emotional responses to this topic. However, as stated in the final report, while open and constructive debate is needed about the findings of the Review and its recommendations, everybody should remember the children and young people trying to live their lives and the families/carers and clinicians doing their best to support them. *All* should be treated with compassion and respect.

The review's approach

The bedrock of the Review was a series of seven systematic reviews commissioned from the University of York, as well as a survey of international practice and a qualitative study examining the range of experiences and outcomes of patients, and the perspectives of parents/carers and clinicians.

The systematic reviews are the largest and most comprehensive to date. The use of a single search strategy across all the reviews was more inclusive than any previous systematic reviews, capturing 237 papers from 18 countries, and providing information on a total of 113 269 children and adolescents.

In this area where views are polarised and uncertainty abounds, it was crucial that there was access to expert experience and opinion to contextualise the emerging evidence. Therefore, in addition to the commissioned work from the University of York, a mixed-methods engagement approach was taken that prioritised two categories of stakeholders: first, people with relevant lived experience (direct or as a parent/carer) and organisations working with LGBTQ+ children and young people generally. Second, clinicians and other

relevant professionals with responsibility for providing care and support to children and young people.

Overall, those conducting the Review met with over 1000 individuals, some in one-to-one meetings, some in bespoke meetings on a particular topic and others in meetings focused on building awareness and improving understanding of the issues among interested parties and organisations.

Dilemma 1: understanding the population

The population of young people presenting to gender services in recent years is markedly different from those who presented 10–15 years ago. At that time, the service offered a therapeutic model of care, and most patients were pre-pubertal birth-registered males presenting with gender incongruence from early childhood. A minority had persisting gender incongruence and were offered masculinising or feminising hormones from age 16, while the majority grew up to be same-sex attracted cis adults.

From about 10 years ago, there was a dramatic rise in the numbers presenting to the Gender Identity Development Service (GIDS) at Tavistock & Portman National Health Service (NHS) Trust, which was the only specialist service for patients in England, Wales and Northern Ireland. Referrals increased from less than 50 per annum before 2009 to around 2500 by 2019. The case mix also changed to largely birth-registered females presenting in early teenage years, with additional complex problems including a history of trauma or adverse childhood experiences, depression, anxiety, neurodiversity and a range of psychosocial issues.

Based on the evidence and on discussion with clinicians and academics, the Review took the view that this is a heterogeneous population of young people, and that a complex mix of biopsychosocial factors, unique to each individual, was responsible for their gender incongruence or distress. Some would continue to have a stable trans identity into adulthood and would benefit from medical transition. For others, the gender-related distress might be a transient phenomenon during a dynamic period of personal and psychosexual development and might resolve in late teens or young adulthood. The conclusion of this analysis was that there could *not* be a 'one size fits all' approach, and that each individual would need a holistic assessment and a personalised care plan.

This conceptualisation of the population is one of the first areas of disagreement from which much of the polarisation arises. A 2015 study³ approached 17 multi-professional treatment teams worldwide to determine their views on the use of early intervention

with puberty blockers. They identified seven themes on which there were widely disparate views, with two being fundamental to attitudes to treatment: ‘the (non-) availability of an explanatory model for gender dysphoria’ and ‘the nature of gender dysphoria (normal variation, social construct or [mental] illness)’.

During the course of the Review, we observed a change in attitudes, from an initial narrative among many trans advocates that only a minority of the young people presenting would have a long-standing trans identity and would benefit from a medical pathway to a belief in some quarters that all the young people on the waiting list for services were ‘trans kids’.

The Review spoke to young people and adults who had long-standing gender incongruence and had gone through a successful medical transition, with positive experiences of the treatment pathway. The team also spoke to individuals who had gone through a period of trans identification that had completely resolved in late teens and/or early adulthood. Neither of these experiences should invalidate the other.

The challenge lies in the lack of a reliable way of predicting the trajectory of any one individual and hence the right approach to treatment.

Dilemma 2: role of puberty in psychosexual and identity development

That puberty and adolescence are times of rapid change, development and emotional challenge is beyond dispute. During this period body image becomes a major preoccupation and can have either positive or negative impacts on mental health. Young people start to explore their sexuality and to understand their sexual orientation. Peers have an increasing influence and parents a lessening influence.

The practice of pausing puberty at Tanner stage 2 was initiated in the Netherlands, and subsequently adopted in the UK and internationally. The idea was based on a theory from Dr Peggy Cohen-Kettenis, whose initial clinical experience was in adult care. Her rationale was that pausing puberty early would help young people to ‘pass’ better in adulthood and ‘extend the diagnostic period’ by buying time to think. The use of puberty blockers for this purpose was initially reported in a single case study and then in the original Dutch cohort,⁴ which had tightly defined inclusion criteria: patients had to be a minimum age of 12, have gender dysphoria from childhood, increasing around puberty, be psychologically stable without serious comorbid psychiatric disorders that might interfere with the diagnostic process and have family support. The Dutch group found some modest improvements in mental health in a pre–post study without a comparison group, but no impact on gender dysphoria or body satisfaction.

In 2011, the GIDS early intervention study was launched in the UK in an attempt to replicate the findings of the Dutch team. This was an uncontrolled prospective observational study of the use of puberty blockers. Preliminary results from the early intervention study in 2015–2016 did not demonstrate benefit. Some 98% of the cohort went on to masculinising or feminising hormones. The results of the study showed a lack of any positive measurable outcomes but were not released until the day after the Bell versus Tavistock judgment in December 2020, and were eventually published in 2021.⁵

Despite this, from 2014, puberty blockers moved from a research-only protocol to being available in routine clinical practice and were given to a broader group of patients with later onset of gender-related distress who would not have met the inclusion criteria of the original protocol. An audit carried out for the Review looked at records of patients who had been discharged from GIDS between 1 April 2018 and 31 December 2022 and found that over

half of the young people prescribed puberty blockers started this medication between 15 and 16 years old, raising questions about the treatment goals at this late stage of puberty.²

The University of York systematic review⁶ found no evidence that puberty blockers improve body image or dysphoria, and very limited evidence for positive mental health outcomes, which without a control group could be caused by the placebo effect or concomitant psychological support. Indeed, given that hormonal surges are a normal part of puberty and are known to lead to mood fluctuations and depression, it is not unexpected that blocking these surges may dampen distress and improve psychological functioning in the short term for some young people.

The adoption of a treatment with uncertain benefits without further scrutiny is a significant departure from established practice. This, in combination with the long delay in publication of the results of the early intervention study, has had significant consequences in terms of patient expectations of intended benefits and demand for treatment.

This leaves many unanswered questions, including whether puberty blockers may be beneficial for a subgroup of young people, and if so which ones, as well as whether there might be negative outcomes for other young people.

A recent study found that gender non-contentedness (i.e. unhappiness with being the gender aligned with one’s sex) was highest in early adolescence and continued to drop into the mid-20s.⁷ This is consistent with accounts shared with the Review by people with lived experience whose gender-related distress resolved in late teens or early adulthood. If pubertal changes are essential to both psychosexual development and resolution of gender-related distress in *some individuals*, does treatment with puberty blockers change the trajectory for that group? Unfortunately, because we have intervened with the later-presenting group by using a treatment that was intended for those presenting in early childhood, and in the absence of an evidence base, we do not know what their natural history would be, nor the appropriate treatment response.

In light of all these uncertainties, the Review recommended that a puberty blocker trial should be established as part of a wider programme of research, and NHS England and the National Institute for Health and Care Research (NIHR) have already initiated this process.

Dilemma 3: weakness of the evidence base informing treatment decisions

The weakness of the evidence base was not limited to treatment with puberty blockers. Across the suite of systematic reviews, the evidence base underpinning both medical and non-medical interventions was remarkably weak compared to other areas of paediatric practice. This was particularly striking in the context of prescription of life-changing medications. The majority of studies had problems such as inadequate follow-up periods, high attrition rates, inappropriate or unclear comparison groups and confounding interventions, limiting the conclusions that could be drawn. The full systematic review series is available here: <https://adc.bmj.com/pages/gender-identity-service-series>.

The Review discussed the high-profile legal cases that have considered the question of whether young people have the capacity or competence to consent to medical treatment for gender dysphoria. However, capacity or competence is only one part of the process underpinning informed consent. Clinicians are responsible for the prescriptions they sign, so before offering a treatment they must make an adequate assessment to determine whether the drug serves the patient’s needs; this is made more difficult in this area because we do not have good predictive tools to determine which

young people will benefit from medical intervention, and which might not. The clinician should also ensure that the patient is fully informed about the risks and benefits of the intervention and, again, the weak evidence base makes it difficult to provide the patient with reliable information.

One of the most challenging difficulties in discussing options with young people is the lack of information about the longer-term outcomes of different treatments. Because this information is not available for interventions in this group of children and young people, a strand of research commissioned by the Review was a data linkage study. The aim of this study was to fill some of the gaps in follow-up data for the approximately 9000 young people who have been through GIDS. The study received full ethical approval, as well as patient and public involvement support, but unfortunately the refusal of the adult gender services to cooperate meant that the research was not possible.

Moving forward in the face of uncertainty

The Review made 32 recommendations about how best to provide services for this group of children and young people. Most of the recommendations were focused on bringing care back in line with the usual standards and processes that are fundamental to good clinical practice.

Core to the recommended approach is the development of a networked group of regional hubs in tertiary paediatric centres, working in close collaboration with local mental health and paediatric teams. By working in a partnership model with a strong focus on education, clinical improvement and research, the goal will be to provide a holistic model of care as close to home as possible, while upskilling the workforce and addressing some of the unresolved research questions set out above.

The healthcare system inadvertently exceptionalised this group of children and young people, placing them on a waiting list for a single specialist service that was not equipped to deal with the full range of their difficulties. This has come about in no small part because clinicians have been disempowered. Many are afraid to conduct the assessments that they would undertake for any other young person, to diagnose other relevant conditions such as neurodiversity and to offer the evidence-based treatments that could help them with their anxiety, depression, trauma or other psychosocial stressors.

If we are to do better for children and young people with gender-related distress, there must be an end to hostile and aggressive discourse, a coming together of professional organisations and the humility to acknowledge the limits of the science and that no one has all the answers. We must also recognise that this is a group of young people who share all the same aspirations, joys, emotional growing pains, triumphs and traumas as every other adolescent, and respond accordingly.

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Declaration of interest

H.C. is chair and author of the *Independent Review of Gender Identity Services for Children and Young People: Final Report*.²

References

- 1 Gawande A. *Complications: A Surgeon's Notes on an Imperfect Science*. Metropolitan Books/Henry Holt & Company, 2022.
- 2 Cass H. *Independent Review of Gender Identity Services for Children and Young People: Final Report*. Cass Review, 2024 (<https://cass.independent-review.uk/home/publications/final-report/>).
- 3 Vrouenraets LJJ, Fredriks AM, Hannema SE, Cohen-Kettenis PT, de Vries MC. Early medical treatment of children and adolescents with gender dysphoria: an empirical ethical study. *J Adolesc Health* 2015; **57**(4): 367–73.
- 4 de Vries ALC, Steensma TD, Doreleijers TAH, Cohen-Kettenis PT. Puberty suppression in adolescents with gender identity disorder: a prospective follow-up study. *J Sex Med* 2011; **8**(8): 2276–83.
- 5 Carmichael P, Butler G, Masic U, Cole TJ, de Stavola BL, Davidson S, et al. Short-term outcomes of pubertal suppression in a selected cohort of 12- to 15-year-old young people with persistent gender dysphoria in the UK. *PLoS One* 2021; **16**(2): e0243894.
- 6 Taylor J, Mitchell A, Hall R, et al. Heathcote C, Langton T, Fraser L, et al. Interventions to suppress puberty in adolescents experiencing gender dysphoria or incongruence: a systematic review. *Arch Dis Childhood* [Epub ahead of print] 9 Apr 2024. Available from: <https://doi.org/10.1136/archdischild-2023-326669>.
- 7 Rawee P, Rosmalen JGM, Kalverdijk L, Burke SM. Development of gender non-contentedness during adolescence and early adulthood. *Arch Sex Behav* 2024 **53**(5): 1813–25.