Dr Hilary Cass
Chair
Review of GIDS for Children and Young People

John Stewart
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Sent by email

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Dear John

INDEPENDENT REVIEW INTO GENDER IDENTITY SERVICES FOR CHILDREN AND YOUNG PEOPLE

I am writing to update you on my current approach to the work of the independent review into gender identity services for children and young people. However, the most pressing issue is how we augment the immediate support for children and young people currently needing assessment and treatment, some of whom have already been waiting for an extended period for an appointment. I will therefore also make some suggestions about interim arrangements and ways in which the review team could help to support and strengthen these.

Commissioned research programme

As you know, a key principle of the review is that it should be evidence-based, and that final conclusions will be developed through a consensus development process contingent on the synthesised evidence.

I am pleased to see that the National Institute for Health and Care Excellence (NICE) evidence reviews of gonadotrophin releasing hormone analogues and gender affirming hormones for children and adolescents with gender dysphoria have now been published. Although this is a helpful starting point, despite following a standard and robust process the NICE review findings are not conclusive enough to inform policy decisions. As part of my review, I am therefore exploring other methodologies to give increased confidence and clarity about the optimal treatment approaches.

My team is commissioning a broader literature review of the existing evidence base on the epidemiology, management and outcomes of children with gender dysphoria. We are also commissioning qualitative and quantitative research, including considering other approaches which might be employed to understand the intermediate and longer-term outcomes of children with gender dysphoria. We intend to include a review of international models and data in this programme of work.

Addressing the immediate situation

Recognising that the outcome of the review is going to take some time, I have been reflecting on the recent court rulings on puberty blockers and consent and the Care Quality Commission (CQC) report on the Gender Identity Development Service (GIDS) run by the Tavistock and Portman NHS Foundation Trust. These significant developments have changed the context in which the review is taking place, and further added to the service pressures.

I note the proposal to establish an independent multidisciplinary professional review group to confirm decision-making has followed a robust process, which seems an appropriate interim measure pending further clarification of the legal situation.

I know that everyone concerned with the delivery of services – both commissioners and providers – are worried about the increasing number of children on the waiting list for assessment by the GIDS service and the resulting distress for the children and young people and their families. The difficulty in managing risk for those on the waiting list is exacerbated by the staff vacancies at GIDS, the increasing volume of new referrals, and the fact that the support and engagement from local services is highly variable and, in some cases, very limited.

Having a single provider may have been a logical position when the GIDS service was first set up, given that this is a highly specialised service that was seeing a relatively small number of cases each year. As the epidemiology has changed and there has been an exponential increase in numbers of children with gender incongruence or dysphoria, concentration of expertise within a single service has become unsustainable. At the same time, local services have not developed the skills and competencies to provide support for children on the waiting list and those with lesser degrees of gender incongruence who may not wish to pursue specialist medical intervention, and / or to provide help for children with additional complex needs.

I know from discussions we have had that your team is working hard to find some practical alternative arrangements, and that you have been in discussion with relevant professional bodies to come up with creative interim solutions while awaiting the outcome of my review.

The review team has also been in discussion with CQC, with the Tavistock and Portman NHS Foundation Trust and with colleagues within and external to NHS England and NHS Improvement to consider which aspects of this situation we can help with in the short to medium term, whilst keeping our focus on the longer-term questions of the appropriate clinical management and whole care pathway for these children and young people. In the past months I have also met with many groups and individuals with expertise and lived experience relevant to the review, including charities and support groups, Royal Colleges and healthcare professionals.

Recommendations to NHS England and NHS Improvement

I would encourage you to consider the following when developing an interim pathway for children and young people experiencing gender dysphoria:

- **Access and referral:** Children and young people need ready access to services. However, it is unusual for a specialist service to take direct referrals. The risk of having a national service as the first point of access is that assessment and treatment of children and young people who have the greatest need for specialist care is delayed because of the lack of differentiation of those on the waiting list. In addition, many children and

young people have complex needs, but once they are identified as having gender dysphoria, other important healthcare issues which would normally be managed by local services can sometimes be overlooked.

- **Assessment and management:** All children and young people who are referred to specialist services should have a competent local multi-disciplinary assessment and should remain under active holistic local management until they are seen at a specialist centre.

  I recognise that developing capacity and capability outside of the existing GIDS service to provide such initial assessment and support will be difficult to achieve at speed and will be incremental. This means that there will likely be a range of different models and options around the country, dependent on local resources, with some of the work being delivered through existing secondary service teams, and some being delivered at regional level. The support of wider services is vital.

- **Data:** The lack of systematic data collection is a significant issue. Therefore, when employing interim measures, I would suggest that particular attention is paid to the gathering of good quality data, which can then be used to inform the evidence base and future model of provision.

Actions for the review team

I would like to suggest how the review team might help with the challenging problem of growing an infrastructure outside of GIDS. From my conversations to date, I believe there are three barriers to the involvement of local services:

- **Capacity** – the staff most appropriately trained to be involved in initial assessment are those who are already most stretched within Child and Adolescent Mental Health Services (CAMHS) and paediatric services, and this situation has been significantly worsened through the impact of the Covid-19 pandemic on children's mental health. However, I know that there is substantial investment in CAMHS services, so close engagement with the relevant national policy teams at NHS England and NHS Improvement and at Health Education England (HEE) will be crucial.

- **Capability and confidence** – clinical teams outside of GIDS do not feel confident in initial assessment and support of children and young people with gender incongruence and dysphoria, in large part because they have not had the necessary training and experience, but also because of the societal polarisation and tensions surrounding the management of this group.

- **Lack of an explicit assessment framework** – currently expertise in assessment of children and young people presenting to GIDS is held in a small body of clinicians and their assessment processes have not been made explicit. The CQC report drew attention to the lack of structured assessment in the GIDS notes, and this is something that the Tavistock and Portman NHS Foundation Trust is already working to address internally. However, it is equally important to develop an initial assessment approach that can be used by first contact professionals, not just those working in the specialist service.

In the first instance, it is important that we test these assumptions with a range of clinical staff and ascertain whether there are other barriers that are preventing local engagement in this work. Then we would plan to prioritise a series of workshops, in collaboration with relevant professional groups, service users and close engagement with HEE. The purpose of these workshops would be to address identified barriers and develop:

- A framework for initial assessment of children and young people presenting with gender dysphoria.

- An approach to training for professionals at local and regional level.

- Some preliminary workforce recommendations, which will be particularly important in meeting the timelines of the three-year Comprehensive Spending Review.

These workshops will serve multiple purposes – firstly to support NHS England and NHS Improvement in the establishment of local and / or regional teams; secondly as an essential component of the work needed to inform the questions that the review is tackling; and thirdly to form the professional networks that will be needed to underpin future service and research networks.

Timelines

As you will recognise, setting up a complex national review is difficult and time consuming at the best of times. It requires a team to support the work and mechanisms for stakeholders to engage safely and with confidence. Starting a review in the midst of a pandemic is even more challenging.

I have committed to a review approach which is participative, consensus-based, evidence-based, transparent, and informed by lived and professional experience. This requires extensive engagement. Pending the appointment of our research team, the review has now launched its website and I have been proactively engaging with the stakeholder community.

It is critical that we get the approach right, particularly the engagement, the evidence review and the quantitative research given the gaps in the evidence highlighted through the NICE review, and this will take time.

My intention is that an interim report will be delivered in the summer, with a report next year setting out my final recommendations.

Yours sincerely

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

Cc: Care Quality Commission
Health Education England
Tavistock and Portman NHS Foundation Trust