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## Translator's Notes

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<sup>i</sup> [Translator's note: Healthcare in Sweden is decentralized – responsibility lies with the regional councils and, in some cases, local councils or municipal governments. The role of the central government is to establish principles and guidelines, and to set the policy agenda for health and medical care. The National Board of Health and Welfare (Socialstyrelsen) is a government agency under the Ministry of Health and Social Affairs that compiles information and develops standards to ensure good health, social welfare and high-quality health and social care for the whole population. The care is delivered through 21 county councils / regions  
<https://sweden.se/life/society/healthcare-in-sweden>]

<sup>ii</sup> [Translator's note: The Swedish term “god vård” is literally translated as “good care.” This term came into existence in connection with the publication of the National Board of Health and Welfare's regulations on the management system for quality and patient safety (SOSFS 2005:12). Six areas are highlighted as important prerequisites for “good care” including: appropriate healthcare based on the best available knowledge, safe healthcare, patient-focused healthcare, effective healthcare, equitable healthcare, and timely delivery of healthcare.  
<https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2009-11-5.pdf> .

<sup>iii</sup> [Translator's note: Appendix 1-3, attached to the Swedish original report, are not included in this translation. They include:

1. Projektorganisation, a list of authors ("organization of the project").
2. Termer och förkortningar, a glossary of terms
3. Förtydliganden av juridiska förutsättningar, “clarifications of legal conditions”]

<sup>iv</sup> [Translator's note: The “knowledge base with methods description” is available at the following link:

<https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2022-12-8302-kunskapsunderlag-med-metodbeskrivning.pdf> ].

<sup>v</sup> [Translator's note: These reports can be found at the following links:

<https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-1-6579.pdf>

<https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2020-1-6580.pdf> ].

<sup>vi</sup> [Translator's note: The appendix has not been translated.]

<sup>vii</sup> [Translator's note: The separate appendix, *Knowledge base with methods description*, has not been translated. It is available in Swedish at the following link:

<https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/kunskapsstod/2022-12-8302-kunskapsunderlag-med-metodbeskrivning.pdf>]

<sup>viii</sup> [Translator’s note: Healthcare in Sweden is decentralized – responsibility lies with the regional councils and, in some cases, local councils or municipal governments. The role of the central government is to establish principles and guidelines, and to set the policy agenda for health and medical care. The National Board of Health and Welfare (Socialstyrelsen) is a government agency under the Ministry of Health and Social Affairs that compiles information and develops standards to ensure good health, social welfare and high-quality health and social care for the whole population. The care is delivered through 21 county councils / regions  
<https://sweden.se/life/society/healthcare-in-sweden>]

<sup>ix</sup> [Translator’s note: The appendix has not been translated.]

<sup>x</sup> [Translator’s note: The guidelines are referring to the difficulty of adjusting their current diagnostic process to the upcoming ICD-11 codes. The Swedish healthcare system has traditionally relied on the “unspecified” ICD-10 code of F64.9 as the provisional gender dysphoria code, pending the evaluation. The goal of the evaluation is to establish whether the person suffers from true gender dysphoria or whether other reasons better explain the experience of gender identity not matching the recorded sex. Patients who are confirmed as having true gender dysphoria (not secondary to other causes) are then assigned either a “binary” diagnostic ICD-10 code of F64.0, or a non-binary diagnostic code ICD-10 code F64.8. The report is pointing out that under the ICD-11 system, the “unspecified” code of HA6Z can no longer serve this provision purpose, complicating coding during assessment process. <https://www.socialstyrelsen.se/om-socialstyrelsen/pressrum/press/vanligt-med-flera-psykiatriska-diagnoser-hos-personer-med-konsdysfori/> ]

<sup>xi</sup> [Translator’s note: The concept of “child’s integrity” involves physical health and mental health integrity. [https://commission.europa.eu/aid-development-cooperation-fundamental-rights/your-rights-eu/know-your-rights/dignity/right-integrity-person\\_en#:~:text=Everyone%20has%20the%20right%20to,procedures%20laid%20down%20by%20law](https://commission.europa.eu/aid-development-cooperation-fundamental-rights/your-rights-eu/know-your-rights/dignity/right-integrity-person_en#:~:text=Everyone%20has%20the%20right%20to,procedures%20laid%20down%20by%20law)]

<sup>xii</sup> [Translator’s note: See <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/meddelandebld/2020-12-7117.pdf> ]

<sup>xiii</sup> [Translator’s note: Highly specialized care is defined as care often requiring the most advanced technical equipment. In Sweden, such care is concentrated in university hospitals to ensure high quality and greater efficiency, and to enable research and development.  
<https://www.commonwealthfund.org/international-health-policy-center/countries/sweden>]

<sup>xiv</sup> [Translator’s note: The Swedish term, “gott bemötande” is literally translated as “good treatment.” This concept has a specific meaning in the Swedish healthcare system, the fundamental aspect of which is showing respect and interest in the person's situation. ‘Good treatment’ means showing personal care, acting on the basis of knowledge and experience, respecting the individual's autonomy and integrity and adopting a professional and humane approach. The goal of “good treatment” is to create trust and security in the provider-patient relationship. <https://www.vardochinsats.se/missbruk-och-beroende/kommunikation-och-delaktighet/gott-bemoetande/> ]

<sup>xv</sup> [Translator’s note: “Distorted patient histories” refers to the phenomenon of patients altering their medical history in order to qualify for the treatment.]



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<sup>xvi</sup> [Translator’s note: There appears to be an error in reference in the Swedish original, incorrectly referring to this report as "I am not alone, there are more like me." The actual name of the report says "I am not alone, there are others like me.”]

<sup>xvii</sup> [Translator’s note: This reference is to the Swedish Health and Medical Care Act [https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag\\_sfs-2017-30#K2](https://www.riksdagen.se/sv/dokument-lagar/dokument/svensk-forfattningssamling/halso--och-sjukvardslag_sfs-2017-30#K2)]

<sup>xviii</sup> [Translator’s note: the literal translation of the term used in the Swedish original is “logopedics,” which refers to the speech therapy <https://www.merriam-webster.com/medical/logopedics> ]

<sup>xix</sup> [Translator’s note: “HSL” is the Health and Medical Care Act. “PSL” is the Patient Safety Act. “PL” is the Patient Act <https://www.vardhandboken.se/arbetssatt-och-ansvar/ansvar-och-regelverk/patientens-rattsliga-stallning/lagstiftning/>]

<sup>xx</sup> [Translator’s note: “HSL” is the Health and Medical Care Act.]

<sup>xxi</sup> [Translator’s note: “PSL” is the Patient Safety Act.]

# The Cass Review

**Independent review  
of gender identity  
services for children  
and young people:  
Interim report**

**February 2022**







# **Independent review of gender identity services for children and young people: Interim report**

February 2022



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# About this report

This interim report represents the work of the independent review of gender identity services for children and young people to date. It reflects a point in time. It does not set out final recommendations; these will be developed over the coming months, informed by our formal research programme.

This Review is forward looking. Its role is to consider how to improve and develop the future clinical approach and service model. However, in order to do this, it is first necessary to understand the current landscape and the reasons why change is needed, so that any future model addresses existing challenges, whilst retaining those features that service users and the professionals supporting them most value.

This report is primarily for the commissioners and providers of services for children and young people needing support around their gender. However, because of the wide interest in this topic, we have included some explanations about how clinical service development routinely takes place in the NHS, which sets the context for some of our interim advice.

The care of this group of children and young people is everyone's business. We therefore encourage the wider clinical community to take note of our work and consider their own roles in providing the best holistic support to this population.

Since the Review began, it has focused on hearing a wide range of perspectives to better understand the challenges within the current system and aspirations for how these could be addressed. This report does not contain all that we have heard during our listening sessions but summarises consistent themes. These conversations will continue throughout the course of the Review and there will be further opportunities for stakeholders to engage and contribute.

It is important to note that the references cited in this report do not constitute a comprehensive literature review and are included only to clarify why specific lines of enquiry are being pursued, and where there are unanswered questions that will be addressed more fully during the life of the Review. A formal literature review is one strand of the Review's commissioned work, and this will be reported in full when complete.



## Independent review of gender identity services for children and young people

### A note about language

There is sometimes no consensus on the best language to use relating to this subject. The language surrounding this area has also changed rapidly and young people have developed varied ways of describing their experiences using different terms and constructs that are relevant to them.

The Review tries as far as possible to use language and terms that are respectful and acknowledge diversity, but that also accurately illustrate the complexity of what we are trying to describe and articulate.

The terms we have used may not always feel right to some; nevertheless, it is important to emphasise that the language used is not an indication of a position being taken by the Review. A glossary of terms is included.

The Review is cognisant of the broader cultural and societal debates relating to the rights of transgender adults. It is not the role of the Review to take any position on the beliefs that underpin these debates. Rather, this Review is strictly focused on the clinical services provided to children and young people who seek help from the NHS to resolve their gender-related distress.

# A letter to children and young people

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**Children and young people accessing the NHS deserve safe, timely and supportive services, and clinical staff with the training and expertise to meet their healthcare needs.**



**Dr Hilary Cass**

I understand that as you read this letter some of you may be anxious because you are waiting to access support from the NHS around your gender identity. Maybe you have tried to get help from your local services, or from the Gender Identity Development Service (GIDS), and because of the long waiting lists they have not yet been able to see you. I hope that some of you have had help – maybe from a supportive GP, a local Child and Adolescent Mental Health Service (CAMHS), or from GIDS.

I have heard that young service users are particularly worried that I will suggest that services should be reduced or stopped. I want to assure you that this is absolutely not the case – the reverse is true. I think that more services are needed for you, closer to where you live. The GIDS staff are working incredibly hard and doing their very best to see you as quickly as possible but providing supportive care is not something that can be rushed – each young person needs enough time and space for their personal needs to be met. So, with the best will in the world, one service is not going to be able to respond to the growing demand in a timely way.

I am advising that more services are made available to support you. But I must be honest; this is not something that can happen overnight, and I can't come up with a solution that will fix the problems immediately. However, we do need to start now.

The other topic that I know is worrying some of you is whether I will suggest that hormone treatments should be stopped. On this issue, I have to share my thoughts as a doctor. We know quite a bit about hormone treatments, but there is still a lot we don't know about the long-term effects.

## Independent review of gender identity services for children and young people

Whenever doctors prescribe a treatment, they want to be as certain as possible that the benefits will outweigh any adverse effects so that when you are older you don't end up saying 'Why did no-one tell me that that might happen?' This includes understanding both the risks and benefits of having treatment and not having treatment.

Therefore, what we will be doing over the next few months is trying to make sense of all the information that is available, as well as seeing if we can plug any of the gaps in the research. I am currently emphasising the importance of making decisions about prescribing as safe as possible. This means making sure you have all the information you need – about what we do know and what we don't know.

Finally, some of you may want the chance to talk to me and share your thoughts about how services should look in the future. Over the coming months we will need your help and there will be opportunities to get involved with the Review, so please keep an eye on our website ([www.cass.independent-review.uk](http://www.cass.independent-review.uk)), where we will provide updates on our work.

A handwritten signature in black ink that reads "Hilary". The signature is written in a cursive style with a large, looped 'y' at the end.

**Dr Hilary Cass, OBE**



# Introduction from the Chair

Anyone with an interest in the care of gender-questioning children and young people, as well as those with lived experience, may have wondered what qualifies me to take on this Review, and whether I have a pre-existing position on this subject.

I am a paediatrician who was in clinical practice until 2018, my area of specialism being children and young people with disability. I have also held many management and policy roles throughout my career, most notably as President of the Royal College of Paediatrics and Child Health (RCPCH) from 2012-15.

Children's services are often at a disadvantage in healthcare because health services are usually designed around the needs of adults. As President of RCPCH, a key part of my role was to advocate for services to be planned with children and families at their heart.

I have not worked in gender services during my career, but my strong focus on hearing the voice of service users, supporting vulnerable young people, equity of access, and strong clinical standards applies in this area as much as in my other work.

With this in mind, the aim of the Review is to ensure that children and young people who are experiencing gender incongruence or gender-related distress receive a high standard of NHS care that meets their needs and is safe, holistic and effective.

I have previously set out the principles governing this Review process, namely that:

- The welfare of the child and young person will be paramount in all considerations.
- Children and young people must receive a high standard of care that meets their needs.
- There will be extensive and purposeful stakeholder engagement, including ensuring that children and young people can express their own views through a supportive process.
- The Review will be underpinned by research and evidence, including international models of good practice where available.
- There will be transparency in how the Review is conducted and how recommendations are made.
- There are no pre-determined outcomes with regards to the recommendations the Review will make.

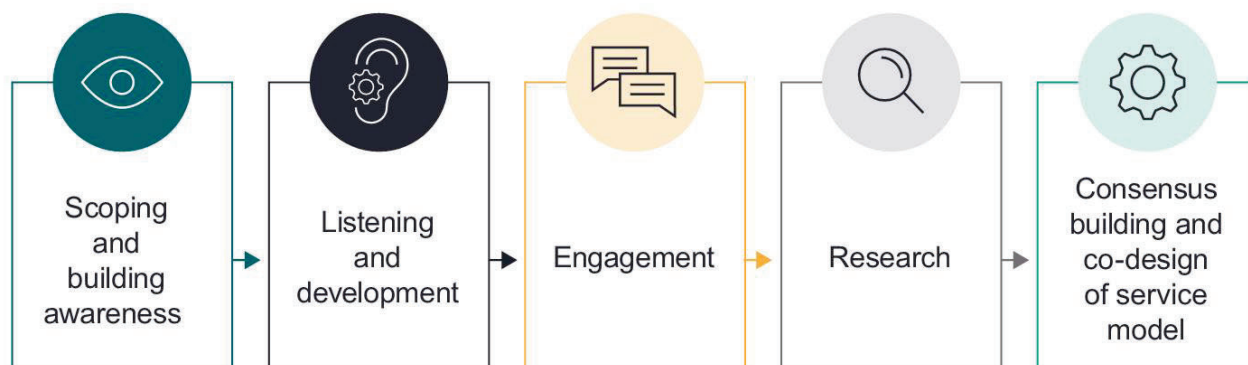
## Independent review of gender identity services for children and young people

The Review's terms of reference (**Appendix 1**) are wide ranging in scope, looking at different aspects of gender identity services across the whole pathway through primary, secondary and specialist services, up to the point of transition to adult services. This includes consideration of referral pathways, assessment, appropriate clinical management and workforce recommendations.

I have also been asked to explore the reasons for the considerable increase in the number of referrals, which have had a significant impact on waiting times, as well as the changing case-mix of gender-questioning children and young people presenting to clinical services.

The Review is taking an investigative approach to understanding what the future service model should look like for children and young people. This means 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.

### The key aspects of the approach to the Review are:



My starting point has been to hear from a variety of experts with relevant expertise and those with lived experience to understand as many perspectives as possible. To date, this has included hearing directly from those with lived experience, from professionals and support and advocacy groups. This listening process will continue.

We have been very fortunate in the generosity of all those who have been prepared to talk to the Review and share their experiences. In addition to some divergent opinions, there are also some themes and views which seem to be widely shared. The commitment of professionals at all levels is striking and I genuinely believe that with collective effort we can improve services for the children and young people who are at the heart of this Review.

These discussions have been valuable to get an in-depth sense of the current situation and different viewpoints on how it may be improved. However, it is essential that this initial understanding is underpinned by more detailed data and an enhanced evidence base, which is being delivered through the Review's academic research programme.

Providing this evidence base for the Review is going to take some time. I recognise there is a pressing need to enhance the services currently available for children, young people, their



## Introduction from the Chair

parents and carers, some of whom are experiencing considerable distress. Clinicians providing their treatment and care are also under pressure and cannot sustain the current workload. As such, I know the time I am taking to complete this Review and make recommendations will be difficult for some, but it is necessary.

I wrote to NHS England in May 2021 (**Appendix 2**) setting out some more immediate considerations whilst awaiting my full recommendations. This report builds on that letter and looks to provide some further interim advice.

Through our research programme, the Review team will continue to examine the literature and, where possible, will fill gaps in the existing evidence base. However, there will be persisting evidence gaps and areas of uncertainty. We need the engagement of service users, support and advocacy groups, and professionals across the wider workforce to work with us in the coming months in a collaborative and open-minded manner in order to reach a shared understanding of the problems and an agreed way forward that is in the best interests of children and young people.

My measure of success for this Review will be that this group of children and young people receive timely, appropriate and excellent care, not just from specialists but from every healthcare professional they encounter as they take the difficult journey from childhood to adulthood.



# 1. Summary and interim advice



## Summary

1.1. In recent years, there has been a significant increase in the number of referrals to the Gender Identity Development Service (GIDS) at the Tavistock and Portman NHS Foundation Trust. This has contributed to long waiting lists and growing concern about how the NHS should most appropriately assess, diagnose and care for this population of children and young people.

1.2. Within the UK, the single specialist service has developed organically, and the clinical approach has not been subjected to some of the usual control measures that are typically applied when new or innovative treatments are introduced. Many of the challenges and knowledge gaps that we face in the UK are echoed internationally,<sup>1</sup> and there are significant gaps in the research and evidence base.

1.3. This Review was commissioned by NHS England to make recommendations on how to improve services provided by the NHS to children and young people who are questioning their gender identity or experiencing gender incongruence and ensure that the best model for safe and effective services is commissioned (**Appendix 1**).

1.4. This interim report represents the Review's work to date. It sets out what we have heard so far and the approach we are taking moving forward. There is still much evidence to be gathered, questions to be answered, and voices to be heard, and our perspective will evolve as more evidence comes to light. However, there is sufficient clarity on several areas for the Review to be able to offer advice at this stage so that action can be taken more quickly.

1.5. The Review is not able to provide definitive advice on the use of puberty blockers and feminising/masculinising hormones at this stage, due to gaps in the evidence base; however, recommendations will be developed as our research programme progresses.

Every gender-questioning child or young person who seeks help from the NHS must receive the support they need to get on the appropriate pathway for them as an individual.

Children and young people with gender incongruence or dysphoria must receive the same standards of clinical care, assessment and treatment as every other child or young person accessing health services.

<sup>1</sup> Vrouenraets LJ, Fredriks AM, Hannema SE, Cohen-Kettenis PT, de Vries MC (2015). [Early medical treatment of children and adolescents with gender dysphoria: an empirical ethical study](#). J Adolesc Health 57(4): 367-73. DOI: 10.1016/.2015.04.004.



## Independent review of gender identity services for children and young people

### Conceptual understanding and consensus about the meaning of gender dysphoria

1.6. In clinical practice, a diagnosis of gender dysphoria is currently based on an operational definition, using the criteria set out in DSM-5 (**Appendix 3**). Some of these criteria are seen by some as outdated in the context of current understanding about the flexibility of gender expression.

1.7. At primary, secondary and specialist level, there is a lack of agreement, and in many instances a lack of open discussion, about the extent to which gender incongruence in childhood and adolescence can be an inherent and immutable phenomenon for which transition is the best option for the individual, or a more fluid and temporal response to a range of developmental, social, and psychological factors. Professionals' experience and position on this spectrum may determine their clinical approach.

1.8. Children and young people can experience this as a 'clinician lottery', and failure to have an open discussion about this issue is impeding the development of clear guidelines about their care.

### Service capacity and delivery

1.9. A rapid change in epidemiology and an increase in referrals means that the number of children seeking help from the NHS is now outstripping the capacity of the single national specialist service, the Gender Identity Development Service (GIDS) at The Tavistock and Portman NHS Foundation Trust.

1.10. The mix of young people presenting to the service is more complex than seen previously, with many being neurodiverse and/or having a wide range of psychosocial and mental health needs. The largest group currently comprises birth-registered females first presenting in adolescence with gender-related distress.

1.11. Until very recently, any local professional, including non-health professionals, could refer to GIDS, which has meant that the quality and appropriateness of referrals lacks consistency, and local service provision has remained patchy and scarce.

1.12. The staff working within the specialist service demonstrate a high level of commitment to the population they serve. However, the waiting list pressure and lack of consensus development on the clinical approach, combined with criticism of the service, have all resulted in rapid turnover of staff and inadequate capacity to deal with the increasing workload. Capacity constraints cannot be addressed through financial investment alone; there are some complex workforce (recruitment; retention; and training) and cultural issues to address.

1.13. Our initial work has indicated that many professionals working at primary and secondary level feel that they have the transferable skills and the commitment to offer more robust support to this group of children and young people, but are nervous about doing so, partly because of the lack of formal clinical guidance, and partly due to the broader societal context.



1.14. Primary and secondary care staff have told us that they feel under pressure to adopt an unquestioning affirmative approach and that this is at odds with the standard process of clinical assessment and diagnosis that they have been trained to undertake in all other clinical encounters.

1.15. Children and young people are waiting lengthy periods to access GIDS, during which time some may be at considerable risk. By the time they are seen, their distress may have worsened, and their mental health may have deteriorated.

1.16. Another significant issue raised with us is one of diagnostic overshadowing – many of the children and young people presenting have complex needs, but once they are identified as having gender-related distress, other important healthcare issues that would normally be managed by local services can sometimes be overlooked.

1.17. The current move to adult services at age 17-18 may fall at a critical time in the young person's gender management. In contrast, young people with neurodiversity often remain under children's services until age 19 and some other clinical services continue to mid-20s. Further consideration will be needed regarding the age of transfer to adult services.

## Service standards

1.18. The Multi-Professional Review Group (MPRG), set up by NHS England to ensure that procedures for assessment and for informed consent have been properly followed, has stated that the following areas require consideration:

- From the point of entry to GIDS there appears to be predominantly an affirmative, non-exploratory approach, often driven by child and parent expectations and the extent of social transition that has developed due to the delay in service provision.
- From documentation provided to the MPRG, there does not appear to be a standardised approach to assessment or progression through the process, which leads to potential gaps in necessary evidence and a lack of clarity.
- There is limited evidence of mental health or neurodevelopmental assessments being routinely documented, or of a discipline of formal diagnostic or psychological formulation.
- Of 44 submissions received by the MPRG, 31% were not initially assured due to lack of safeguarding information. And in a number of cases there were specific safeguarding concerns. There do not appear to be consistent processes in place to work with other agencies to identify children and young people and families who may be vulnerable, at risk and require safeguarding.

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- Appropriate clinical experts need to be involved in informing decision making.

1.19. Many of these issues were also highlighted by the Care Quality Commission (CQC) in 2020.<sup>2</sup>

### International comparisons

1.20. The Netherlands was the first country to provide early endocrine interventions (now known internationally as the Dutch Approach). Although GIDS initially reported its approach to early endocrine intervention as being based on the Dutch Approach,<sup>3</sup> there are significant differences in the NHS approach. Within the Dutch Approach, children and young people with neurodiversity and/or complex mental health problems are routinely given therapeutic support in advance of, or when considered appropriate, instead of early hormone intervention. Whereas criteria to have accessed therapeutic support prior to starting hormone blocking treatment do not appear to be integral to the current NHS process.

1.21. NHS endocrinologists do not systematically attend the multi-disciplinary meetings where the complex cases that may be referred to them are discussed, and until very recently did not routinely have

direct contact with the clinical staff member who had assessed the child or young person. This is not consistent with some international approaches for this group of children and young people, or in other multi-disciplinary models of care across paediatrics and adult medicine where challenging decisions about life-changing interventions are made.<sup>4,5</sup>

1.22. In the NHS, once young people are started on hormone treatment, the frequency of appointments drops off rather than intensifies, and review usually takes place quarterly. Again, this is different to the Dutch Approach.<sup>6</sup> GIDS staff would recommend more frequent contact during this period, but the fall-off in appointments reflects a lack of service capacity, with the aspiration being for more staff time to remedy this situation.

### Existing evidence base

1.23. Evidence on the appropriate management of children and young people with gender incongruence and dysphoria is inconclusive both nationally and internationally.

<sup>2</sup> Care Quality Commission (2021). [The Tavistock and Portman NHS Foundation Trust Gender Identity Service Inspection Report](#). London: CQC.

<sup>3</sup> de Vries ALC, Cohen-Kettenis PT (2012). [Clinical management of gender dysphoria in children and adolescents: the Dutch approach](#). J Homosex 59: 301–320. DOI: 10.1080/00918369.2012.653300.

<sup>4</sup> Ibid.

<sup>5</sup> Kyriakou A, Nicolaidis NC, Skordis N (2020). [Current approach to the clinical care of adolescents with gender dysphoria](#). Acta Biomed 91(1): 165–75. DOI: 10.23750/abm.v91i1.9244.

<sup>6</sup> de Vries ALC, Cohen-Kettenis PT (2012). [Clinical management of gender dysphoria in children and adolescents: the Dutch approach](#). J Homosex 59: 301–320. DOI: 10.1080/00918369.2012.653300.



1.24. A lack of a conceptual agreement about the meaning of gender dysphoria hampers research, as well as NHS clinical service provision.

1.25. There has not been routine and consistent data collection within GIDS, which means it is not possible to accurately track the outcomes and pathways that children and young people take through the service.

1.26. Internationally as well as nationally, longer-term follow-up data on children and young people who have been seen by gender identity services is limited, including for those who have received physical interventions; who were transferred to adult services and/or accessed private services; or who desisted, experienced regret or detransitioned.

1.27. There has been research on the short-term mental health outcomes and physical side effects of puberty blockers for this cohort, but very limited research on the sexual, cognitive or broader developmental outcomes.<sup>7</sup>

1.28. Much of the existing literature about natural history and treatment outcomes for gender dysphoria in childhood is based on a case-mix of predominantly birth-registered males presenting in early childhood. There is much less data on the more recent case-mix of predominantly

birth-registered females presenting in early teens, particularly in relation to treatment and outcomes.

1.29. Aspects of the literature are open to interpretation in multiple ways, and there is a risk that some authors interpret their data from a particular ideological and/or theoretical standpoint.

### **The mismatch between service user expectations and clinical standards**

1.30. By the time children and young people reach GIDS, they have usually had to experience increasingly long, challenging waits to be seen.<sup>8</sup> Consequently, some feel they want rapid access to physical interventions and find having a detailed assessment distressing.

1.31. Clinical staff are governed by professional, legal and ethical guidance which demands that certain standards are met before a treatment can be provided. Clinicians carry responsibility for their assessment and recommendations, and any harm that might be caused to a patient under their care. This can create a tension between the aspirations of the young person and the responsibilities of the clinician.

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<sup>7</sup> National Institute for Health and Care Excellence (2020). [Evidence Review: Gonadotrophin Releasing Hormone Analogues for Children and Adolescents with Gender Dysphoria](#).

<sup>8</sup> Care Quality Commission (2021). [The Tavistock and Portman NHS Foundation Trust Gender Identity Service Inspection Report](#). London: CQC.



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### Interim advice

1.32. The Review considers that there are some areas where there is sufficient clarity about the way forward and we are therefore offering some specific observations and interim advice. The Review will work with NHS England, providers and the broader stakeholder community to progress action in these areas.

### Service model

1.33. It has become increasingly clear that a single specialist provider model is not a safe or viable long-term option in view of concerns about lack of peer review and the ability to respond to the increasing demand.

1.34. Additionally, children and young people with gender-related distress have been inadvertently disadvantaged because local services have not felt adequately equipped to see them. It is essential that they can access the same level of psychological and social support as any other child or young person in distress, from their first encounter with the NHS and at every level within the service.

1.35. A fundamentally different service model is needed which is more in line with other paediatric provision, to provide timely and appropriate care for children and young people needing support around their gender identity. This must include support for any other clinical presentations that they may have.

1.36. The Review supports NHS England's plan to establish regional services, and welcomes the move from a single highly specialist service to regional hubs.

1.37. Expanding the number of providers will have the advantages of:

- creating networks within each area to improve early access and support;
- reducing waiting times for specialist care;
- building capacity and training opportunities within the workforce;
- developing a specialist network to ensure peer review and shared standards of care; and
- providing opportunities to establish a more formalised service improvement strategy.

### Service provision

1.38. The primary remit of NHS England's proposed model is for the regional hubs to provide support and advice to referrers and professionals. However, it includes limited provision for direct contact with children and young people and their families.

## Summary and interim advice

**1:** The Review advises that the regional centres should be developed, as soon as feasibly possible, to become direct service providers, assessing and treating children and young people who may need specialist care, as part of a wider pathway. The Review team will work with NHS England and stakeholders to further define the proposed model and workforce implications.

**2:** Each regional centre will need to develop links and work collaboratively with a range of local services within their geography 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.

**3:** Clear criteria will be needed for referral to services along the pathway from primary to tertiary care so that gender-questioning children and young people who seek help from the NHS have equitable access to services.

**4:** Regional training programmes should be run for clinical practitioners at all levels, alongside the online training modules developed by Health Education England (HEE). In the longer-term, clearer mapping of the required workforce, and a series of competency frameworks will need to be developed in collaboration with relevant professional organisations.

### Data, audit and research

1.39. A lack of routine and consistent data collection means that it is not possible to accurately track the outcomes and pathways children and young people take through the service. Standardised data collection is required in order to audit service standards and inform understanding of the epidemiology, assessment and treatment of this group. This, alongside a national network which brings providers together, will help build knowledge and improve outcomes through shared clinical standards and systematic data collection. In the longer-term, formalisation of such a network into a learning health system<sup>9</sup> with an academic host would mean that there was systematised use of data to produce a continuing research programme with rapid translation into clinical practice and a focus on training.

<sup>9</sup> Scobie S, Castle-Clarke S (2019). [Implementing learning health systems in the UK NHS: Policy actions to improve collaboration and transparency and support innovation and better use of analytics](#). Learning Health Systems 4(1): e10209. DOI:10.1002/lrh2.10209.



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**5:** The regional services should have regular co-ordinated national provider meetings and operate to shared standards and operating procedures with a view to establishing a formal learning health system.

**6:** Existing and future services should have standardised data collection in order to audit standards and inform understanding of the epidemiology, assessment and treatment of this group of children and young people.

**7:** Prospective consent of children and young people should be sought for their data to be used for continuous service development, to track outcomes, and for research purposes. Within this model, children and young people put on hormone treatment should be formally followed up into adult services, ideally as part of an agreed research protocol, to improve outcome data.

## Clinical approach

### Assessment processes

1.40. We have heard that there are inconsistencies and gaps in the assessment process. Our work to date has also demonstrated that clinical staff have different views about the purpose of assessment and where responsibility lies for different components of the process within the pathway of care. The Review team has commenced discussions with clinical staff across primary, secondary and tertiary care to develop a framework for these processes.

**8:** There needs to be agreement and guidance about the appropriate clinical assessment processes that should take place at primary, secondary and tertiary level.

**9:** Assessments should be respectful of the experience of the child or young person and be developmentally informed. Clinicians should remain open and explore the patient's experience and the range of support and treatment options that may best address their needs, including any specific needs of neurodiverse children and young people.

## Hormone treatment

1.41. The issues raised by the Multi-Professional Review Group echo several of the problems highlighted by the CQC. It is essential that principles of the General Medical Council's Good Practice in Prescribing and Managing Medicines and Devices<sup>10</sup> are closely followed, particularly given the gaps in the evidence base regarding hormone treatment. Standards for decision making regarding endocrine treatment should also be consistent with international best practice.<sup>11,12,13</sup>

**10:** Any child or young person being considered for hormone treatment should have a formal diagnosis and formulation, which addresses the full range of factors affecting their physical, mental, developmental and psychosocial wellbeing. This formulation should then inform what options for support and intervention might be helpful for that child or young person.

**11:** Currently paediatric endocrinologists have sole responsibility for treatment, but where a life-changing intervention is given there should also be additional medical responsibility for the differential diagnosis leading up to the treatment decision.

1.42. Paediatric endocrinologists develop a wide range of knowledge within their paediatric training, including safeguarding, child mental health, and adolescent development. Being party to the discussions and deliberations that have led up to the decision for medical intervention supports them in carrying out their legal responsibility for consent to treatment and the prescription of hormones.

**12:** Paediatric endocrinologists should become active partners in the decision making process leading up to referral for hormone treatment by participating in the multidisciplinary team meeting where children being considered for hormone treatment are discussed.

<sup>10</sup> General Medical Council (2021). [Good practice in prescribing and managing medicines and devices \(76-78\)](#).

<sup>11</sup> Hembree WC, Cohen-Kettenis PT, Gooren L, Hannema SE, Meyer WJ, Murad MH, et al (2017). [Endocrine treatment of gender-dysphoric/gender-incongruent persons: an Endocrine Society clinical practice guideline](#). J Clin Endocrinol Metab 102(11): 3869–903. DOI: 10.1210/jc.2017-01658.

<sup>12</sup> Cohen-Kettenis PT, Steensma TD, de Vries ALC (2001). [Treatment of adolescents with gender dysphoria in the Netherlands](#). Child Adolesc Psychiatr Clin N Am 20: 689–700. DOI: 10.1016/j.chc.2011.08.001.

<sup>13</sup> Kyriakou A, Nicolaidis NC, Skordis N (2020). [Current approach to the clinical care of adolescents with gender dysphoria](#). Acta Biomed 91(1): 165–75. DOI: 10.23750/abm.v91i1.9244.



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1.43. Given the uncertainties regarding puberty blockers, it is particularly important to demonstrate that consent under this circumstance has been fully informed and to follow GMC guidance<sup>14</sup> by keeping an accurate record of the exchange of information leading to a decision in order to inform their future care and to help explain and justify the clinician's decisions and actions.

**13:** Within clinical notes, the stated purpose of puberty blockers as explained to the child or young person and parent should be made clear. There should be clear documentation of what information has been provided to each child or young person on likely outcomes and side effects of all hormone treatment, as well as uncertainties about longer-term outcomes.

**14:** In the immediate term the Multi-Professional Review Group (MPRG) established by NHS England should continue to review cases being referred by GIDS to endocrine services.

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<sup>14</sup> General Medical Council (2020). [Decision making and consent](#).

## 2. Context



## Independent review of gender identity services for children and young people

### Transgender, non-binary and gender fluid adults

- 2.1. NHS clinical services to support transgender adults with hormone treatment and subsequent surgery began in 1966.
- 2.2. Services were initially established within a mental health model, in conjunction with endocrinology and surgical services.
- 2.3. Currently, NHS services for transgender adults do not have adequate capacity to cope with demand.<sup>15</sup> In addition, the broader healthcare needs of this group are not well met. This is important in the context of the current generation of gender-questioning children and young people in that there are now two inflows into adult services – individuals transitioning in adulthood, and those moving through from children’s services.
- 2.4. Legal rights and protections for transgender people lagged behind the provision of medical services, with the Gender Recognition Act 2004 coming into force in April 2005. Over the last few years, broader discussions about transgender issues have been played out in public, with discussions becoming increasingly polarised and adversarial. This polarisation is such that it undermines safe debate and creates difficulties in building consensus.

2.5. It is not the role of this Review to take any position on the cultural and societal debates relating to transgender adults. However, in achieving its objectives there is a need to consider the information and support that children and young people access from whatever source, as well as any pressures that they are subject to, before they access clinical services.

### Terminology and diagnostic frameworks

- 2.6. The Office for National Statistics defines sex as “referring to the biological aspects of an individual as determined by their anatomy, which is produced by their chromosomes, hormones and their interactions; generally male or female; something that is assigned at birth”.<sup>16</sup>
- 2.7. The Office for National Statistics defines gender as “a social construction relating to behaviours and attributes based on labels of masculinity and femininity; gender identity is a personal, internal perception of oneself and so the gender category someone identifies with may not match the sex they were assigned at birth”.<sup>17</sup>
- 2.8. Societal attitudes towards gender roles and gender expression are changing. Children, teenagers and younger adults may more commonly see gender as a fluid, multi-faceted phenomenon which

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<sup>15</sup> Gender Identity Clinic, The Tavistock and Portman NHS Foundation Trust. [Waiting times](#).

<sup>16</sup> Office for National Statistics (2019). [What is the difference between sex and gender?](#)

<sup>17</sup> Ibid.



does not have to be binary, whereas older generations have tended to see gender as binary and fixed. It is not unusual for young people to explore both their sexuality and gender as they go through adolescence and early adulthood before developing a more settled identity. Many achieve this without experiencing significant distress or requiring support from the NHS, but this is not the case for all.

2.9. For those who require support from the NHS, there are two widely used frameworks which provide diagnostic criteria. The International Classification of Diseases (ICD), which is the World Health Organization (WHO) mandated health data standard, and the Diagnostic and Statistical Manual of Mental Disorders (DSM), which is the classification system for mental health disorders produced by the American Psychiatric Association. The current editions of these manuals – ICD-11 and DSM-5 – came into effect in January 2022 and 2013 respectively.

2.10. ICD-11<sup>18</sup> has attempted to depathologise gender diversity, removing the term ‘gender identity disorders’ from its mental health section and creating a new section for gender incongruence and transgender identities in a chapter on sexual health. These changes are part of a much broader societal drive to remove the stigma previously associated with transgender healthcare. ICD-11

defines gender incongruence as being “characterised by a marked incongruence between an individual’s experienced/ expressed gender and the assigned sex.” Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis. The full criteria for gender incongruence of childhood and gender incongruence of adolescence or adulthood are listed in **Appendix 3**.

2.11. DSM-5<sup>19</sup> is currently the framework used to diagnose gender dysphoria. This diagnostic category describes gender dysphoria as “the distress that may accompany the incongruence between one’s experienced or expressed gender and one’s assigned gender”. A diagnosis of gender dysphoria is usually deemed necessary before a young person can access hormone treatment, and criteria are listed in **Appendix 3**.

## Conceptual understanding of gender incongruence in children and young people

2.12. Children and young people presenting to gender identity services are not a homogeneous group. They vary in their age at presentation, their cultural background, whether they identify as binary, non-binary, or gender fluid, whether they are neurodiverse and in a host of other ways.

<sup>18</sup> World Health Organization (2022). [International Classification of Diseases Eleventh Revision](#).

<sup>19</sup> American Psychiatric Association (2013). [Diagnostic and Statistical Manual of Mental Health Disorders: DSM-5™, 5th ed.](#)