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NHS England

Public consultation

Interim service specification for specialist gender dysphoria services for children and young people

20 October 2022

Contents

Purpose of this document

NHS England is committed to working with a wide range of patients, patient groups and other stakeholders in the development of its commissioning of services. A public consultation is an opportunity to check whether proposals are right and supported, the public understand their impact, and identify any alternatives before decisions are made.

NHS England is the responsible commissioner for specialised services for individuals with gender dysphoria, and it is holding this consultation to seek views on a proposed interim service specification for services for children and young people with gender dysphoria- this represents phase 1 of our service transformation programme. Once agreed, this interim service specification will be operational for a limited time only until a new service specification is formed in 2023/24 following final advice from the independent Cass Review. This will be used by a new configuration of regional providers- representing phase 2 of our service transformation programme.

The public consultation will run for 45 days from 20 October to 4 December 2022.

This consultation guide summaries the proposals and sets out:

- How care is currently provided.
- How the interim service specification could change care and the way that services are delivered, and the reasons for these changes.
- How the proposed changes will be implemented.

The document also has information about how you can share your views with NHS England. At the end of the consultation period, all feedback will be considered before the interim service specification is published.

We recommend that you read this consultation guide alongside the other documents published as part of the consultation. While this single consultation guide has been produced to summarise the proposals, the other documents provide additional detail.

Documents included in this consultation:

- **Interim service specification** – The service specification is a contractual document that describes the clinical service and sets out appropriate standards and quality measures that provider organisations must satisfy.
- **Equality and Health Inequalities Impact Assessment** (EHIA) – This document assesses the potential impact of the interim service specification on population groups that may be disproportionately affected by changes and make appropriate recommendations to mitigate any inequity.

Background

The term used to describe a discrepancy between birth-assigned sex and gender identity is 'gender incongruence'. Gender incongruence is frequently, but not universally, accompanied by the symptom of gender dysphoria: *"a disorder characterized by a strong and persistent cross-gender identification (such as stating a desire to be the other sex or frequently passing as the other sex) coupled with persistent discomfort with his or her sex".*

There is currently only one provider of specialist services for children and young people (up to the 18th birthday) with gender dysphoria in England – this is the Gender Identity Development Service (GIDS) for children and adolescents, delivered by the Tavistock and Portman NHS Foundation Trust in London.

The GIDS is also directly commissioned by NHS Wales, and the changes described in this document will impact on patients who are the commissioning responsibility of NHS Wales.

Interim service specification: the case for change

In September 2020, NHS England commissioned an independent and wide-ranging review of gender identity services for children and young people. The Review, which is ongoing, is being led by Dr Hilary Cass, past president of the Royal College of Paediatrics and Child Health. It was established in response to a complex and diverse range of issues including:

1. A significant and sharp rise in referrals

In 2021/22 there were over 5,000 referrals into the Gender Identity Development Service (GIDS) run by the Tavistock and Portman NHS Foundation Trust. This compares to just under 250 referrals in 2011/12.

2. Marked changes in the types of patients being referred which are not well understood

There has been a dramatic change in the case-mix of referrals from predominantly birth-registered males to predominantly birth-registered females presenting with gender incongruence in early teen years. Additionally, a significant number of children are also presenting with neurodiversity and other mental health needs and risky behaviours which requires careful consideration and needs to be better understood.

3. Scarce and inconclusive evidence to support clinical decision making

This has led to a lack of clinical consensus on what the best model of care for children and young people experiencing gender incongruence and dysphoria should be; and a lack of evidence to support families in making informed decisions about interventions that may have life-long consequences.

4. Long waiting times for initial assessment and significant external scrutiny and challenge surrounding the clinical approach and operational capacity at GIDS

This has contributed to the current service being unable to meet the scale of rising demand and concerns being raised by healthcare regulators about the standard of care.

Next steps

In February 2022, Dr Cass published an interim report in which she set out initial findings and advice from her Review. She emphasised the need to urgently move away from the current model of a sole provider, and to establish regional services that work to a new clinical model that can better meet the holistic needs of a vulnerable group of children and young people. She began to describe the need for these new services to work as networked centres that connected with other local services including children and young people's mental health services and primary care to support all a patient's clinical needs.

In July, Dr Cass gave further advice on the core components of this model. You can read the advice in full here.

In summary, she has said:

- 'Regional centres should be led by experienced providers of tertiary paediatric care to ensure a focus on child health and development, with strong links to mental health services. These will generally be specialist children's hospitals.

- 'They should have established academic and education functions to ensure that ongoing research and training is embedded within the service delivery model'.

- 'The services should have an appropriate multi-professional workforce to enable them to provide an integrated model of care that manages the holistic needs of this population'.

- 'Staff should maintain a broad clinical perspective to embed the care of children and young people with gender uncertainty within a broader child and adolescent health context'.

- In view of the uncertainties surrounding their use, consideration should be given to the rapid establishment of the necessary research infrastructure to prospectively enroll young people being considered for puberty blocking drugs

into a formal research programme, with adequate follow-up into adulthood.

Establishing New (Phase 1) Services

Given the urgent need to stabilise service provision for patients and begin building a more resilient service by expanding provision, we are establishing two 'Phase 1'[1] services. Consistent with Dr Cass' advice, these services will be led by specialist children's hospitals and, once established, will take over clinical responsibility for and management of all current GIDS patients as part of a managed transition, and they will begin to see children and young people who are currently on the GIDS waiting list.

One Phase 1 service will be based in London and will be led by a partnership between Great Ormond Street Hospital for Children NHS Foundation Trust and Evelina London Children's Hospital (part of Guys and St Thomas' NHS Foundation Trust), with South London and Maudsley NHS Foundation Trust providing specialist CYP mental health support.

A second Phase 1 service will be based in the North West, led by a partnership between Alder Hey Children's NHS Foundation Trust and the Royal Manchester Children's Hospital (part of Manchester University NHS Foundation Trust), where both trusts also provide specialist CYP mental health services.

The Tavistock and Portman NHS Foundation Trust and the endocrine teams based at University College London Hospitals NHS Foundation Trust and Leeds Teaching Hospitals NHS Trust will play a vital role in supporting both Phase 1 services as they establish the new services building on their extensive experience of working with this patient group.

A single national transformation programme has been established to oversee a smooth and seamless transition for patients to the new Phase 1 services, including bringing the GIDS contract to a managed close because of these changes. The establishment of the Phase 1 services will happen as quickly as possible, but crucially at a pace that appreciates the complexity of the change, while minimising

[1] When NHS England announced plans in July 2022 to establish new services we referred to them as 'Early Adopter' service providers. We are now using the term 'Phase 1' service providers instead.

disruption and any additional anxiety for patients. The aim is for the Phase 1 services to be operational by Spring 2023.

The Phase 1 services will be commissioned against an interim service specification which will replace the current service specification used by the GIDS. There is now an urgent need to agree this specification to give the Phase 1 services time to recruit staff and set up the new services a quickly as possible.

The interim service specification builds out from the existing specification to both incorporate advice from the Cass Review following its extensive stakeholder engagement, and to provide points of clarification in certain areas. It has been worked up and endorsed by the Phase 1 providers, as well as senior clinical leads including the National Medical Director for Specialised Services, the National Clinical Director for Children and Young People and the Associate National Clinical Director for Children and Young People's Mental Health. It is important to note that this is an interim service specification to support the rapid mobilisation of the new Phase 1 services. It will be replaced in due course with a final service specification which will be subject to a further period of engagement and public consultation at a later date and once further advice has been received from Dr Cass as part of her ongoing independent review. This will mark the start of Phase 2 of our service transformation programme when additional regional services will be commissioned.

What are the proposed changes?

The interim service specification proposes the following changes and points of clarification over the current service specification.

1. **Composition of the clinical team – substantive change**

The current service specification for GIDS describes that the service is delivered through a specialist multidisciplinary team with contributions from specialist social workers, family therapists, psychiatrists, psychologists, psychotherapists, paediatric and adolescent endocrinologists and clinical nurse practitioners. *The new interim service specification proposes to extend the clinical team so that it is a more integrated multi-disciplinary team that, in addition to gender dysphoria specialists, will include experts in paediatric medicine, autism, neurodisability and mental health.*

The reason for this proposal is to respond to evidence that there is a higher prevalence of other complex presentations in children and young people who have gender dysphoria, that the Phase 1 services will also address, working with local services where appropriate. The proposal also responds to the findings of the Care Quality Commission's 2021 inspection report of GIDS, which highlighted the need for a better multi-disciplinary mix of care providers for some children and young people referred to the service. Furthermore, the interim advice of the Cass Review concluded (page 69) that "*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*".

2. **Clinical leadership – substantive change**

The current service specification for GIDS does not describe criteria for the clinical lead for the service. *The new interim service specification proposes that the clinical lead for the service will be a medical doctor*.

The reason for this change is to reflect that the new integrated clinical teams will have a broader range of clinical disciplines, including medical professionals, who will be addressing a broader range of medical conditions in addition to gender dysphoria;

and that oversight of the service by a medical doctor is appropriate given that the service may provide medical interventions to some children and young people..

3. **Collaboration with, and support for, referrers and local services – substantive change**

The current service specification for GIDS describes a tiered approach for progression through the clinical pathway: the first tier involves meetings between the GIDS team and local professionals involved in the care of the child or young person and the second tier involves the child or young person accessing local services for mental health needs with GIDS offering advice to local services. There are numerous references in the current GIDS service specification to joint working between GIDS and local services including through consultation and liaison. However, GIDS has struggled to provide this support to local services in a consistent way given the constraints on the service. *The new interim service specification proposes to retain this tiered approach to progression through the pathway and describes a more structured approach for collaboration with local services in the interests of the child and young person; a referral to The Service will require a consultation meeting between the Phase 1 service and the relevant local secondary healthcare team and / or the GP. Where the outcome of the initial professional consultation between the Service and the referrer is that the patient does not meet the access criteria for The Service, the child or young person will not be added to the waiting list - but the family and professional network will have been assisted to develop their formulation of the child or young person's needs and a local care plan and will be advised of other resources for support that are appropriate for individual needs. The proposed interim service specification also proposes that not all children and young people who meet the access criteria will need to be seen directly by The Service. A key intervention that will be delivered by The Service is the provision of consultation and active support to local professionals, including support in formulation of needs and risks and individualised care planning. The level and type of consultation offered to the professional network will be determined according to the individual needs of each case and through a process of clinical prioritisation.*

4. **Referral sources – substantive change**

The current service specification for GIDS states that referrals can be made by staff in health and social services, schools, colleges of further education and by voluntary organisations. *The new interim service specification proposes that referrals may be made by GPs and NHS professionals.* The reason for the proposal is to ensure that children and young people are already engaged with the local health system before a referral is considered by a local health professional into the highly specialist gender dysphoria service, including for the reason that a proposed core feature of the new pathway is a consultation meeting between the specialist service and local health professionals before a referral can be considered for acceptance. The proposal would impact on fewer than 5% of referrals at current referral patterns, in that around 65% of referrals into GIDS are currently made by GPs and around 30% are made by NHS professionals. This proposal relates only to the interim service specification for the Phase 1 services. The interim report of the Cass Review begins to describe a future clinical pathway approach that operates within a managed clinical network, including other statutory agencies, and this pathway will be worked up by NHS England in the coming months through engagement with the Cass Review and other stakeholders.

5. **Social transition – clarification**

The current GIDS service specification acknowledges that social transition in pre-pubertal children is a controversial issue, that divergent views are held by health professionals, and that the current evidence base is insufficient to predict the long-term outcomes of complete gender-role transition during early childhood.

The interim Cass Report has advised that although there are differing views on the benefits versus the harms of early social transition, it is important to acknowledge that it should not be viewed as a neutral act. Dr Cass has recommended that social transition be viewed as an ‘active intervention’ because it may have significant effects on the child or young person in terms of their psychological functioning.

In line with this advice, the interim service specification sets out more clearly that the clinical approach in regard to pre-pubertal children will reflect evidence that in most cases gender incongruence does not persist into adolescence; and that for

adolescents the provision of approaches for social transition should only be considered where the approach is necessary for the alleviation of, or prevention of, clinically significant distress or significant impairment in social functioning and the young person is able to fully comprehend the implications of affirming a social transition.

Endocrine Interventions

Building the research protocol

The interim service specification reads:

> "*Consistent with advice from the Cass Review highlighting the uncertainties surrounding the use of hormone treatments, NHS England is in the process of forming proposals for prospectively enrolling children and young people being considered for hormone treatment into a formal research programme with adequate follow up into adulthood, with a more immediate focus on the questions regarding GnRHa. On this basis NHS England will only commission GnRHa in the context of a formal research protocol. The research protocol will set out eligibility criteria for participation.*"

In due course NHS England will share details of this work, including plans for how stakeholders and the public will be engaged and consulted on eligibility criteria.

Placing the use of GnRHa in the context of clinical research will have several important benefits:

- It responds directly to Dr Cass' advice that *'Without an established research strategy and infrastructure, the outstanding questions will remain unanswered and the evidence gap will continue to be filled with polarised opinion and conjecture, which does little to help young people, and their families and carers, who need support and information on which to make decisions'*. In this respect the NHS has the opportunity to make a major international contribution to the evidence base in this area.

- Secondly, it will ensure that there is greater transparency for children and their parents / carers around the uncertain clinical benefits and longer-term health impacts surrounding their use.

- Thirdly, it will further strengthen the consent and information sharing process to support informed decision making by young people.

Unregulated drugs

The current service specification for GIDS states that GIDS does not offer shared care with private clinicians, and that in cases where puberty blocking drugs or hormone drugs are prescribed or accessed outside the service, the GIDS will make the young person and their family aware of the risks, contraindications and any irreversible or partly reversible effects of any interventions, and will be unable to provide ongoing clinical supervision for the management of these interventions.

The proposed interim specification reads:

> *"Children, young people and their families are strongly discouraged from sourcing GnRHa and masculinising / feminising hormone drugs from unregulated sources or from on-line providers that are not regulated by UK regulatory bodies. In such cases The Service will make the child or young person and their family aware of the risks, contraindications and any irreversible or partly reversible effects of the drugs and will advise the GP to initiate local safeguarding protocols.*
>
> *"Should a child or young person access GnRHa from unregulated sources or unregulated providers The Service will not assume responsibility for prescribing recommendations nor will it enter into shared cared arrangements in these circumstances.*
>
> *"Where a child or young person has obtained masculinising / feminising hormones from an unregulated source (such as the internet) The Service will not accept clinical responsibility for management of the endocrine intervention.*

> *"Where a child or young person has been prescribed masculinising / feminising hormones by an unregulated provider outside of the eligibility and readiness criteria described in the current NHS clinical commissioning policy The Service will not accept clinical responsibility for management of the endocrine intervention."*

The reason for the revised wording is to provide greater clarity and retain and strengthen current safeguards. Senior clinicians have advised NHS England on the need for the new interim service specification to have much clearer wording in this regard so that the interim service specification is less open to interpretation, so that young people, families and professionals are clear on the approach that will be adopted by the NHS in such cases.

How will the proposed changes be implemented?

The proposed interim service specification will inform how the Phase 1 services deliver care and support to young people referred into the gender identity service over the next year.

In parallel, the Cass Review will continue its work to describe the new clinical model to which the Phase 1 services and the new regional services will work in the future. Once Dr Cass has delivered this advice the NHS will build a new service specification and put it out for stakeholder engagement and formal public consultation.

Give us your views on the proposed changes

NHS England would like to hear what patients, parents and carers, clinicians, providers and other interested parties think about the proposed interim service specification for gender dysphoria services.

These are the questions we're asking as part of the public consultation:

1. **In what capacity are you responding?** (Patient / Parent / Clinician / Service Provider / Other; If you have selected 'Other', please specify.)

2. **Are you responding on behalf of an organisation?** (yes / no; If you have selected "yes", which organisation are you responding on behalf of?)

3. **To what extent do you agree with the four substantive changes to the service specification explained above?**

    A. **Composition of the clinical team**
    (Agree / Partially Agree / Neither Agree nor Disagree / Partially Disagree / Disagree; comments)

    B. **Clinical leadership**
    (Agree / Partially Agree / Neither Agree nor Disagree / Partially Disagree / Disagree; comments)

    C. **Collaboration with referrers and local services**
    (Agree / Partially Agree / Neither Agree nor Disagree / Partially Disagree / Disagree; comments)

    D. **Referral sources**
    (Agree / Partially Agree / Neither Agree nor Disagree / Partially Disagree / Disagree; comments)

4. **To what extent do you agree that the interim service specification provides sufficient clarity about approaches towards social transition?** (Agree / Partially Agree / Neither Agree nor Disagree / Partially Disagree / Disagree; comments)

5. **To what extent do you agree with the approach to the management of patients accessing prescriptions from un-regulated sources?**
   (Agree / Partially Agree / Neither Agree nor Disagree / Partially Disagree / Disagree; comments)

6. **Are there any other changes or additions to the interim service specification that should be considered in order to support Phase 1 services to effectively deliver this service?**
   (comments)

7. **To what extent do you agree that the Equality and Health Inequalities Impact Assessment reflects the potential impact on health inequalities which might arise as a result of the proposed changes?**
   (Agree / Partially Agree / Neither Agree nor Disagree / Partially Disagree / Disagree; comments)

You can provide your views with NHS England by completing the online survey: https://www.engage.england.nhs.uk/specialised-commissioning/specialist-gender-interim-specification

Your views will help NHS England to further shape and refine this interim service specification for gender dysphoria services, until a new service specification is agreed in 2023, which will be informed by a full consultation and engagement process.

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