Guidance for consultation responses:

Interim service specification for specialist gender dysphoria services for children and young people in England
(*Phase 1 services*)

November 2022

Stonewall

These guidelines are to help you fill in the public consultation on the '*Interim service specification for specialist gender dysphoria services for children and young people*' published by NHS England, which **closes on December 4th**. You can read more general context in this explainer blog.

The guidance will take you through the questions as they are on the response form. The bullet points under each question are suggestions of key issues to raise, as well highlighting relevant research. Differences between this new specification and the previous specification are also highlighted where useful.

This guidance has been co-produced by Stonewall, Mermaids, Gendered Intelligence and Trans Learning Partnership.

To complete the consultation, click here

Or visit www.shorturl.at/cdoyS

What are the overall concerns you might want to raise?

The key issues we suggest raising throughout are:

- **Risk of denying access to the waiting list for children and young people who need assessment and care:** Access to the interim service will include an additional consultation stage between Phase 1 services and the patient's GP, before joining the waiting list, which may cause further delays to accessing care or deny access to it.
- **Medicalisation of social transition:** the service specficiation attempts to treat social transition as a medical intervention which is only recommended after receiving a diagnosis of gender dysphoria and experiencing clinically significant levels of distress. This is despite there being no evidence to suggest that social transition is harmful. It also seeks to remove from children and their parents the ability to make choices about how to live their day to day life happily, something that is extremely important in the context of a waiting list for services that is now several years long.
- **Implications that accessing private healthcare is a safeguarding issue:** According to the specification, safeguarding referrals will be initiated when service users are accessing hormones from private healthcare providers, or providers who are regulated outside the UK, and there is a conflation between private and 'unregulated' providers.
- **Restricted access to puberty blockers that is not based on clinical need:** puberty blockers will only be accessible with mandatory enrolment onto long-term research programmes. This would require children and young people to be part of a clinical trial to access essential care that is clinically indicated for them (and is not in line with ethical standards for healthcare research). The specification also implies that the criteria to access blockers may be further limited.
- **Contradictions with international best practice:** The specification makes no reference at all to the newest international best practice guidelines for trans healthcare, WPATH SOC 8 (World Professional Association for Transgender Health, Standards of Care Version 8), which outlines the latest evidence and clinical guidance developed by experts in the field.
- **Lack of evidence:** the previous service specification included a 4-page reference list of relevant research, but this interim service specification cites one flawed study. None of the abundant research in the field, including in WPATH SOC 8, are referenced or reflected.

How might you respond to each question?

You can respond to the consultation via an online survey on the NHS England webpage any time before **December 4.**

Questions 1 and 2 – Are you responding on behalf of an organisation? / In what capacity are you responding?

- Responses from patients, parents, clinicians, and service providers - who are considered stakeholders - are likely to be weighted more heavily than responses from other members of the public.
- If you can respond on behalf of your organisation, please do so.
- If you are under 18 and would like to respond, either as a patient or prospective patient, please do so.

Question 3 - To what extent do you agree with the four substantive changes to the service specification listed in the supporting documents?

a) Composition of the clinical team

- **Proposed change:** to extend the clinical team to include experts in paediatric medicine, autism, neurodisability, and mental health.
- **What you might want to raise:**
    - That more support and expertise are welcomed, but these experts must receive thorough and appropriate training on how to support trans and gender-diverse children and young people *prior to beginning clinical work*;
    - That the involvement of more people should not lead to even longer delays before assessment and treatment. This may be the result of these changes, as this will decrease the number of clinic hours available to other patients, meaning fewer patients are seen;
    - That the extension of the clinical team should not lead to differential diagnoses that prevent or prohibit treatment for gender incongruence, except where this is clinically indicated;
    - That the focus on neurodiversity expertise must be about ensuring quality of care for patients with neurodiversity, and not negatively impact their access to care;

b) Clinical leadership

- **Proposed change:** the clinical lead for the service must be a medical doctor.
- **What you might want to raise:**
    - That this doctor must be an expert in the care of trans and gender diverse children, informed by global experts in the area, prior to beginning clinical work;
    - That this shift should not infer that gender diversity is inherently a medical issue, and therefore pathologise the experiences of patients, recognising that the World Health Organisation and other leading health bodies have committed to depathologising trans people.

c) Collaboration with referrers and local services

- **Proposed changes:**
    - More collaboration with local services;
    - Referrals require a consultation meeting between the new service and local secondary healthcare team and/or the GP to determine if the patient meets the criteria for the service;
    - If patients don't meet these criteria, they 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'*;

- If patients meet these criteria, they may be added to the waiting list or supported through local provision as above. This will be determined by individual needs and through clinical prioritisation processes.

- **What you might want to raise:**
  - That having better integration with local services, who are better trained in supporting gender-diverse patients, and providing more support to those on the waiting list, are positive changes;
    The new requirement for a pre-referral consultation may cause more delays and barriers to access. This is especially concerning for those with unsupportive GPs;
  - That this point raises very serious concerns: '*Although new referrals will be made to the Service it is recognised that it is unlikely that the interim Service will be able to offer direct assessment and / or intervention for patients who are new referrals, or to a large proportion of the existing waiting list, before these individuals are transferred to one of the new regional services as they become operational.*' This appears to suggest that the interim service will only see those children and young people who are currently on the waiting list for GIDS at the Tavistock. There is no specified destination for new referrals, which leaves children and families in limbo.;
  - When practitioners conclude an individual has not met the criteria for accessing the service, there is no information on how individuals can get a second opinion, make an appeal, or whether there is any other recourse to challenge that decision;
  - The care pathways have no timelines, which is concerning considering the NHS guidance requires an 18-week maximum waiting time for non-urgent referrals.[1]

d) Referral sources

- **Proposed change:** referrals will only be accepted from GPs and NHS professionals, when previously referrals could also be made by schools or youth workers.

- **What you might want to raise:**
  - This raises concerns about what happens if a GP is unsupportive or does not refer correctly. Having alternative referrers such as teachers, social workers and charities, alongside self-referral from the family, can be critical for those unable to access supportive medical professionals.
  - There is evidence that GPs already struggle to know how to refer trans adults and children, so adding this extra step could lead to further confusion and delays;
  - There is no information about which NHS professionals are included within those who can refer, and whether this will include care providers that are contracted but not employed by the NHS.

1 "Guide to NHS waiting times in England." *NHS Services*, 2 Dec. 2019, www.nhs.uk/nhs-services/hospitals/guide-to-nhs-waiting-times-in-england/

Question 4 - To what extent do you agree that the interim service specification provides sufficient clarity about approaches towards social transition?

- **Proposed change:** '*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.*'
- **What you might want to raise:**
  - Social transition (e.g., changing one's name, pronouns and/or gender presentation) is not a medical intervention, and should not and cannot be restricted by medical professionals. Requiring 'clinically significant distress' before recommending social transition is unevidenced as an approach to care and runs counter to the autonomy of young people and their families. Individual children and their families should be free to follow a path of social transition where this makes the child or young person feel happier or more comfortable.
  - Contemporary evidence and international best practice (i.e., WPATH SOC 8) document numerous benefits of social transition (including improved mental health and wellbeing)[2], and social transition was supported in the previous specification. There is no evidence cited to support this substantial change of direction.
  - The recognition that someone's gender may change or develop over time 'is not sufficient justification to negate or deter social transition for a prepubescent child when it would be beneficial'[3], and that preventing or attempting to reverse an adolescent's gender expression may be

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2 Durwood et al. "Mental Health and Self-Worth in Socially Transitioned Transgender Youth." *Child & Adolescent Psychiatry*, 2017, https://doi.org/10.1016/j.jaac.2016.10.016.;
Durwood et al. "Social support and internalizing psychopathology in transgender youth." *Journal of Youth and Adolescence*, 2021, https:// doi.org/10.1007/s10964-020-01391-y.;
Olson et al. "Mental health of transgender children who are supported in their identities." *Pediatrics*, 2016, https://doi.org/10.1542/peds.2015-3223;
Olson, K. R., Gülgöz, S., 2018. "Early findings from the TransYouth Project: Gender development in transgender children." *Child Development Perspectives*, 2018, 12, 93–97. https://doi.org/10.1111/cdep.12268.
Gibson, D. J., Glazier, J. J., Olson, K. R. "Evaluation of anxiety and depression in a community sample of transgender youth." *JAMA Network Open*, 2021, 4, e214739. https://doi.org/10.1001/jamanetworkopen.2021.4739.

3 World Professional Association for Transgender Health. "Standards of Care for the Health of Transgender and Gender Diverse People, Version 8." *International Journal of Transgender Health*, 2022, p. S75. https://doi.org/10.1080/26895269.2022.2100644.

tantamount to conversion therapy.[4] The Memorandum of Understanding (MoU), a joint document signed by over 25 health, counselling and psychotherapy organisations which aims to end the practice of conversion therapy in the UK, includes in its definition of conversion therapy 'any model…[which] seeks to suppress an individual's expression of sexual orientation or gender identity' on the basis that one orientation or identity is preferable to any other.[5]

- A uniformly applied 'watchful waiting' approach (i.e., preventing any form of social transition until adolescence) is based on a harmful, outdated model which runs counter to evidence.[6]
- The lack of evidence is clear throughout the specification, with only one flawed citation in the entire document, used to justify the statement that '*in most pre-pubertal children, gender incongruence does not persist into adolescence*' (p. 13).
- This is taken from The Endocrine Society's Clinical Practice Guidelines, which in turn is based on outdated studies from the 20th century largely concerned with problematising 'deviant gender role behaviour'.[7] More recent studies refute this claim, including a 2022 longitudinal study[8] of 317 participants which found that an average of 5 years after initial social transition, 94% of children retained a trans identity.
  Further research supports this, with some key quotes below:
    - Olsen's 2022 study further states that "detransitioning" is infrequent. '*More commonly, transgender youth who socially transitioned at early ages continued to identify that way.*'[9]
    - The longest and largest study to date on the continuation of gender-affirming hormones in transgender people starting puberty suppression in adolescence to date found that '*(98%) people who had started gender-affirming medical treatment in adolescence continued to use gender-affirming hormones at follow-up.*'[10]

4 World Professional Association for Transgender Health. "Standards of Care for the Health of Transgender and Gender Diverse People, Version 8." *International Journal of Transgender Health*, 2022, p. S53. https://doi.org/10.1080/26895269.2022.2100644.

5 Memorandum of Understanding group. "Memorandum of Understanding on Conversion Therapy in the UK (Version 2)." *BACP*, 1 Mar. 2022, www.bacp.co.uk/media/14985/memorandum-of-understanding-on-conversion-therapy-in-the-uk-march-2022.pdf.

6 Ehrensaft et al. "Prepubertal social gender transitions: What we know; what we can learn—A view from a gender affirmative lens." *International Journal of Transgenderism*, 2018, 19(2), 251–268. https://doi.org/10.1080/15532739.2017.1414649

7 Horton, Cal. "NHS service specification: A dangerous attack on trans kids." *Growing Up Transgender*, 2 Nov. 2022, growinguptransgender.com/2022/11/02/nhs-service-specification-a-dangerous-attack-on-trans-kids/.

8 Olson et al. "Gender Identity 5 Years After Social Transition." *American Academy of Pediatrics*, vol. 150, no. 3, 2022, https://doi.org/10.1542/peds.2021-056082.

9 *ibid*

10 van der Loos et al. "Continuation of gender-affirming hormones in transgender people starting puberty suppression in adolescence: a cohort study in the Netherlands." *The Lancet*, 2022, https://doi.org/10.1016/S2352-4642(22)00254-1.

- Research from 2022 with 30 parents of pre-pubertal trans children found that *'Parents, in turn, observed profound and sustained improvements in mental health, well-being, educational attainment, and happiness once their children had socially transitioned.'*[11]
- One study found that 60% of trans male and 53% of trans female clients knew their gender identity before the age of 5; as Vincent states, this demonstrates two important things: '*many people who* do *transition had a strong sense of their genders from a young age*,' and that '*just because someone didn't express gender difference in childhood, this is not evidence that they are not trans.*'[12]

11 Horton, Cal. ""Euphoria": Trans children and experiences of prepubertal social transition." *Family Relations*, 2022, https://doi.org/10.1111/fare.12764.

12 Vincent, Ben. *Transgender Health: A Practitioner's Guide to Binary and Non-Binary Trans Patient Care*. *Jessica Kingsley Publishers*, 2018. p. 120.

Question 5 - To what extent do you agree with the approach to the management of patients accessing prescriptions from unregulated sources?

- **Proposal:**
  - *A reinforcement:* people accessing hormone blockers or hormones from unregulated sources or unregulated providers (such as via the internet) will not be managed or monitored by the NHS, i.e., shared care - this is currently the case.
  - *What's new:* if the new service is made aware of access to unregulated medications, they '*will advise the GP to initiate local safeguarding protocols*.'

- **What you might want to raise:**
  - That there is a conflation between 'unregulated' sources and private providers. Private health care providers are regulated, as are providers from other countries. Will those with prescriptions from regulated private providers or from international providers be refused access and face safeguarding protocols?
  - That accessing regulated private healthcare, especially given the 3+ year waiting time, should not be treated as a safeguarding concern.; Safeguarding referrals should be done on the basis of risk of harm to the child. Accessing regulated private care, or internationally regulated care is not evidence of risk of harm. It is unclear how the proposal in any way meets the requirements of child centred safeguarding set out in Working Together to Safeguard Children (2018).
  - This approach may be experienced as coercive: the NHS does not, and will not under this service specification, offer a care pathway that meets time limits set out in the NHS constitution. For children and families waiting for years to have a first meeting with a clinician, this approach to 'safeguarding' may be experienced as a threat: that if they seek care through any other route they will be punished, whether or not that care is clinically indicated for the child.
  - That this provision will prevent some patients and their families from seeking other support from GPs, for fear of being reported to Local Authority safeguarding teams. This contradicts the harm reduction approach of the NHS (Domain 5 of NHS outcomes, as stated within the specification), and the General Medical Council's ethical guidance.[13]

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13 "Trans healthcare." *General Medical Council*, www.gmc-uk.org/ethical-guidance/ethical-hub/trans-healthcare#Mental%20health%20and%20bridging%20prescriptions.

Question 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?

- **What you might want to raise:**
  - That WPATH Standards of Care 8 includes an extended discussion around the evidence base for the use of puberty blockers (GnRHa)[14], whereas this service specification presents the use of blockers as experimental, and restricts them to children and young people who agree to participate in a research project;
  - That this version makes no reference to local endocrine services or fertility preservation;
  - That this version does not explain access or prescription protocols for cross-sex hormones;
  - That the previous version of this specification refers to regular reviews, which appears absent from this version;
  - That there is no acknowledgement that not all parents, carers, schools, and local authorities will be supportive. WPATH Standards of Care 8 does acknowledge this, and states that sometimes it's not appropriate to include parents/carers in decision making.[15]
  - There is no longer reference to public and patient involvement in innovation and service development. Embedding the patient voice into any new service is critical.
  - The mandatory enrolment onto a research protocol in order to access puberty blockers is out of line with best practice recommendations regarding ethical research into trans healthcare: it is advised that 'any provision of transgender healthcare is also available in a manner that is explicitly independent of research participation', as informed consent must be 'without coercion or undue influence.'[16] It appears this will not be the case within this specification.

14 World Professional Association for Transgender Health. "Standards of Care for the Health of Transgender and Gender Diverse People, Version 8." *International Journal of Transgender Health*, 2022, p. S64, S123. https://doi.org/10.1080/26895269.2022.2100644.

15 World Professional Association for Transgender Health. "Standards of Care for the Health of Transgender and Gender Diverse People, Version 8." *International Journal of Transgender Health*, 2022, p. S58. https://doi.org/10.1080/26895269.2022.2100644.

16 Adams et al. "Guidance and Ethical Considerations for Undertaking Transgender Health Research and Institutional Review Boards Adjudicating this Research." *Transgender Health*, 2016, p. 170, https://doi.org/10.1089/trgh.2017.0012.

Question 7 - To what extent do you agree that the Equality and Health Inequalities Impact Assessment (EHIA) reflects the potential impact on health inequalities which might arise as a result of the proposed changes?

- **What you might want to raise:**
  - The EHIA states that *'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'.* No evidence is given to support this, and in fact there is a significant body of evidence to suggest the opposite (see above);
  - On the impact of those with the protected characteristic of 'gender reassignment', the EHIA presents an inaccurate interpretation of the Equality Act 2010, stating that: '*Children and young people who are on the waiting list for GIDS, or who may be referred to a Phase 1 service in the future, or who are receiving an assessment by GIDS and who are without a diagnosis of gender dysphoria, do not share the protected characteristic of 'gender reassignment' as a class or cohort of patients. They cannot be treated as "proposing to undergo" a process (or part of a process) for the "purpose of reassigning" their sex "by changing physiological or other attributes of sex.'*
  - It is beyond any reasonable doubt that within the cohort of patients referred to GIDS is a subset who do meet the definition of 'gender reassignment'. In fact, this is acknowledged in the interim service specification itself, where it concedes that children and young people may have socially transitioned prior to accessing assessment and treatment at GIDs (largely as a consequence of the substantial waiting times). Therefore the EHIA should account for how the interim service will avoid discrimination in access to care for this subpopulation of children and young people.
  - On disability, the EHIA should include an assessment of how the service will avoid discriminating in access to gender affirming healthcare for people with the protected characteristic of disability. In particular, given the focus on neurodiverse children and young people in the service specification, it is important to demonstrate how this will ensure the provision of better and more holistic care, rather than simply introducing barriers to treatment for children and young people who are diagnosed both as having gender incongruence and neuro developmental conditions.
  - That limiting referral routes could exclude children and young people with unsupportive families, as well as children accommodated away from the family home, and no provisions have been made for this.
  - The EHIA states that '*there is evidence that transgender people from BAME groups are more likely to face discrimination on the basis of their race and gender'* but does not describe what it will do about this or to mitigate against this.

- The EHIA states that it has not consulted on how to address or reduce inequalities; this is concerning as the NHS has access to various groups to consult with on this. This suggests that little care has been taken to ensure that individuals accessing the service will not experience discrimination, inequalities, or worse health outcomes.

Support Resources

If you have found some of this information distressing and would like some support, you can call the Mermaids helpline on 0808 801 0400 or look at our other support services on the Mermaids website.

Support for children and young people from Gendered Intelligence can be found here. Support for over 18s on the waiting list for an adult Gender Identity Clinic is available through Gendered Intelligence's support line at 0330 355 9678.

Support for young LGBTQ+ people of colour, including trans people, is available through the Colours Youth Network.