

## **NHS England's Interim Service Specification for Specialist Gender Dysphoria Services for Children and Young People - Public Consultation: Mermaids' Consultation Response**

This is Mermaids' official consultation response to the [NHS England consultation](#), which closed December 4, 2022. This is based on [the guidance](#) jointly produced by Mermaids with Gendered Intelligence, Trans Learning Partnership and Stonewall, as well as [focus groups](#) held by Mermaids with young people and parents.

### **1. Are you responding on behalf of an organisation?**

1.1. Mermaids

### **2. In what capacity are you responding?**

2.1. Service Provider

2.1.1. Mermaids has been supporting transgender, non binary and gender diverse children and their families since 1995. evolving into one of the UK's leading charities supporting gender-diverse people.

2.1.2. We empower thousands of people with secure online communities, local community groups, helpline services, web resources, events and residential weekends. The extent and importance of our work is underlined by the fact that between April 2021 and March 2022, Mermaids received over 34,000 referrals to the helpline.

2.1.3. Our direct work supporting young trans, non-binary and gender-diverse children offers us unique insight into the challenges facing this community.

2.1.4. Following the publication of the interim service specification, Mermaids held a series of engagement sessions with our service users - both young people and their parents who had direct experience of the Gender Identity Development Service. These views have guided our response to this consultation, and we have included quotes from these sessions throughout.

### **3. Composition of the clinical team**

3.1.1. We believe that all experts involved must be provided with specific, appropriate and in depth training on how to support gender-diverse children and young people before taking up clinical work with the service.

3.1.2. A consistent theme we heard from our service users was about the challenges they faced engaging with GPs or local CAMHS services who lacked training and understanding of gender diversity. The parents we spoke to were in agreement, one of whom stated *"that there is wildly different experiences of CAMHS, therapists, some of which are completely transphobic, some of which have no knowledge whatsoever, some of which don't want to touch it with a barge, some of which give massively misleading and inaccurate information, they don't have the training. So who's going to train them?"*

3.1.3. Our service users reflect how being required to repeatedly talk about their gender identity to a myriad of different clinicians can be exhausting, especially when a clinician does not have experience with

gender diversity. It is therefore vital every member of the extended clinical team does not inadvertently, through a lack of training, cause patients additional distress.

- 3.1.4. Mermaids would be concerned that the involvement of an extended clinical team could lead to even longer delays, currently at 3 years for a first appointment, through decreasing the number of clinical hours available to other patients, meaning fewer patients are seen overall.
- 3.1.5. Many young people expressed their concern that a focus on neurodiversity could lead to denial of access to care and treatment because of their neurodisability, autism, or mental health. The focus on neurodiversity expertise must be about ensuring improved, holistic care. There is research which suggests that treatments should not be refused on the basis of the co-occurrence of gender dysphoria and autism (Van Der Miesen et al. 2016).
- 3.1.6. In our experience, children and young people have a strong inherent understanding of their gender and of their neurodiversity. A young person said that *"I am autistic and it scares me how people will invalidate my identity. I'm autistic and trans. You can't separate the two and you can't blame my autism on my transness"*. Another told us that *"My GP put my gender dysphoria down to my autism – said I was distressed because of thoughts and sensations that could be attributed to my ASD like not wanting to wear tight feminine clothing and preferring baggy clothing"*.
- 3.1.7. Mermaids wishes to emphasise that the extended clinical team should not contribute to the pathologisation of trans identities, treating being gender-diverse as an undesirable outcome. Service users also fear clinicians will start from the harmful premise that there is 'something else' causing the distress a child or young person experiences.
- 3.1.8. In summary, Mermaids believes an extended clinical would be beneficial only if thorough and appropriate training is provided and is not used to justify denying care to children and young people on the basis of disability and/or neurodiversity.

### 3.2. **Clinical Leadership**

- 3.2.1. If the clinical lead for the service must be a medical doctor, they must already have received specific additional training in gender diversity and development, as well as trans identities, informed by global experts in the area, prior to beginning clinical work.
- 3.2.2. One parent who had accessed support from doctors working at the GIDS satellite clinic in Leeds highlighted concerns over losing the expertise from the current service in the transfer to new Phase 1 services.
- 3.2.3. Mermaids does not believe that being trans is inherently a medical issue, rather an expression of someone's authentic self which may require additional support depending on the individual's needs. This proposed change should not lead to gender diversity being pathologised, a view shared by the World Health Organisation and

other leading health bodies who no longer treat being transgender as a 'disorder.'

### 3.3. **Collaboration with referrers and local services**

- 3.3.1. Mermaids agrees that local services can play an important role in supporting trans and gender diverse children and young people. Improved integration with these services such as local LGBT charities, who often are better trained in supporting gender diverse patients particularly those experiencing long periods on the waiting list, is welcomed.
- 3.3.2. The waiting times for a first appointment with GIDS are currently around 3 years - whereas NHS guidance requires an 18 week maximum. Our service users were highly concerned about the requirement for a pre-referral consultation, which they fear aims to prevent people from joining the waiting list at all, with no recourse for appeal. For those who do meet the criteria to join the waiting list, they fear it will only lengthen the waiting time, given clinicians' time will be diverted to this task. The criteria for being accepted on to the waiting list is also opaque, and we are concerned that the bar for accessing care will be too high.
- 3.3.3. A young person questioned this, saying: *"So you have to meet an eligibility requirement in order to be assessed to see if you are eligible to join yet another waiting list? All this is going to do is add more time to the process and add more anxiety. What happens if you don't meet the requirement – can you reapply?!"*
- 3.3.4. In addition, Mermaids are concerned that the consultation meeting does not involve the patient or their family, but relies on a GP or secondary healthcare team. This is of particular concern considering the negative experiences that we know many young people and their families have with unsupportive GPs.
- 3.3.5. In summary, Mermaids notes that local service providers, with appropriate training, can play an important role in supporting a child or young person; however, we have concerns that these changes, particularly the prereferral assessment, may increase barriers and delays to access care.

### 3.4. **Referral Sources**

- 3.4.1. We are concerned by the limitations proposed on referral sources. The experiences of young people and their parents with GPs has been mixed. One young person stated that *"each GP comes with their own methods and views on gender identity. I was the first trans person my GP claimed to ever have met, yet he was in charge of the next steps for me!"*
- 3.4.2. It is common for GPs not to be aware of the correct process for referrals and this additional step is likely to result in additional confusion and further delays.
- 3.4.3. Having alternative referrers such as teachers, social workers and charities, alongside self-referral from the family, is critical for those unable to access supportive medical professionals. Mermaids would

like to know what steps the NHS are taking to ensure that primary care does not act as a barrier for referrals.

- 3.4.4. Mermaids finally have a concern that 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.

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

- 4.1. 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.
- 4.2. The proposal around social transition caused the most distress of any part of the interim service specification. It is also entirely unenforceable and unethical.
- 4.3. The requirement for 'clinically significant distress' to socially transition is unevidenced and runs counter to the autonomy of young people and their families. Individuals shouldn't need to experience significant distress, but instead acknowledge that they could be happier or more comfortable with such changes in their life.
- 4.4. Our service users felt this requirement represented a further attempt to pathologise transgender identity. A young person said that *"just because children may not be showing significant stress now doesn't mean they won't in the future. Why should children have to wait until they are so distressed before they can access services."*
- 4.5. For many young people, the process of accessing gender healthcare can itself be a distressing experience, with the requirement of needing to 'prove' your gender identity a painful one. A parent who told us how her child had *"already had to speak to 10 or 12 people" about their body. "Why should I force my child to traumatise themselves just to get medication?"*
- 4.6. One young person remarked, social transition is *"a thing that people should be allowed to do freely because people, even children, have bodily autonomy. Changing names etc only seems to have become an issue when applied to a trans context."* Another said that: *"Social transition is not permanent - it doesn't involve medical care at all, and can simply present as experimenting with your gender identity and how it links with your appearance"*
- 4.7. The latest evidence and international best practice (i.e., WPATH SOC 8) demonstrate the numerous benefits of social transition, including improved mental health and wellbeing (Ehrensaft et al et al. 2018), which was supported in the previous NHS specification.
- 4.8. 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', and that preventing or attempting to reverse an adolescent's gender expression may be tantamount to conversion therapy (WPATH SoC 8). 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.

- 4.9. The evidence of negative consequences of social transition is absent.
- 4.10. A parent of a trans young person told us that, *“When making decisions on how to respond to my own child’s request for social transition, this was the most important factor I considered – how can I maximise and protect their mental health right now AND if their transgender identity is persistent? In my mind the answer is loud and clear – listen, trust, respect and affirm their expressed identity.”*
- 4.11. Parents and carers, health, social care and educational professionals look to the Service for guidance on how best to support gender diverse children and young people. We are concerned that the approach to social transition will lead to such professionals discouraging social transition, despite the absence of evidence indicating it causing harm.
- 4.12. Our parents highlighted concerns about the practicalities of this approach. After long periods on the waiting list, many young people will have socially transitioned and use names and pronouns reflecting their gender. Would clinicians respect the wishes of patients, or be compelled to use a person’s previous name and pronouns?
- 4.13. 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.
- 4.14. Mermaids therefore believes that the approaches towards social transition are out of step with available evidence, pathologise transgender identity and will erode trust between trans young people and children and the service.

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

- 5.1. The approach to patients accessing prescriptions from ‘unregulated’ was received with significant concern, particularly by the parents of trans children.
- 5.2. Mermaids believe that NHS England have conflated ‘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?
- 5.3. Of greatest concern was the proposal that GPs refer supportive parents to safeguarding measures. With waiting times now over 3 years, and growing, accessing regulated private care should not be viewed as a safeguarding concern, particularly in cases where parents & carers are taking action to relieve the significant distress their child may experience. This was reflected by the experience of parents, one of whom stated that “Not acting is not neutral: hearing your children saying I am, you know, whatever gender they are, and doing nothing, that’s where you need to go to social services.”

- 5.4. 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).
- 5.5. One parent told us that *“every single one of them says that it was just because of the desperation of having been just left on the waiting list for years, is why they've gone to a private provider as being the only place there. And so they feel that it's very, it seems like they are shirking their responsibility for providing an inadequate service, and then blaming the parents for supporting their own children in the only way they can”*.
- 5.6. There is a lack of clarity about what local safeguarding protocols mean. The British Association of Social Workers (BASW) Position Statement on Social Work with Transgender People states that social workers should respect the right to self determination. Mermaids are concerned that the specification may contradict this position statement, with social workers lacking clarity on how to progress a referral where patients are accessing private healthcare.
- 5.7. Similarly, the harm reduction approach of the NHS (Domain 5 of NHS outcomes) and General Medical Council's ethical guidance is contradicted given 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.
- 5.8. In summary, with the current waiting times, some parents and carers have little choice but to seek out private, regulated healthcare. The approach fails to promote harm reduction, and comes across as coercive to our service users who are likely to experience it as a threat when they are trying to best support a child or young person.

**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?**

- 6.1. The World Professional Association for Transgender Health (WPATH) Standards of Care 8 was released online on September 15th 2022, prior to the publication of the proposed interim service specification. WPATH, composed of hundreds of clinical experts in trans health, provides clinical guidance for health professionals to assist transgender and gender diverse people with safe and effective pathways to achieve lasting personal comfort with their gendered selves, and to maximize their overall health, psychological well-being, and self-fulfillment. It is based on the best available science and expert professional consensus.
- 6.2. WPATH Standards of Care 8 includes an extended discussion around the evidence base for the use of puberty blockers (GnRHa), 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;
- 6.3. The lack of evidence for the proposals in this service specification is quite alarming, 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 a small number of outdated studies from the 20th century largely concerned with problematising 'deviant gender role behaviour'. Material cited in the Guideline dates as far back as 1967 with titles including "the cissy boy syndrome", focused on how to prevent homosexuality. More recent studies refute this claim, including a 2022 longitudinal study of 317 participants which found that an average of 5 years after initial social transition, 94% of children retained a trans identity (Olson et al. 2022).

- 6.4. One parent of a trans young person stated that *"it is being suggested that access to healthcare will be dependent on the young person signing up to a mandatory research project. While I absolutely agree that further ongoing research should be conducted into trans youth healthcare, it is a significant breach of ethics and human rights to make access to healthcare reliant on cooperation into an undefined research project. Can you imagine making access to contraception or abortion conditional to signing up to a long-term research project?"*
- 6.5. Mermaids believes that 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' (Adams et al., 2016). It appears this will not be the case within this specification
- 6.6. We note 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.
- 6.7. Our service users highlighted that there was significant absences about important areas of care in the specification, including no reference made to local endocrine services or fertility preservation and not explanation about access of prescription protocols for access to cross sex hormones.
- 6.8. There is no detail on the criteria for accessing puberty blockers or gender-affirming hormones, which is of significant importance and concern.
- 6.9. Both parents and young people highlighted the absence of any reference to embedding patient voice in service review and development. One young person told us that *"The NHS need to listen to us! Please please hear what we have to say and how this affects us. This new service has the chance to actually help people and save lives. Stop seeing transness as something that needs to be contained and actually just let the people who need these services access them. We are sick of being treated so differently from other areas of medicine. It just adds to the feeling that we are different and just gives more ammunition to the right-wing press and those who don't respect our identities or who believe in trans-trending or other stupid stuff like this."*
- 6.10. In summary, there are notable absences in the service specification which require more information to reassure those seeking care. No reference is made to WPATH 8, despite it offering the best available evidence on

supporting trans young people and children. We are concerned that no provision is made for embedding patient voice in the service, something our service users feel is already reflected in this service specification.

**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?**

- 7.1. 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.
- 7.2. 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.’
- 7.3. 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.
- 7.4. 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.
- 7.5. As mentioned, many young people had experienced discrimination by healthcare professionals on the basis of their neurodiversity - with one saying that *“This whole process is a hoop-jumping and emotionally taxing exercise which is inevitably going to be a problem for those with additional needs”*
- 7.6. 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.
- 7.7. 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. Young people expressed concern about the way race and gender intersect, noting the way that some people of colour can be excluded from Western definitions of binary gender categories. A young person stated that "We need more support services, not only Tavistock but all over the country.....and not just for binary, white trans people"

- 7.8. 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. More care must be taken to ensure that individuals accessing the service will not experience discrimination, inequalities, or worse health outcomes.