



Independent review  
into gender identity  
services for children  
and young people

## **REVIEW RESPONSE TO NHS ENGLAND'S CONSULTATION ON THE INTERIM SERVICE SPECIFICATION FOR SPECIALIST GENDER DYSPHORIA SERVICES FOR CHILDREN AND YOUNG PEOPLE**

The Independent Review of gender identity services for children and young people has considered the consultation document and draft interim service specification and makes the following response.

In formulating this response, we have taken into account our ongoing work and research since the interim report, the Review's longer-term ambition for these services, and our engagement with stakeholders to understand their perspectives.

### **GENERAL OBSERVATIONS**

We understand the imperative for NHS England to take action at this point in order to stabilise services and to build capacity in a managed way. We also recognise that this is an interim service specification describing the specialist gender service and does not describe the wider care pathway, which the Review will be providing further advice about in due course.

In responding, we are keen to ensure that interim arrangements are in line with the direction of travel outlined by the Review and that children, young people and their families are kept central to any approach. Because the specification describes both a consultation service to local professionals and a direct care service, the process of arriving at an individualised plan through joint decision-making with young people and their families is not articulated as clearly as it could be and our engagement with stakeholders indicates that a more explicit description of this would be reassuring.

In addition to the specific comments below, there is a general point regarding language. Through the work of the Review, it has become clear that people have different interpretations of many of the terms used, particularly in relation to gender affirming care and explorative, therapeutic care. In the interim report, we tried to reflect that this is not an either/or situation. We advised that NHS services should be respectful of the experience of the child or young person and be developmentally informed, with clinicians remaining open to explore the patient experience and the range of support and treatment options that may best address their needs. We recognise the draft interim service specification has tried to reflect this, but more clarity would help to move away from artificial binary opposition between exploratory and affirmative approaches and break down the current ideological tensions.

## **PROPOSED SUBSTANTIVE CHANGES**

### **Composition of the clinical team**

The Review welcomes the proposals around the composition of the clinical team. The new regional centres should have an appropriate multi-professional workforce to enable them to manage the holistic needs of this population, as well as the ability to provide essential related services, or be able to access such services through provider collaborations. This is more in line with models of care across paediatrics and mirrors approaches being taken in other countries.

It will, however, be crucial that appropriate training and development initiatives are available to support the existing workforce. Also, that comprehensive workforce planning is undertaken to build the future workforce across all related services, if we are to embed the care of children and young people with gender-related distress within a broader child and adolescent health context.

### **Clinical leadership**

The introduction of medical oversight is a welcome change, which would bring the service in line with other multi-disciplinary models of care across paediatric medicine, where challenging decisions about life-changing interventions are made; this is more consistent with some international approaches for this group of children and young people.

We also welcome the recognition that this is a heterogenous group and that not all children and young people will want or require a medical pathway, and that the service needs to include the appropriate skill mix to support both those individuals who do require medical intervention and those who do not.

### **Collaboration with, and support for, referrers and local services**

Better integration with local services is needed and the Review welcomes the support for referrers. A key concern of the Review has been that once gender issues have been raised, children and young people are placed on a long waiting list for the gender service with little or no support for their wider holistic needs. The new service needs to ensure children and young people receive support much earlier in the pathway to reduce the risk of diagnostic overshadowing.

This approach also aligns with findings of the Review's work with primary and secondary care professionals, many of whom feel they have the skills to support these children and young people but need additional training to build confidence and capability. Building a better understanding of the needs of gender questioning children and young people across the wider workforce is the only way to improve support for the increasing numbers of children and young people seeking help, whilst also ensuring that the smaller number who are most in need of specialist services are able to access them in a timely way.

Additionally in this area, it will be important to keep in mind the long-term model the Review has described in relation to operational delivery networks and the formalised

vertical structure that should allow care and risk to be actively managed at different levels according to need.

Further consideration also needs to be given to the national provider collaborative as described in the interim report and subsequent letter (July 2022). This will be essential to ensuring consistency of care and a learning environment. We would advise establishing the collaborative, at least in shadow form, as soon as possible.

### **Referral sources**

As highlighted in the interim report, direct referral to specialist services from outside the NHS is highly unusual. Therefore, these suggested changes would bring the service in line with more usual practice. Direct referral also currently means that there is inadequate support for children and young people whilst on the waiting list, which does nothing to alleviate the distress these children and young people may feel, and indeed may serve to exacerbate it.

This change, as reflected in the draft interim service specification, should ensure that children and young people are appropriately engaged within the health system and that the NHS has clear responsibility for their care. This will, however, need to be underpinned by access to support and information for referrers, so the whole health system better understands the needs of this population.

Providing clarity around which NHS professionals can refer, ensuring training for GPs and NHS professionals in the needs of these children and young people, and a process which enables standardisation of approach will be important.

### **Social transition**

Through our discussions with stakeholders, it is clear that references to social transition are a cause of concern. We acknowledge that the interim service specification describes how the specialist services will operate and is not a statement about wider society. This is an important distinction.

Social transition is a very broad term. Gender stereotypes are unhelpful, and in some instances push young people into feeling they have to present a rigid binary male or female appearance; changes in hairstyle and/or clothing may be part of a more fluid or non-gender conforming expression of identity.

At the point of presentation to NHS services, some children and young people will have socially transitioned already, while others may be considering this. When there is clinical involvement in the decision-making process, it is important that the risks and benefits of social transition as a planned intervention, sometimes as part of a medical care pathway, are discussed carefully, referencing best available evidence. Decisions will be individual, and the agency to make the decision will ultimately rest with the young person, along with their family/carers. The role of the professional is to facilitate parents/carers, children and young people to engage in an in-depth process of discussion and thinking around this decision, including considering how this will fit within the broader holistic approach to addressing the

young person's needs, how the process might proceed, how they will be supported and how they will be given opportunities to reflect on their lived experience.

Although we agree that pre-pubertal children have different needs to older adolescents, some of the distinctions between these two groups, which are set out in the section on social transition in the service specification, will need to be further informed by the evolving evidence base. At this stage it is important to specify that different groups will need different pathways, but the detail of the clinical approach within these pathways will need to develop collaboratively as the services evolve and the Review progresses.

## **ENDOCRINE INTERVENTIONS**

### **Building the research protocol**

The Review thanks NHS England for progressing the advice set out in its letter of 19 July 2022, in relation to the need to embed research into clinical practice. This research capacity will ultimately need to be built into the national network and is needed to provide ongoing appraisal of new literature and rapid translation into clinical practice; to continue to identify areas of practice where further research is needed; and to develop a research portfolio that will inform policy on assessment, support and clinical care of children with gender dysphoria, from presentation through to appropriate social, psychological and medical management.

The Review already has a comprehensive research programme underway, but this will not provide all the answers needed, and further work is required if the short- medium- and longer-term impacts of all clinical interventions are to be understood, starting most immediately with the effects of puberty blockers on neurocognitive and psychosexual development, gender maturation and executive function.

The Review welcomes the opportunity to support NHS England in developing the detail of its prospective research programme, and improving the reliability and transparency of information and advice available to support children, young people, parents and carers, and clinicians in making potentially life-changing decisions.

### **Management of patients accessing prescriptions from un-regulated sources**

We understand and share the concerns expressed by senior clinicians and NHS England about the use of unregulated medications and of providers that are not regulated within the UK. However, we believe there is a risk that the approach outlined could have unintended consequences.

It is clearly important that any clinician from primary through to tertiary care who ascertains that a young person is being given drugs from an un-regulated source, should make the young person and their family aware of the risks of such treatment. These risks are different depending on whether the source is through private providers not regulated in the UK or through on-line sources of medication, and the specific risks in each case should be explained. However, we would advise against suggesting that the GP should initiate local safeguarding protocols; firstly, because this is likely to make young people and their

families/carers fearful of seeking NHS help and increase their reliance on un-regulated sources; secondly, because it is unclear what action safeguarding services could or should take in response, and so would take up their time to no effect.

In terms of shared care and prescribing responsibility, this should mirror other areas of practice. Specifically, no clinician should prescribe outside their competence, nor should GPs be expected to enter into a shared care arrangement with a private provider acting outside of NHS guidance. Secondary and tertiary care clinicians should not take over responsibility for prescribing a medication initiated privately without satisfying themselves that the treatment is indicated, appropriate and safe for the young person who is receiving it. However, following appropriate referral and acceptance by the service, they should then make an independent assessment and/or ensure that such an assessment is carried out within NHS protocols. Prescription could then be continued if the clinician was satisfied that the treatment was in the best interests of the patient.

Regarding monitoring investigations when a young person is accessing un-regulated medications, the situation is somewhat different. We have been in discussion with clinical colleagues about this and will comment further in due course, but would suggest that there is an argument to ensure that a young person is not coming to harm by carrying out relevant investigations (e.g. monitoring bone density) as this is a best interests intervention.