



Independent review
into gender identity
services for children
and young people

Dr Hilary Cass
Chair
Independent Review of Gender Identity
Services for Children and Young People

John Stewart
National Director
Specialised Commissioning
NHS England

Sent by email

19 July 2022

Dear John

INDEPENDENT REVIEW OF GENDER IDENTITY SERVICES FOR CHILDREN AND YOUNG PEOPLE – FURTHER ADVICE

In my interim report I provided advice that in order to meet current demand and provide a more holistic and localised approach to care, gender identity services for children and young people need to move from a single national provider to a regional model.

I have since met with potential providers, Royal Colleges and support and advocacy groups to discuss the essential components of the proposed new model. I will continue with these conversations, including a programme of engagement with service users and their families, but wanted to share the outcome of discussions to date.

Essential components of a new model

A comprehensive patient and family centred service and package of care is needed to ensure children and young people who are questioning their gender identity or experiencing gender dysphoria get on the right pathway for them as an individual. A shared care arrangement is needed to enable children and young people to receive supportive care and appropriate treatment as close to home as possible. This would also improve integration between different children's services, facilitate appropriate access to local community support services, improve the experience of care, and support the transition between children's and adult services that are appropriate for the individual.

Regional centres

Regional centres should be commissioned as specialist centres to manage the caseload of children requiring support around their gender identity. The regional centres should be experienced providers of tertiary paediatric care to ensure a focus on child health and development, with strong links to mental health services. They should have established academic and education functions to ensure that ongoing research and training is embedded within the service delivery model. The 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. These should include, but not be limited to: mental health services; services for children and young people with autism and other neurodiverse presentations; and for the subgroup for whom medical treatment may be considered appropriate, access to endocrinology services and fertility services. There should also be expertise in safeguarding, support of looked-after children and children who have experienced trauma. Staff should maintain a broad clinical perspective by working across related services within the tertiary centre and between tertiary and secondary centres in order to embed the care of children and young people with gender-related distress within a broader child and adolescent health context.

Designated local specialist services

The regional centres will need to work collaboratively with local services within their geography. However, recognising that not all local services will have the capacity, capability and/or aspiration to support the care of children and young people with gender-related distress, I would recommend initially identifying a smaller number of secondary services within Child and Adolescent Mental Health Services (CAMHS) and paediatrics to act as **designated local specialist services** within each area. This would give the opportunity to provide targeted training, upskilling and additional staffing to a more manageable number of centres within a geography. Similar models exist in the provision of children's cancer services where there are designated Paediatric Oncology Shared Care Units (POSCUs)¹ and in neonatal care where there are designated Local Neonatal Units (LNUs).²

Operational delivery network

The regional centres should be responsible for overseeing the shared care model, working through an **operational delivery network (ODN)** or similar mechanism that can fulfil the stated purposes of ODNs³ which include:

- ensuring effective clinical flows through the provider system through clinical collaboration for networked provision of services
- taking a whole system, collaborative provision approach to ensure the delivery of safe and effective services across the patient pathway

¹ [NHS England \(2021\). Service Specification: Children's Cancer Network - Principal Treatment Centres](#)

² [NHS England. Service Specification: Neonatal Critical Care \(Intensive Care, HDU and Special Care\)](#)

³ [NHS Commissioning Board \(2012\). Developing Operational Delivery Networks: The Way Forward](#)

- improving cross-organisational, multi-professional clinical engagement to improve pathways of care
- enabling the development of consistent provider guidance and improved service standards, ensuring a consistent patient and family experience
- focusing on quality and effectiveness through the facilitation of comparative benchmarking and auditing of services, with implementation of required improvements
- fulfilling a key role in assuring providers and commissioners of all aspects of quality as well as coordinating provider resources to secure the best outcomes for patients across wide geographical areas
- supporting capacity planning and activity monitoring with collaborative forecasting of demand, and matching of demand and supply

Key to this model is the governance role of the network in maintaining standards of care and ensuring equitable access.

Pathways of care

I would recommend that consideration is given to **intake procedures** that ensure that children and young people referred to these services are able to access the most appropriate package of support at the earliest feasible point in their journey. One model might be that each regional centre would host a regular **intake meeting** involving multi-professional staff from the tertiary centre, the designated local specialist services and other relevant local children's services. Discussions with Gender Identity Development Service clinicians have highlighted the importance of differentiating different subgroups within the referred population who may be at risk and/or need more urgent support, assessment or intervention; there may also be subgroups where early advice to parents or school staff may be a more appropriate first step. Given that it is not always possible to make these judgements based on written referral information, consideration should be given to ring-fencing senior clinical time to make early contact with referrers or families in order to ensure that children and young people are allocated to an appropriate pathway.

There should be a whole system approach to care across the network so that children and young people can access a broad range of services relevant to their individual needs, including supportive exploration and counselling. This is important both for those who go on to medical transition and those who resolve their gender distress in other ways. There should be the ability to move flexibly between different elements of the service in a step-up or step-down model, allowing children and young people and their families/carers to make decisions at their own pace without requiring rereferral into the system.

Stakeholders have raised the need for individuals who are distinct from the professionals that they view as 'gatekeeping' access to the medical treatment to provide support and a safe space for questioning. There is considerable scope for local innovation and partnerships with voluntary sector organisations in developing these services in a range of settings.

The appropriate age for transition to adult services will need further discussion, balancing the workload and capacity of services for children and young people with the need to provide ongoing holistic family-centred care during a critical point in the young person's gender care, particularly for those with neurodiversity/special educational needs or other vulnerabilities.

National provider collaborative/research network

I have already stated that the regional centres should have regular co-ordinated national provider meetings and operate to shared standards and operating procedures. The development of protocols for assessment and treatment to ensure such consistency is an important strand of the work of the Review, and this will be based on best available evidence, the findings from our commissioned research, and expert opinion.

There should also be agreement regarding collection of a core dataset to inform service improvement and research, based on similar approaches already established in other specialities, for example, in paediatric critical care.⁴

To achieve this end, I would recommend that a formal **national provider collaborative** with an **integral research network** is established, bringing together clinical and academic representatives from the regional centres. The national provider collaborative should undertake a range of functions including:

- a forum for discussion of complex cases and/or decisions about medical care, and ultimately subsuming the role of the Multi-Professional Review Group
- an ethics forum for cases where there is uncertainty or disagreement about best interests or appropriate care
- providing opportunities for peer review between regional centres
- development of a programme of ongoing Continuing Professional Development for staff at all levels, as well as educational standards for practitioners within the various tiers of service provision
- collation of the national dataset and conduct of national audit
- development of a quality improvement programme to ensure evolving best practice
- ongoing research in areas of weak evidence

Independent oversight of data collection, audit and quality improvement (for example, through a Healthcare Quality Improvement Partnership-commissioned approach) will ensure the highest possible standards of data management and utilisation.

Embedding research in clinical practice

My interim report highlighted the gaps in the evidence base regarding all aspects of gender care for children and young people, from epidemiology through to

⁴ [PICANet – Paediatric Intensive Care Audit Network for the UK and Ireland](#)

assessment, diagnosis, support, counselling and treatment.⁵ NHS England asked me to give some further thought as to how these gaps may be addressed.

The Review has already commissioned a research programme which includes a literature review and both qualitative and quantitative research components. However, I recognise that this programme will not provide all the answers that are needed, and an ongoing programme of work will be required.

Given the particular uncertainties regarding long-term outcomes of medical intervention, and the broader knowledge gaps in this area, there is an imperative to build research capacity into the national network. This research capacity 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.

As already highlighted in my interim report, the most significant knowledge gaps are in relation to treatment with puberty blockers, and the lack of clarity about whether the rationale for prescription is as an initial part of a transition pathway or as a 'pause' to allow more time for decision making. For those who will go on to have a stable binary trans identity, the ability to pass in later life is paramount, and many will decide that the trade-offs of medical treatment are a price that is fully justified by the ability to live confidently and comfortably in their identified gender. The widely understood challenge is in determining when a point of certainty about gender identity is reached in an adolescent who is in a state of developmental maturation, identity development and flux.

It is the latter option regarding a 'pause' for decision making about which we have the least information. The rationale for use of puberty blockers at Tanner Stage 2 of development was based on data that demonstrated that children, particularly birth-registered boys who had early gender incongruence, were unlikely to desist once they reached early puberty; this rationale does not necessarily apply to later-presenting young people, including the predominant referral group of birth-registered girls. We do not fully understand the role of adolescent sex hormones in driving the development of both sexuality and gender identity through the early teen years, so by extension we cannot be sure about the impact of stopping these hormone surges on psychosexual and gender maturation. We therefore have no way of knowing whether, rather than buying time to make a decision, puberty blockers may disrupt that decision-making process.

A further concern is that adolescent sex hormone surges may trigger the opening of a critical period for experience-dependent rewiring of neural circuits underlying

⁵ [Olson-Kennedy, J, Cohen-Kettenis, P. T, Kreukels, B. P, Meyer-Bahlburg, H. F, Garofalo, R, Meyer, W, & Rosenthal, S. M. \(2016\). Research priorities for gender nonconforming/transgender youth: gender identity development and biopsychosocial outcomes. *Current opinion in endocrinology, diabetes, and obesity* 23\(2\), 172–179. DOI:10.1097/MED.0000000000000236.](#)

executive function⁶ (i.e. maturation of the part of the brain concerned with planning, decision making and judgement). If this is the case, brain maturation may be temporarily or permanently disrupted by puberty blockers, which could have significant impact on the ability to make complex risk-laden decisions, as well as possible longer-term neuropsychological consequences. To date, there has been very limited research on the short-, medium- or longer-term impact of puberty-blockers on neurocognitive development.

In light of these critically important unanswered questions, I would suggest that consideration is given to the rapid establishment of the necessary research infrastructure to prospectively enrol 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 puberty blockers. The appropriate research questions and protocols will need to be developed with input from a panel of academics, clinicians, service users and ethicists.

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 the children and young people, and their families and carers, who need support and information on which to make decisions.

I hope this further advice is helpful as you look to develop a detailed service specification. I appreciate you will want some time to consider my advice and am happy to discuss both the longer-term ambition and any interim arrangements that may be necessary, particularly in relation to the development of the clinical and research protocols.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Hilary Cass'. The signature is written in a cursive style with a large, looped 'y' at the end.

Dr Hilary Cass
Chair, Independent Review of Gender Identity Services for Children and Young People

⁶ [Sisk C L \(2017\). Development: Pubertal Hormones Meet the Adolescent Brain: Current Biology. 27\(14\): 706-708. DOI: 10.1016/j.cub.2017.05.092.](#)